MEDICAL TREATMENT OF DOWN SYNDROME AND GENETIC DISEASES

Henry Turkel, M.A., M.D.

Ilse Nusbaum, M.A.

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ABOUT THE AUTHOR

HENRY TURKEL, M.D., was born in Austria in 1903 and came to the United States in 1923. He received a B.A. in Chemistry from Ohio State University and an M.A. in Anatomy and M.D. from the University of Michigan. He is licensed to practice medicine in Michigan, Ohio, and the District of Columbia.

He invented the Turkel Trephine Instruments for bone marrow infusion and tissue biopsies. During World War II and thereafter, this instrument was adopted by the U.S. Armed Forces and has saved many thousands of lives. They are mentioned in scientific papers by some 800 different authors and in some 350 textbooks in more than ten different languages. He has been mentioned in the *International Who's Who in the World of Medicine* and the *World Who's Who* among numerous other publications. He has received many international honors for his work. He is a member of the Academy of Orthomolecular Psychiatry, American Association for the Advancement of Science, American Association on Mental Deficiency, International Society of Hematology, Southern Medical Association, and many other professional organizations, and is a life member of the American Medical Association, Royal Society of Medicine, and Association of Military Surgeons.

He has lectured about Down syndrome and inborn errors of metabolism at many medical conventions around the world, including the American Academy of General Practice, the Philosophical Society of England, the International Congress of Genetics in Holland, the Second International Congress on Mental Retardation in Vienna, and many others.

Dr. Turkel lives and practices medicine in Southfield, Michigan. He and his wife have five grown children.

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INTRODUCTION

It is proper that the medical profession should be conservative. A physician who gave his patients a drug that had not been carefully tested may be guilty of an unethical action, in that the side effects of the drug, over a long period of time, might turn out to be so serious as to neutralize completely any benefit conferred on the patient by the drug. Even after a new treatment has been shown to have value, a rather long period of time, often ten or twenty years, may be required before it is accepted by the medical profession as a whole.

This problem of delay is especially acute in the case of a treatment that does not promise great financial benefit to some pharmaceutical company or other part of our society. An example is the delay of more than twenty years in the acceptance of lithium therapy for depression in the United States. Lithium salts cannot be patented, and no one was willing to go to the expense of getting FDA approval for the drug. Another example is the use of EDTA chelation therapy for the treatment of atherosclerosis and other diseases. The company that owned the United States rights to the EDTA patent decided not to apply for FDA approval for these uses, because of an economic study that showed that the patent would expire before the company would have been able to make a profit from it.

There is a class of substances, called orthomolecular substances normally present in the human body, usually required for life. The vitamins and minerals are good examples. There is an increasingly great and increasingly convincing body of evidence that the use of vitamins, minerals, and other orthomolecular substances in the proper amounts, the amounts leading to optimum health and to the best treatment of disease, has great value in the

control of infectious diseases, cancer, heart disease and genetic diseases. There seems, however, to be a bias against these substances on the part of the medical profession and of nutritionists. The result is that there is opposition to orthomolecular medicine.

The work of Dr. Henry Turkel provides a striking example of the way in which this opposition operates to the detriment of the health and well being of a large number of people. Dr. Turkel has developed, over a period of decades, a treatment of mentally retarded children with the use of vitamins, minerals, cerebral stimulants, and other substances. He has gathered together a convincing body of clinical observations showing that the genetic condition of mental retardation need not be accepted as inevitably leading to permanent defect and inability of the individual to function in normal society. Dr. Turkel has indeed provided new hope for the mentally retarded and for members of their families, hope that a great improvement in functioning can be achieved.

I trust that everyone who is faced with a problem of mental retardation will read this book and give it serious consideration, and strive to gain its acceptance also by the medical profession in general.

Linus Pauling, Ph.D.
Palo Alto, California
February 15, 1983

AUTHOR'S STATEMENT

College education was my first major goal. The year was 1928. It had been less than five years since I had emigrated from Austria. I was 25 years old when I entered Ohio State University as a Chemistry major. The following year, I reached another landmark: I became an American citizen. In 1930, I observed a need, and invented the first biopsy instrument for the bone marrow.[1] I graduated three eyars later, in 1931, and earned a Master's degree in Anatomy from the University of Michigan in 1932. The same year, I was admitted to the Medical School of the University of Michigan.

Because I was not required to repeat the anatomy program, I had the opportunity to do independent research in arteriosclerosis, diabetes, allergies, and other diseases associated with metabolic accumulations. I discovered that the pancreas of patients with maturity onset diabetes had more insulin-producing glands than normal and that the accumulations of specific substances, such as calcifications, fats, sugars, or edema, that were diagnostic of these diseases, could be reduced by using combinations of nutrients and medicines simultaneously, to obtain a synergistic effect.[2]

The combinations for arteriosclerotic patients included carotene, thyroglobulin, and organic iodides, to remove calcifications. For

[1]Turkel, H. and Bethell, F.G.: A New and Simple Instrument for Administration of Fluids through Bone Marrow. War Med. 5:222-225 (April) 1944.

[2]Turkel, H.: Medical Amelioration of Down's Syndrome Incorporating the Orthomolecular Approach. Jrl. Orthomolecular Psych. 4:102:115. 1975.

diabetics, they included lipotropic substances such as betaine-choline tartrate, choline-methionine tartrate, inositol, unsaturated fatty acids, and dessicated liver. As a student, I discovered the importance of ascorbic acid in allergic disorders by sensitizing guinea pigs to proteins. Guinea pigs protected by vitamin C survived the sensitization process; the others died of anaphylactic shock. This study, in 1935, one of the first linking vitamin C to the immune system, was repeated by others in 1979 with the same results.[3] The "U" Series, as I called this corrective group of medicines and nutrients (adapting the Greek prefix eu- : well, or good), was based on this early research. I earned the medical degree in 1936 and went into private practice.

I perfected the biopsy instruments during the years before World War II. The Turkel Trephine Instruments facilitated safe and rapid infusion of plasma and other fluids, so that the wounded could be treated on the front lines and during transport. During World War II, Turkel needles became standard equipment of the U.S. Armed Forces. I lectured at may military and veteran hospitals. In 1952, I was appointed Consultant to the Surgeon General. During the years, I have continued to lecture and publish extensively about the trephine technique of bone marrow infusion and biopsy.[4]

Following a scientific lecture about the instruments in 1940, the father of a "mongoloid" patient inquired about possible treatment for his son, Peter. Although I knew nothing about the disease at the time, I soon discovered that

[3]Vitamin C and Immune Protection. Science News 115:295 (May 5) 1979.

[4]Turkel, H.: Emergency Infusion Through the Bone. Mil. Med. 149:349-350 (June) 1984.

many of the same accumulations that were present in other genetic diseases could be seen, together with severe retardations. When I first treated Peter, maternal exhaustion, low thyroid, depleted ovarian function, and similar deficiencies were proposed as the cause of the disease.[5]

Peter was fortunate that the properties of vitamins were being investigated during my student days. Instead of considering the underlying cause of Down syndrome, I looked at the anomalies and realized that many of them were similar to those diagnostic of genetic diseases that I had already treated. I immediately considered the possibility of medical/nutritional therapy. I dispensed the three units of the "U" Series simultaneously,[6] adding a broad spectrum of vitamins and minerals in pharmocological dosages, as well as enzymes, to correct the physical retardations that I attributed to malnutrition caused by the accumulations. As Dr. Rimland has pointed out,[¶] this was the first time that nutrients were scientifically combined to act synergistically.

[5]Benda, C.E.: Mongolism and Cretinism. Grune & Stratton. New York. 1949.

[6]Turkel, H. Biochemical Breakthrough in Mongolism. Bull. N.J. Ac. Sci. 7:19. 1962. Previous presentations included: 12/6/59- U. Cuba School of Medicine; 12/16/59; Am. Assoc. for Adv. Sci., Chicago; 3/60 U. Dominica School Med.; 5/6/60 & 11/60- Pan Am. Med. Cong. in Mexico City; 6/16/60- U. Haiti School of Med.; 7/60- Nat. Assoc. Osteopath. Phys. & Surg. 9/27/60 - Illinois Ac. Gen Pract. 12/60 U. Cuba School Med.; 3/20/61 Phi Lambda Kappa; 5/7/61- Am. Ost. Assoc.; 5/61 - U. Dominica School Med. 8/61 - 2nd Int. Cong. M.R. in Vienna.

[¶]at a convention of the National Academy for Child Development in Anaheim, Ca., October 1984.

Peter improved, and news about the "U" Series spread. With few exceptions, since the 1950's, I have restricted my practice to the treatment of patients with Down syndrome and other diseases associated with mental retardation.[7] The first section of this book is about treatment.

Beginning in 1959, I attempted to obtain New Drug Approval from the Food and Drug Administration. The struggle to make the "U" Series available to all who can benefit, a goal still to be attained, is presented in the second section of this book, by Ilse Nusbaum.[§] The final section of this book - "Dear World" - has been written by the patients, or by their parents, about their progress.

[7]Turkel H. and Nusbaum, I.: Treatment of the "Slow Learner." In: Ecologic-Biochemical Approaches to Treatment of Delinquents and Criminals. Ed.: Hippchen, L.J., Van Nostrand Reinhold Co. New York. 1978. pp. 254-268.

[§]Ilse Nusbaum, a 1955 graduate of Radcliffe College with a degree in English and Philosophy, received her Master's degree in English Language and Literature from the University of Michigan in 1956 and postgraduate training in Education in 1957. Following a decade of teaching (grades 4 through the university level), she became educational specialist at my office to evaluate the academic progress of the patients and to consult with parents about their children's education. Other joint publications include the prior editions of the book for parents.

Foreword
by
Bernard Rimland, Ph.D.
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How naive we are! Most of us believe that we live in a world in which important matters are directed by rational people. Especially where health and medicine are concerned are we inclined to believe that truth and reason prevail. A myth, I assure you. Dig a bit beneath the surface and you will find, as many others have, that our lives and welfare all too frequently hinge upon decisions based upon ignorance, bias and arrogant irrationality. History abounds in illustrations of this point–Pasteur, Lister, and Semmelweis are but the better known names on the long list of pioneers rejected and reviled by their contemporaries, and later proven correct. "But," you might argue, "those men were persecuted by their medical colleagues many years ago. This is the twentieth century. We have certainly learned by now to look at the evidence rather than be guided by our preconceptions. . . ."

Regrettably, the dogmatists in positions of authority today are as virulent and as impervious to reason and to objective evidence as were their predecessors in centuries past.

Take, as a case in point, the matter of Dr. Henry Turkel and the treatment he has developed for use with retarded children, especially those diagnosed as having Down's syndrome (mongolism). The facts are simple:

1. Dr. Turkel, by training a chemist as well as a physician, a man who had already proven himself as a creative innovator by developing a surgical instrument credited with saving hundreds of thousands of lives, developed a treatment (the "U" series, consisting of certain vitamins, minerals and drugs) which he asserts can greatly improve the physical and mental functioning of children with Down's syndrome. He does not assert that it will *cure* Down's syndrome, but only that it will improve the child's condition, in somewhat the same sense that insulin can greatly improve the health and lengthen the life span of diabetics without changing the genetic or biochemical defect that causes the illness.

2. He not only *asserts* that the "U" series will help these children, he *documents* it with copious objective evidence. He presents serial photographs, x-rays, and growth curves showing the child before treat-

ment and dramatically illustrating the child's progress at repeated points during the treatment. This evidence is published in books and journals and is clearly visible and understandable even to the layman. No one has questioned the authenticity of this evidence.

3. There are no competing treatments. For the most part, children with Down's syndrome have a completely bleak future. Their mental and physical abilities are so low as to preclude most of them from functioning in society. Their health is usually very poor. Parents are frequently urged to institutionalize these children and forget they ever existed. Thus, the "treatment of choice," with which the Turkel treatment must be compared, is to ignore these children, to offer no treatment, to assign them to oblivion.

4. The Turkel treatment is harmless. Even those who are opposed to it, irrational though their opposition may be, do not deny this. It has been used on thousands of Down's syndrome children throughout the world, children in frail-to-terrible health, with no harm reported.

5. Supporting Dr. Turkel's position that the "U" series is effective are the reports of dozens of other physicians around the world who have used the treatment successfully, including some 50 U.S. physicians who were using it until the U.S. Food and Drug Administration (FDA) arbitrarily interposed itself between the doctor and the family of the sick child and forced the doctors to discontinue the treatment.

These are the pro-Turkel arguments. You will agree, I think, that until conclusive contrary evidence is produced, until some evidence turns up showing that the treatment does not work or is harmful, any physician who wishes to use the treatment to try to help his pathetically helpless patients should be permitted to do so. Surely, one would think, it would take substantial and convincing negative evidence to withhold the use of this harmless, promising treatment when there are no alternative methods and the disorder is so devastating.

There is no substantial and convincing negative evidence. There is only one study in the world literature which questions Dr. Turkel's findings, and it is a trivial, improperly conducted, and inadequately reported study.

It is trivial because only twelve children were in the experimental treatment group. So small a sample can lead to findings which are suggestive but not conclusive, even if the study were properly done. It was improperly conducted because, among other shortcomings, it did not follow Dr. Turkel's specifications for the "U" series drugs it was supposed to be evaluating. For example, the investigators included vita-

min D in their version of the "U" series drugs, and vitamin D counteracts the effects the Turkel treatment is designed to achieve! It is inadequately reported because the authors wrote up their findings as a one-page article with no tabulation of data, for publication in the *Journal of the American Medical Association*. (Anyone familiar with the politics involved will be aware that had the investigators submitted positive findings, the JAMA and virtually all other orthodox medical journals would have rejected the paper, even if the study had been thoroughly and competently reported.) Note that the authors of the negative report did not report any adverse effects on the children—they said simply that the treatment did not help.

Although the FDA will refer you to the single negative report, if you inquire about the Turkel Treatment, you should not believe that FDA's official position would be different if the negative report (the massive report based on 12 cases!) did not exist. The FDA has a long and incredibly sordid record of opposition to consumer-benefiting substances, such as vitamins, and an even more sordid, if that is possible, record of failure to control industry-profiting substances such as harmful drugs and non-nutritious food additives including dyes, carcinogenic preservatives, and sugar. FDA opposition to the Turkel treatment should not surprise you.

The FDA is the organization that is trying to place vitamins on a prescription basis, vitamins such as C, E and the B complex which are quite literally safer than sugar and salt. No deaths or serious harm has resulted from the availability of these vitamins on the open market for decades, in unlimited amounts, yet the FDA is not trying to place aspirin (for example) on a prescription basis—aspirin which causes thousands of deaths each year. Such is the logic of the FDA.

The FDA is the organization which recently threatened to close down a small high-quality cannery because the owners insisted on violating the FDA standards for strawberry jam. The owners wanted to continue using 85 percent fruit, after the FDA, upon the advice of the food industry moguls, had decided that 60 to 75 percent fruit was enough. Such is the interest of the FDA in the welfare of the general public.

The FDA is the agency which prohibits the use in the U.S. of vitamin B15 (pangamic acid) which was discovered by U.S. researchers and is now widely used in Russia, where it has been found to be helpful in numerous maladies. Translations of the Russian medical literature are available in the U.S. (the FDA has not yet banned freedom of the press)

but the vitamin cannot be legally obtained, even on prescription. So progressive is the FDA.

The FDA is the organization which wrote Dr. Turkel that since mongolism is a genetic disease, it is therefore incurable and thus his treatment could not be effective such is the scientific competence of the FDA.

The FDA is the organization that is about to be investigated by Senator Kennedy's Subcommittee on Health because so many of its employees have complained of being harassed and intimidated by their superiors when their investigations turned up findings contrary to the interests of the food and drug industry. Such is the morality of those who run the FDA.

Books have been written which document the amazingly anti-humanitarian performance of the FDA. Dr. Turkel will tell you in this book of his own battle with the FDA, in his own words.

Just a few months ago Dr. Turkel showed me a letter he had received from Japan reporting that the "U" series had been used on many thousands of Down's syndrome children in Japan, at over 60 medical centers, for 10 years, with great benefit. Rather than fighting the Turkel treatment, as the U.S. government does, the Japanese government had sanctioned and sponsored the treatment of these thousands of Japanese children, and was now sending representatives to the U.S. for more help from Dr. Turkel.

Does it strike you that something rotten is going on? It is a strange, sick, incredible world that permits such things to happen.

Government-sponsored research designed to thoroughly evaluate the Turkel treatment should have been started 30 years ago. Perhaps, if the readers of this book write to their representatives in Congress in sufficient numbers, such research may yet be done.

In the meantime, what of the millions of retarded children whose treatment could have begun years ago but for FDA opposition? What has this delay cost them? The thought is appalling. If I were the parent of a child with Down's syndrome I would move heaven and earth to have the child placed under Dr. Turkel's treatment.

If enough people who read this book are moved to action, it may in the future become unnecessary to move heaven and earth if one wishes to try the safe and promising Turkel treatment on a child who otherwise has a near-hopeless prognosis. Perhaps, if enough of us protest loudly enough the FDA can be prevented from banning harmless substances such as vitamin tablets and the Turkel treatment, and instead be made to devote its attention to banning the multitudes of profitable poisons to which we are all exposed daily, in our food, our water and in the air we breathe.

CHAPTER I

Parents of an infant with Down syndrome want to know everything possible about this condition, but first and foremost, they want to know how they can help their own child. Some parents have been told that their child would disrupt family life. Some have even been advised to withhold surgery needed to save the infant's life.[8] This practice was denounced in the first (1972) edition of my book, New Hope for the Mentally Retarded, many years before the federal government decided that starving newborns to death was a form of child abuse.

When they come to my clinic, parents are given new hope regarding their child's potential, which, with or without treatment, was probably not nearly so bleak as some doctors predict. Misinformed parents have come in tears. One mother was told that all Down syndrome children develop leukemia, sooner or later. Parents have been told that their child will never walk, talk, or be toilet trained. With rare exceptions, the child will accomplish all of these skills and more, even without medical intervention. Other parents have been told about infant stimulation or educational programs, but few have been given information about medical treatment.

Down syndrome can be treated. Treatment is expected to raise the child's potential to develop skills. It is expected to accelerate development of the entire body, to help normalize physical development and function, and to improve the child's appearance, health, and educability. It is based on sound nutritional principles and empirical findings. The "U" Series therapy to remove accumulations

[8]Turkel, H.: Who Killed Baby Doe? Child's Play. Nat. Ac. Child Dev. 2:5-6 (Feb.) 1984.

pioneered the medical/ nutritional therapies for Down syndrome.[9] Despite the reluctance of some pediatricians to refer their patients for "U" Series therapy, parents by the thousands have learned about it through their own reading and research. Members of US for DS, the National Academy of Child Development, the Institutes for the Achievement of Human Potential, Parents of Down's Syndrome, and various other resource groups have visited parents of newborns with Down syndrome to share information about diet, training, and medical treatment.

Parents want to learn about the safety and efficacy of the components of the "U" Series. They also want to know about the scientific background and the effect of the third copy of chromosome 21 on their child's development. Finally, they want to know why the "U" Series is not on the market in the United States.

Before a patient's first examination, records are sent to my office. These records include the birth and medical histories, chromosome reports and a karyogram, hospital and medical records, school and I.Q. reports, T_3, T_4 TSH (thyroid) studies, and 5 X 7 photographs. In this way, I obtain background information on the child's condition before the examination and can prepare the medication. Following a thorough examination of all organ systems, and including photographs of the characteristics of the syndrome such as the elevated palate, palm prints, and assessment of the patient's social or mental age, specific ways to help that particular child reach his potential are discussed. Next, X-rays are taken at an independent clinic. Any necessary dosage adjustments or supplements are prepared at this time.

[9]Horwitz, N.: Practical Clinician Found out early on: Vitamin-Mineral Regimen Lifts Retarded. Med. Trib. (Feb. 18) 1981.

A patient's first appointment includes an overview of Down syndrome. The chromosomal basis of the disorder is reviewed, together with the implications of the excessive gene products and how their presence interferes with their child's development. Parents observe how the accumulations manifest themselves in their own child: puffiness around the eyes, chin line, neck, abdomen; the enlarged tongue, wide gum line; skeletal abnormalities seen on X-rays. I also demonstrate improvements seen in other patients. If treatment is ended too soon, new accumulations block further development.

Evelyn

Eveyln was one of the first patients to undergo long-term "U" Series therapy. Her case has demonstrated improvements that can be attributed to the treatment. "To eliminate variables of home environment, heredity, individual types and severity of abnormalities. . . the body of each patient provides its own control."[10] Effects of treatment and non-treatment were recorded over a ten-year period. The results supported the hypothesis that treatment improved general health and structural development.

Evelyn was born in Detroit on February 13, 1945, the youngest of seven children. She was 19 in. long and weighed 7 lbs. 5 oz. Her mother was 46 years old. Mongolism was diagnosed at birth. When Evelyn was 3 days old, her father was advised to file an application for Lapeer Institution. Her parents were determined to do their best for Evelyn. Even so, she was described as a child who, for almost 8 years "did not talk, was apathethic, ate if fed, and sat all the hours until it was time to put her to bed." As can be seen (figs. 4, 5), her condition became worse as she grew older, a typical phenomenon in Down syndrome. Because her digestive organs were underdeveloped, she felt starved. She was malnourished, yet heavy. She was hospitalized 7 times in 5 years. The diagnosis, photographs, X-rays, and measurements were made at Henry Ford Hospital, Detroit.

Treatment began when Evelyn was 7-9 (seven years nine months old). The parameter used for measuring improvements was the standard deviation (S.D.) of her measurements from the mean of the normal population. Her height was

[10]Turkel, H.: Medical Treatment of Mongolism. Proc. 2nd Int. Cong. Ment. Retard. Vienna, 14-19 Aug. 1961. S. Karger, N.Y. pp. 409-416 (1963).

39 1/2 in., 4.4 standard deviations below the norm, and her weight was 99 lbs., which was 4.2 standard deviations above the norm for her age cf. p. 196). Down syndrome features included: epicanthal folds, thick skin, coarse hair, underdeveloped nasal bridge, large and furrowed tongue, high-arched palate, humpback, spinal curvature, incurved fifth fingers, single palm lines, protruding abdomen, widely spaced toes, congestion of the lungs, enlarged heart, and cardiac murmurs. Her I.Q. on the Detroit Adaptation Test 11/17/52 was 46 (cf. fig. 30). Adaptive behavior studies generally test the person's social proficiency. At that time, a score of 46 was considered too low to qualify a child for special education.

Treatment was given without interruption for 10 months. November 29, 1952, Evelyn weighed 94 lbs.; December 15, 1952, 88 lbs.; March 15, 1953, 85.5 lbs. Her lungs became clearer and her heart smaller.

July 1953 - Evelyn's height was 44 in., and her weight was 88 lbs. Measurements made at Henry Ford Hospital, Detroit, were as follows: head circumference, 19.5 in.; neck, 13 in.; chest, 30.5 in., waist, 27 in., thighs, 18.5 in.; calves, 12 in.; ankles, 7.6 in. Two months later medication was discontinued.

November 1953 - new measurements were made at the same hospital. Evelyn's height was 44 in.; head circumference, 21.7 in. (accumulations, not growth); neck, 15 in.; chest, 34 in.; waist 33 in.; thighs, 21.5 in.; calves, 13 in.; ankles, 8.5 in. Serial photographs and X-rays, made at the hospital, demonstrated the rapid weight gain.

August 17, 1954 - medication was resumed. This time weight loss was sudden. Evelyn was 45 in. tall (-3 S.D.) and weighed 96 lbs. (+2 S.D.) Measurements were made September 1, 1954: weight, 90 lbs.; chest, 30.5 in.; waist, 26.5 in.; hips, 32.5 in.; thighs, 20.5 in.; calves,

12.5 in. Measurements made October 24, 1954 were as follows: weight, 87 lbs.; chest, 30 in.; waist, 25 in.; hips, 32 in.; thighs, 19 in.; calves, 12.25 in.

Treatment was again discontinued between January 1955 and May 1955. In January (age 9.11), Evelyn was 49 in. tall (-2 S.D.). During the following months she did not grow at all. Treatment was resumed between May 1955 to October 1955 (ages 10.3 to 10.8), during which time she grew 2.5 in.

August 24, 1955, her I.Q. on the Stanford-Binet, Form L, was 36. IQ variation may result from different tests and differences in standardization norms. A test of adaptive behavior is likely to yield a higher score for a Down syndrome patient than a test that emphasizes language and logic.

Evelyn's height from ages 11 to 17 was as follows: Age 11, 51.5 in. (-1.38 S.D.); 12, 55 in. (-.92 S.D.); 13, 57 in. (-1.17 S.D.); at the age of 14, her height, 59.5 in., placed her only 1.09 standard deviations below normal; by the age of 17, at the same height, she was 1.66 standard deviations below the norm. Other members of her family are also well below the norm in height. Evelyn's weight became proportional to her height, both being approximately -1.5 S.D. at the end of treatment.

She progressed from the lowest percentile of the population in height (1%) to approximately the fifth percentile, by the age of 18 (fig. 6). The gain in height and loss of weight corresponded directly to administration of medication, and failure to grow, together with weight gain, corresponded to the discontinuation of the medication. Accumulations were stored throughout her body; all structures were involved. In such a situation examination of

plasma is of limited value because of the tissue-storage problem.[11]

Treatment of Evelyn with the "U" Series led to the following improvements:

1) Improvement in general health Before the age of 5, she was hospitalized 7 times with upper and lower respiratory infections, tonsillectomy and adenoidectomy, and asthma. At home, she was continuously treated with sulfa drugs. Her hospital record weighed 2 pounds. After "U" Series treatment, she remained healthy, and no further hospital care was required.

2) Improvement in appearance Her nasal bridge developed, neck and chin lines were defined, spine straightened, fingers lengthened, skin softened, abdomen flattened, and her tongue became smaller. Proportions of height to weight normalized.

3) Social improvement At the start of treatment (age 7-9), she was not completely toilet trained; she was unable to talk, recognize letters or colors, wash, dress, or feed herself; she refused to play with toys, pets, or other children, listen to the radio, or watch television. One year later, she was toilet trained, could speak in sentences, tried to print letters, recognized primary colors, became interested in music and television, played cooperatively, and started to feed and dress herself. She knew when her favorite television programs were on and could turn to the proper channel.

April 26, 1956 (age 11-2), her I.Q. was 42 on the Stanford-Binet, Form M, although the I.Q. in Down syndrome is expected to drop with

[11]Baron, D.N.: Down with Plasma! Intracellular Chemical Pathology Studied by Analysis of Cells of Solid Tissues, Erythrocytes, and Leucocytes. Proc. Royal Soc. Med. 62:945, 1969.

age (cf. pp. 196-198 for study of decline in IQ with advancing patient age).[12] [13] [14] October 1956 (age 10-8), she helped her mother with the housework. She danced, played dress-up, and amused herself. June 1956 (age 11-5), she printed words, ran the vacuum, and babysat with her sisters' children. September 1960, she began religious training; she received sacraments of communion and confirmation the following year. October 1961 (age 16-8), she helped cook, shop; she was trusted with money. She organized her belongings in her closet, dresser, purse; she communicated experiences.

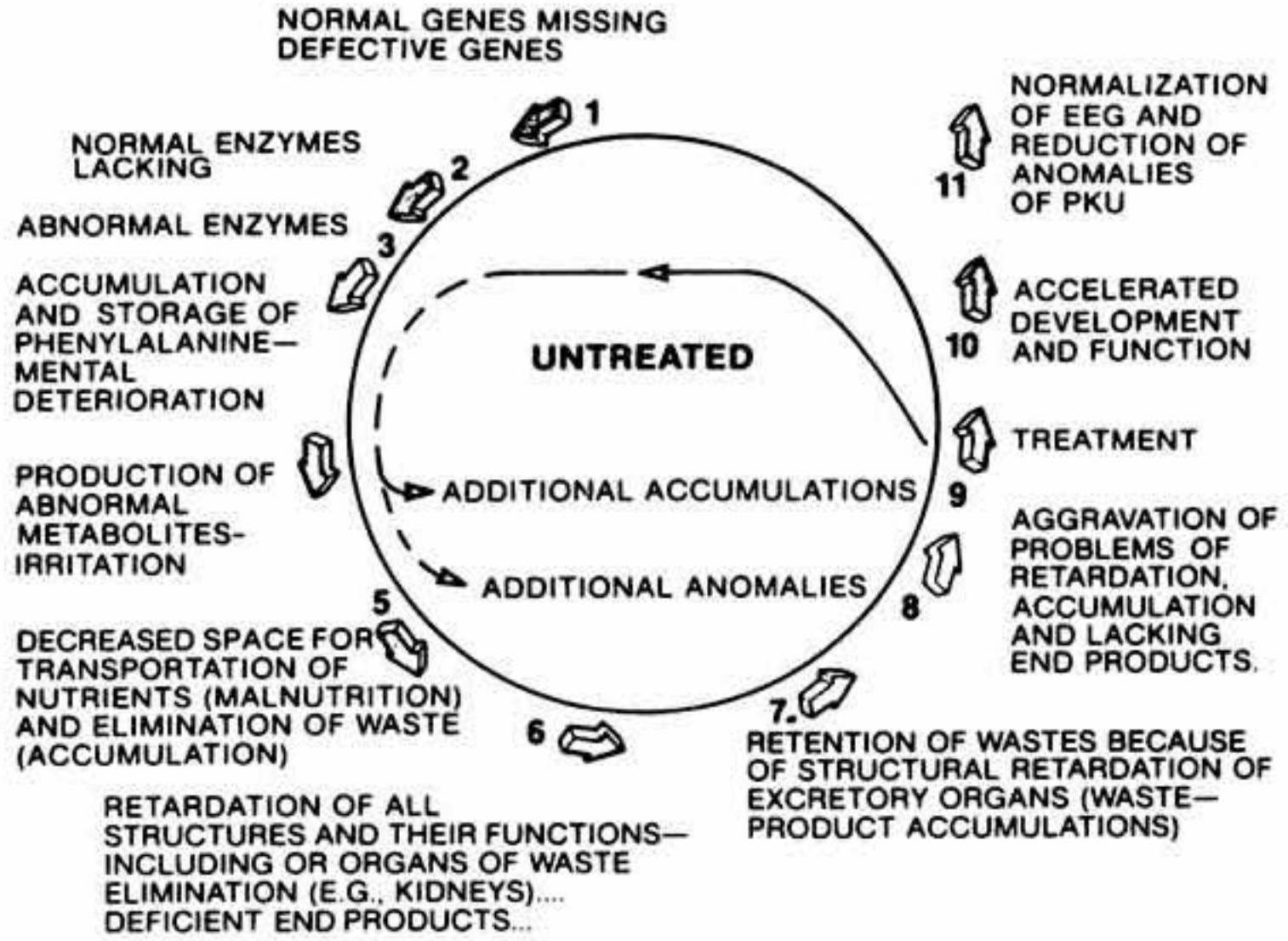
She now lives in a community home, the only Down syndrome person among six residents, where she is fully responsible for her share of housework. Despite a lack of formal education, verbal recognition abilities remained relatively high during the many years following treatment. On May 5, 1980, she attained a mental age of 11 on the Peabody Picture Vocabulary Test.

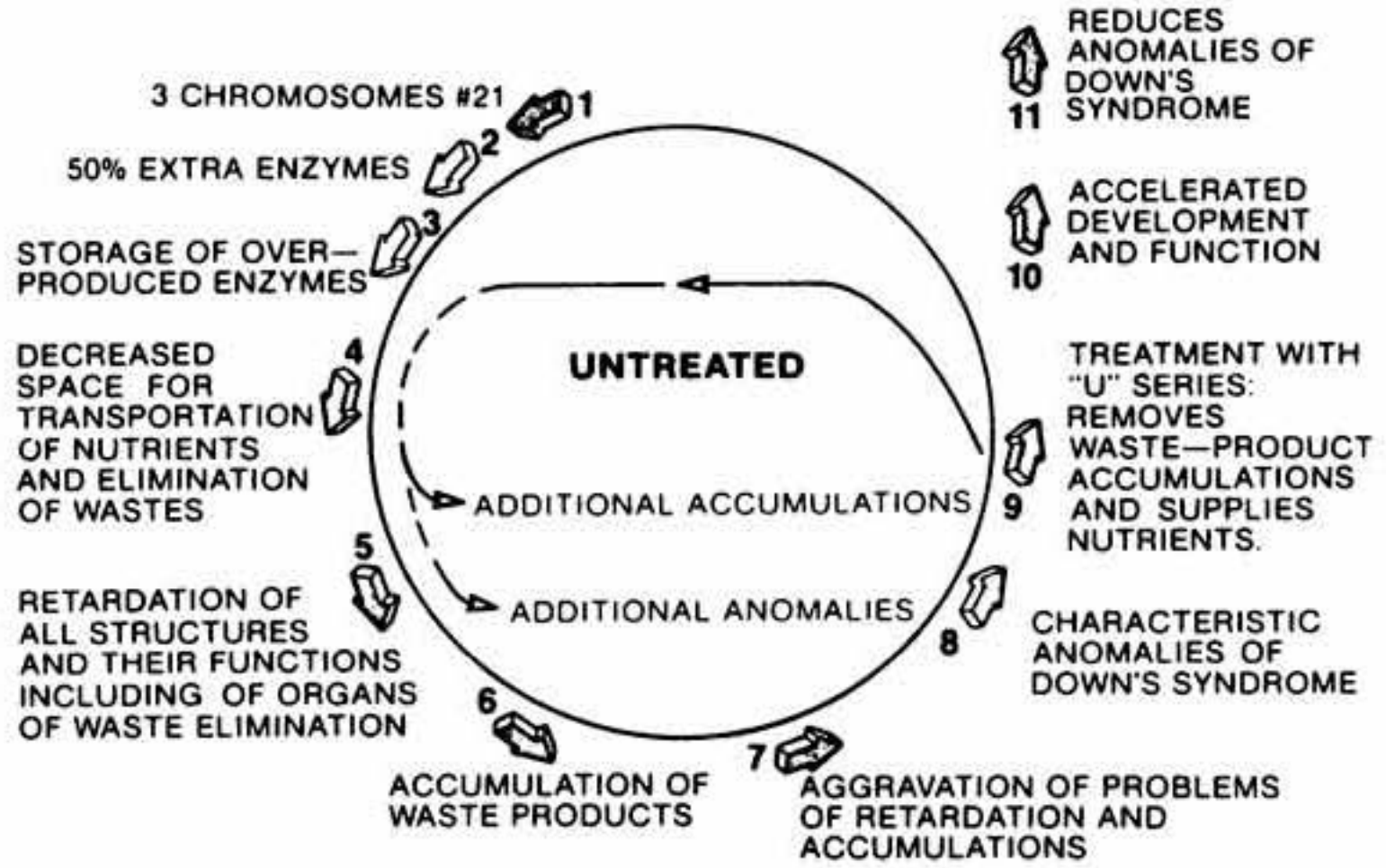
[12] Øster, J.: Mongolism. Danish Sci. Press. Copenhagen. 1953.

[13] Clements, P.R., Bates, M.V., Jafter, M.: Variability within Down's Syndrome (Trisomy 21): Empirically Observed Sex Differences in I.Q's. Ment. Ret. 14:30. 1976.

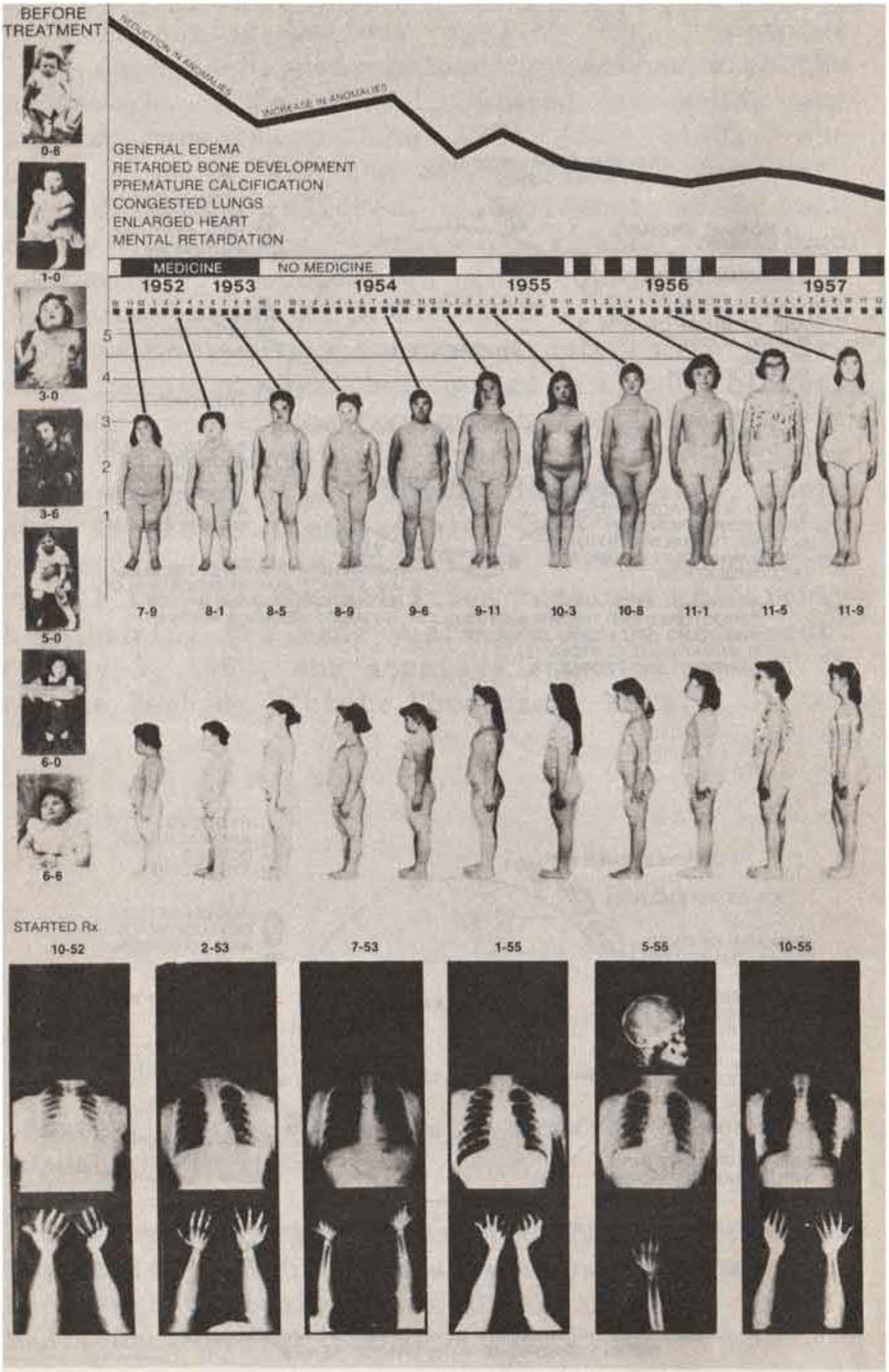
[14] Benda, C.: Down's Syndrome. Grune and Stratton. N.Y. 1969. pp. 66-70, 238.

TREATMENT WITH THE "U" SERIES

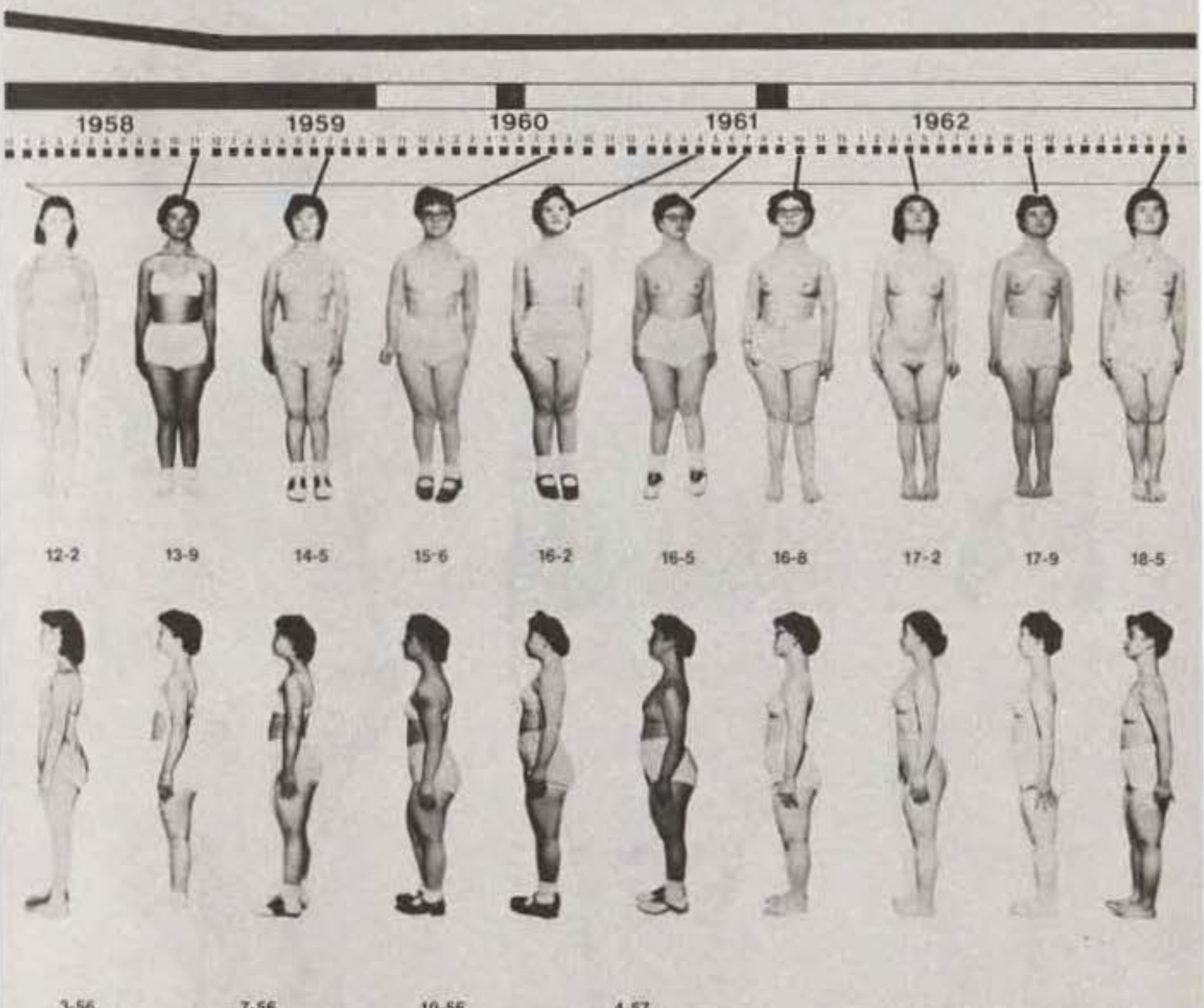


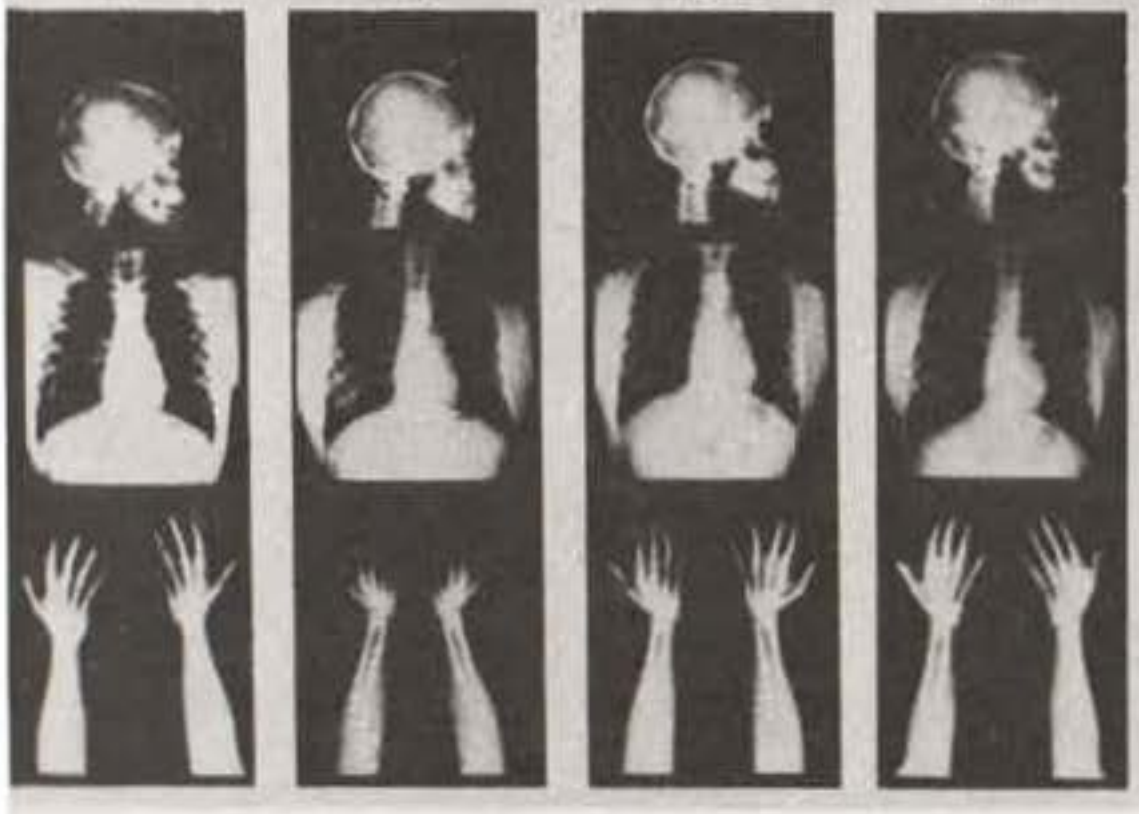


BREAKING THE CYCLE OF DEVELOPMENTAL ANOMALIES OF DOWN'S SYNDROME WITH THE "U" SERIES

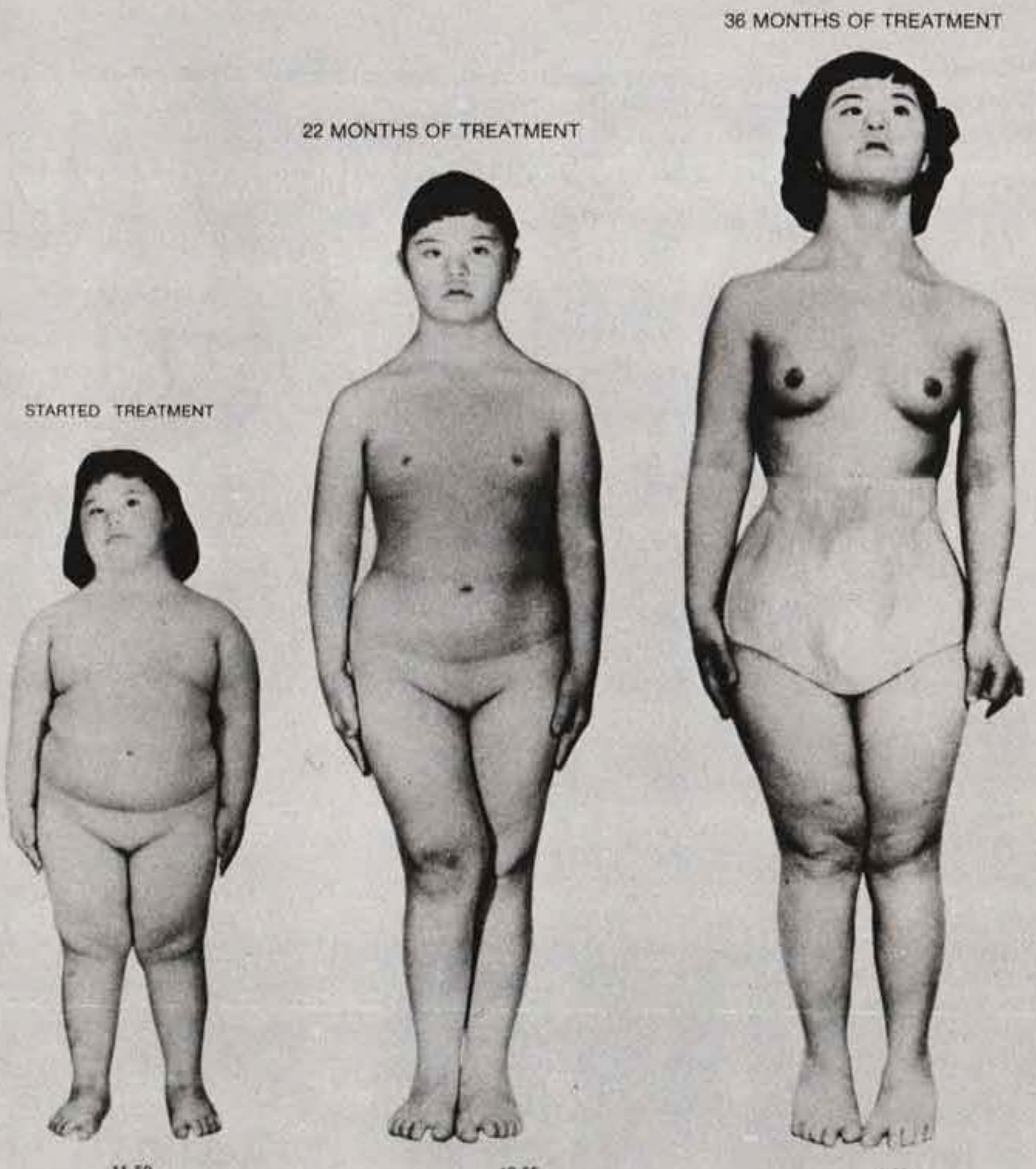

BEFORE TREATMENT
REDUCTION IN ANOMALIES
INCREASE IN ANOMALIES
GENERAL EDEMA
RETARDED BONE DEVELOPMENT
PREMATURE CALCIFICATION
CONGESTED LUNGS
ENLARGED HEART
MENTAL RETARDATION
MEDICINE
NO MEDICINE
1952
1953
1954
1955
1956
1957
0-6
1-0
3-0
3-6
5-0
6-0
6-6
7-9
8-1
8-5
8-9
9-6
9-11
10-3
10-8
11-1
11-5
11-9
STARTED Rx
10-52
2-53
7-53
1-55
5-55
10-55

EFFECT OF "U" SERIES ON DOWN'S SYNDROME

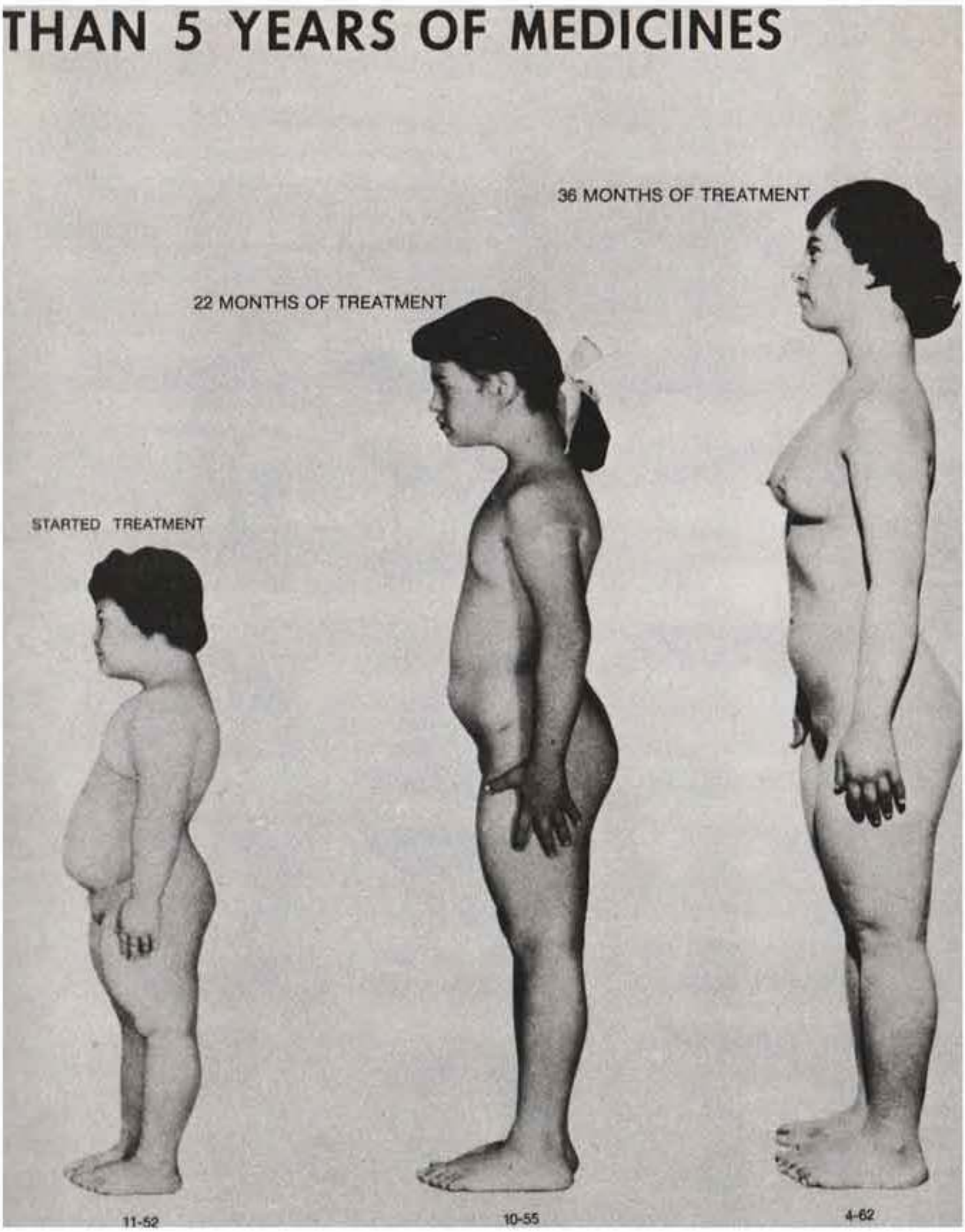




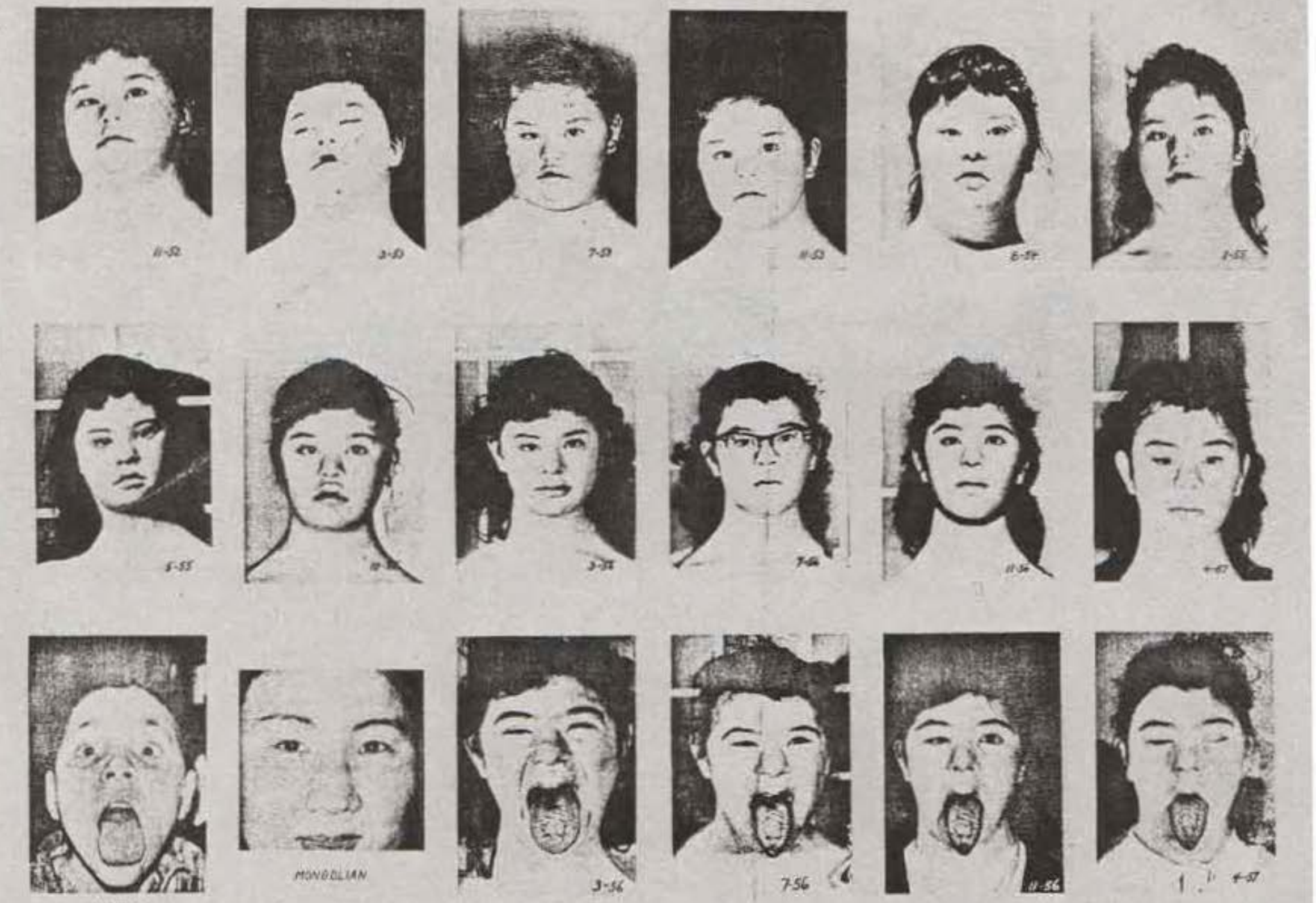
DURING THESE 10 YEARS PATIENT RECEIVED LESS



THAN 5 YEARS OF MEDICINES

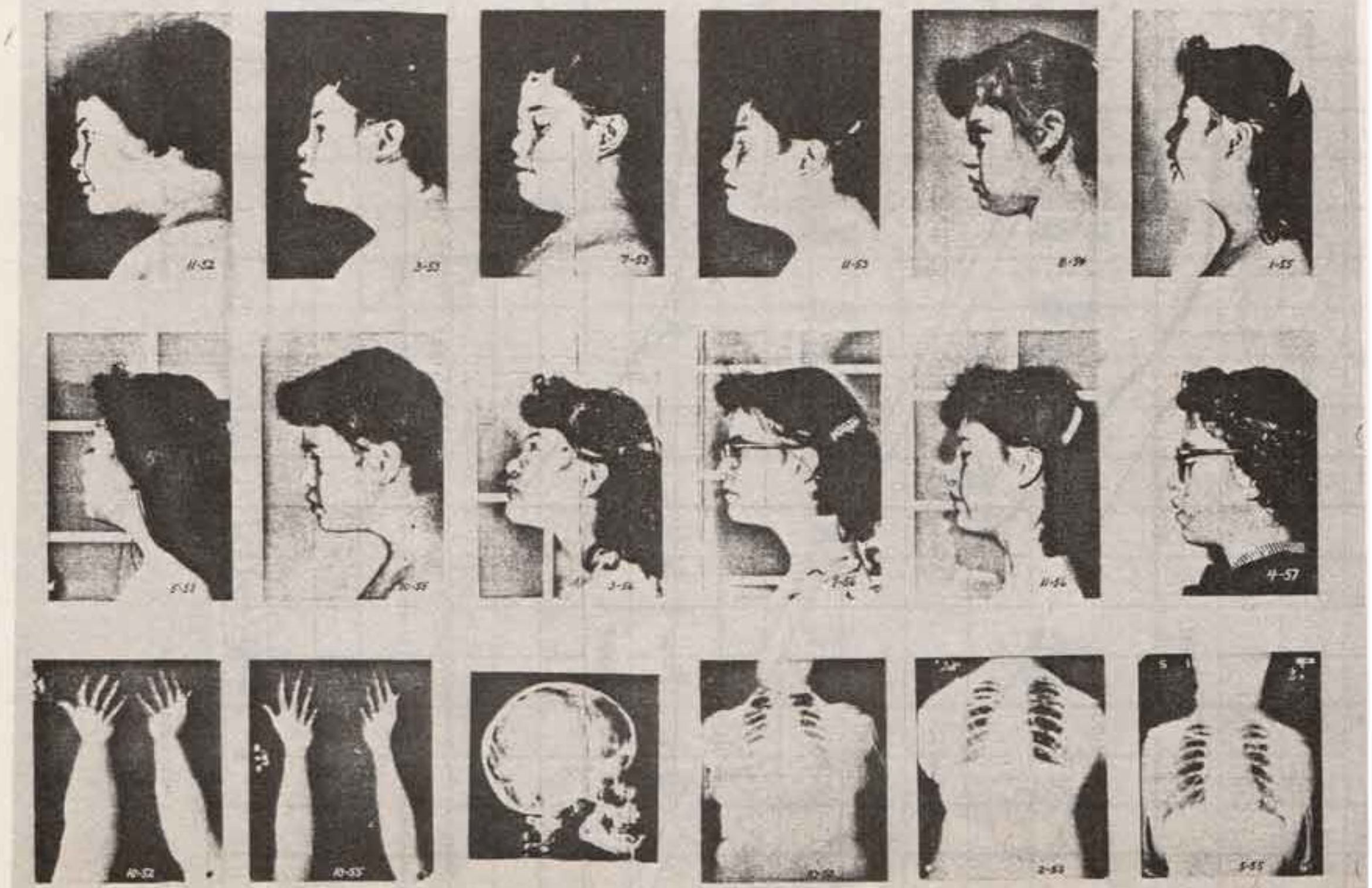


MEDICAL TREATMENT OF MONGOLOIDS



MEDICATION WITHHELD FROM NOV. 1953 TO AUG. 1954 AND JAN. 1955 TO MAY 1955

MEDICAL TREATMENT OF MONGOLOIDS



MEDICATION WITHHELD FROM NOV. 1953 TO AUG. 1954 AND JAN. 1955 TO MAY 1955

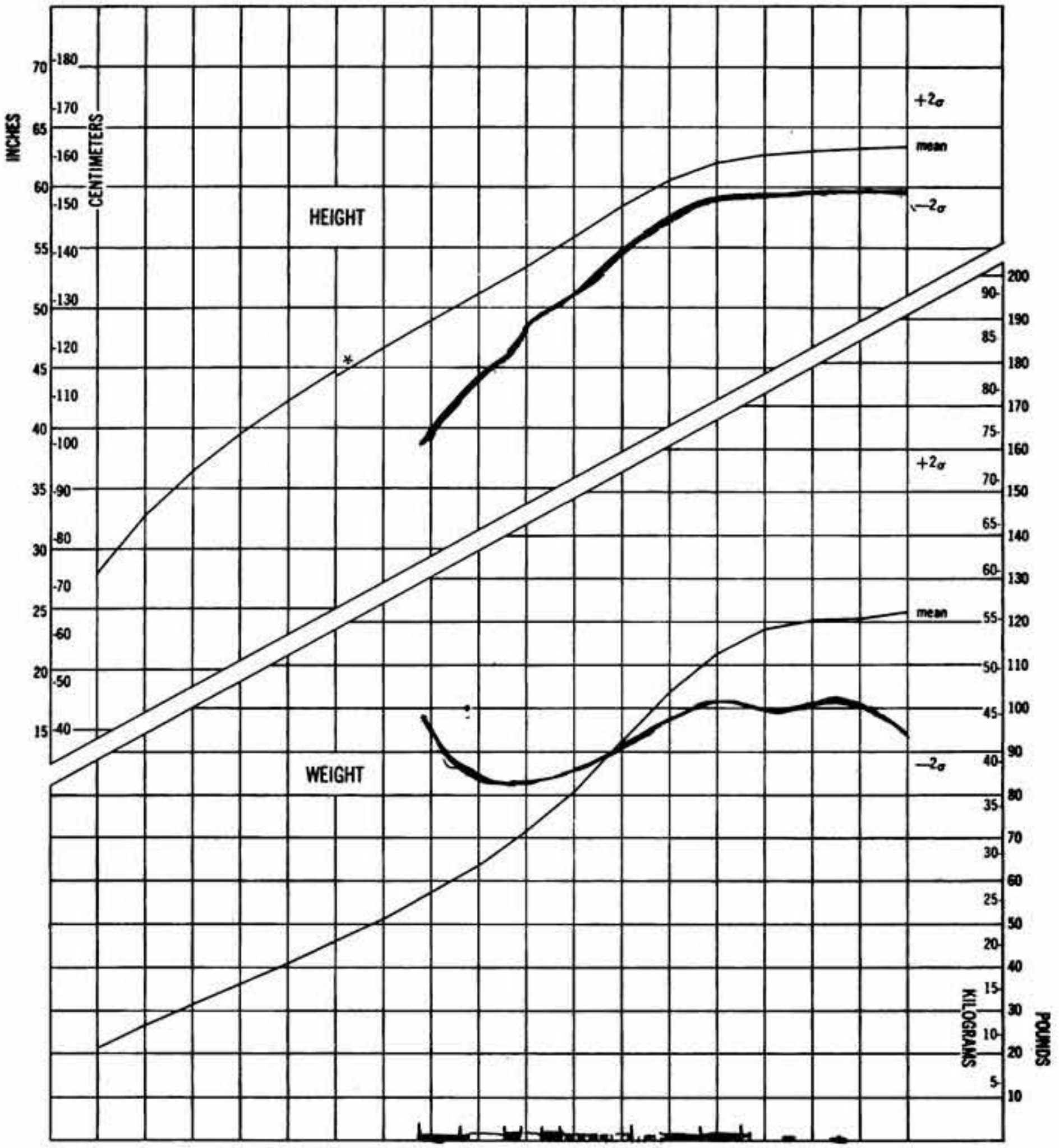
NAME Evelyn P

B/D 2-13-43

7-9 5

GIRLS / PHYSICAL DEVELOPMENT
1 TO 18 YEARS

*supine length to 6 years, standing height from 6 to 18 years



Stanford Hospital

CHROMOSOME ANALYSIS

Req. by Dr. Howard
Service Endo.
Spec. Bld.

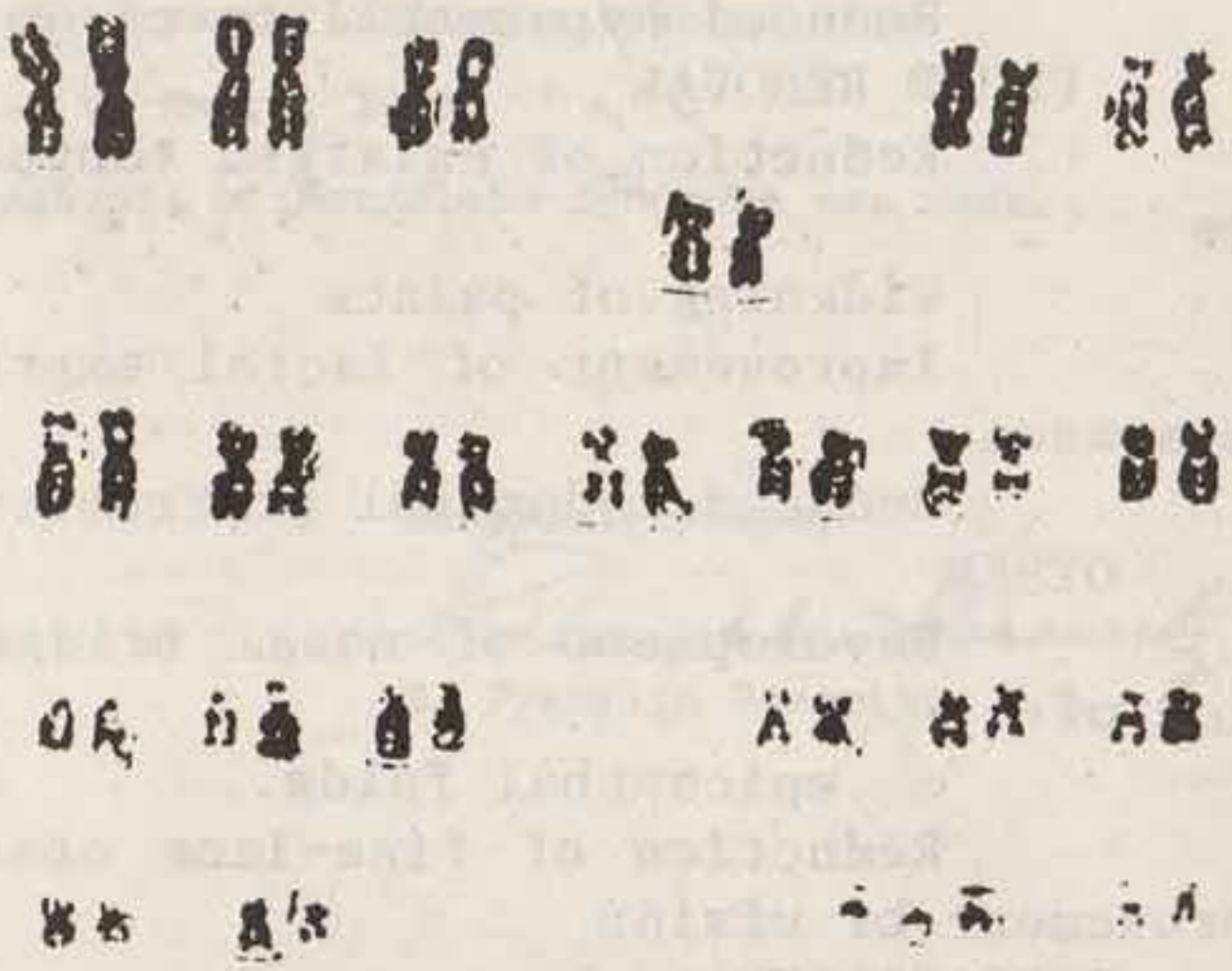
M.R.N. 043 94 72-7
NAME [redacted], Evelyn

I CHROMOSOME COUNT AND DISTRIBUTION:

	45	45	46	47	48	49	Total
Cells Counted	___	___	___	15	___	___	15

II CLINICAL FINDINGS: Down's syndrome.

III KARYOTYPE 47,XX,+21 133.4-8.5 13,611



IV INTERPRETATION: G-banded chromosome analysis of 15 peripheral blood lymphocytes revealed a karyotype of 47,XX,+21.

Impression: 47,XX,+21 - female with Down's syndrome.

Daniel Van Dyke Ph.D./M.D.

The features of Down syndrome that usually improve are those associated with metabolic accumulations, especially fluid retention.
Improvements that occur most of the time:

GENERAL HEALTH

Enlarged heart

Pulmonary congestion and increased lung capacity

SKELETAL DEVELOPMENT

Hip sockets

Bone age - general growth

Reduced hypermotility of joints

FLUID REMOVAL

Reduction of enlarged tongue and fissures

Widening of palate

Improvement of facial expression and appearance

Reduced abdominal protrusion

OTHER

Development of nasal bridge with reduction of epicanthal folds.

Reduction of fine-lens opacities and improvement of vision

EDUCABILITY

Increased attention span

Improvements that occur some of the time

SIGNIFICANT IMPROVEMENT IN I.Q.

SKELETAL

Reduction of scoliosis (with foot support)

Improvements that occur rarely

SKELETAL

Single-palm line divides

Incurved fifth fingers straighten

S. Franklin Horowitz, M. D.
Center Medical Building 1415 Center Avenue
Bay City, Michigan

June 23, 1956

TO WHOM IT MAY CONCERN

Re:Judy Krzywosinski

The above named child was seen at this office on Nov.6, 1953.

A diagnosis of Mongoloid Syndrome was made.

Sincerely yours,

S. Franklin Horowitz M.D.

S. Franklin Horowitz, M.D.

SFH/ger

CYTOGENETIC CONSULTATION

BDDL No.: 2046

Reg. No.: 1540 219 2
Krzywosinski, Judy

ferring Service: Dr. Turkel

—R. ring to: E. H. Y. Chu, Ph.D.
R.D. Schmickel, M.D.
K2015 Holden Building
764-0579

Karyotype requested on 38 y.o. retarded white female.

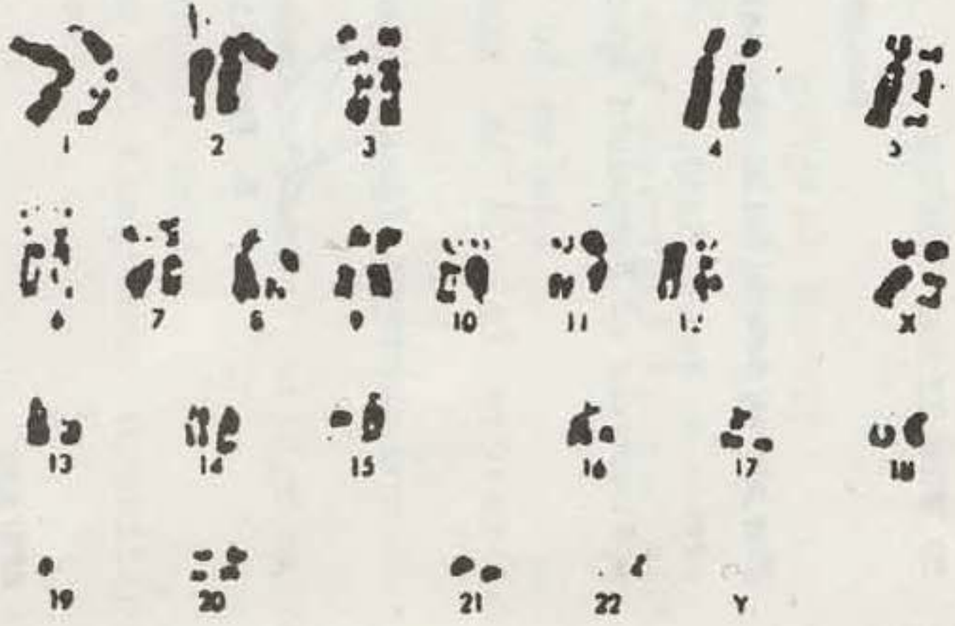
Location: Lab

Date: 9/8/78

CONSULTANT'S STATEMENT

Chromosome Analysis and Buccal Smear: 24/25 cells 46XX
1 25 cells 44

KARYOTYPE



Ernest H. Y. Chu, Ph.D.
Roy D. Schmickel, M.D.
Birth Defects Diagnostic Labora
University Hospital
Ann Arbor, Michigan 48109

Cytogenetic Diagnosis: 46XX female with no detectable chromosomal abnormalities by Giemsa banding.

Judy

Judy was born October 12, 1939, the fifth of six children. She stopped growing when she was 5. On the basis of a clinical diagnosis of mongolism, "U" Series therapy began August 1, 1956. Judy's face was prematurely aged; however, her bone age was only 5 to 6 years. She was 40.5 in. tall and weighed 58 lbs. Features characteristic of Down syndrome included a depressed nasal bridge, high-arched palate, furrowed tongue, enlarged heart, nasal and pulmonary congestion, incurved fifth fingers, hypermotile joints, underdeveloped sinuses, protruding abdomen.

After 2 months of medication, she was 43 in. tall and her bone age was 7 years. During the following months, there was rapid growth, development of the sinuses and breasts, and considerable increase in the length of the long bones. During 10-1/2 months of treatment, Judy grew 9-1/2 in. Her heart size decreased, and she became considerably healthier, with fewer colds. When she was 20-9 years old, her bone age was 13-14 years, and at age 21-9 her bone age was 15 years. Virtually all improvements occurred while Judy was given the "U" Series. There was no improvement when medication was discontinued.

At the age of 16-10. Judy did not speak, dress, or feed herself. She was uncooperative and did not socialize with others. Three months later, her attitude was more cooperative and she was eager to learn. By the age of 17-5, she was trying to dress and feed herself and was saying a few words. She was able to follow verbal instructions. At the age of 17-11, she was helping with simple household chores, such as cooking, cleaning, setting the table. She began to speak in short sentences. By the age of 21-8, she was able to shop and babysit.

REDUCTION IN INBORN STRUCTURAL AND FUNCTIONAL ANOMALIES
DECREASE IN PREMATURE AGING AND CALCIFICATION
RAPID DEVELOPMENT OF RETARDED ORGANS AND TISSUES

BEFORE TREATMENT

2Y10M

PREMATURE AGING
PREMATURE CALCIFICATION
DELAYED SINUS DEVELOPMENT
DELAYED BONE DEVELOPMENT
DELAYED BREAST DEVELOPMENT
ENLARGED HEART
MENTAL RETARDATION

REDUCTION IN ANOMALIES

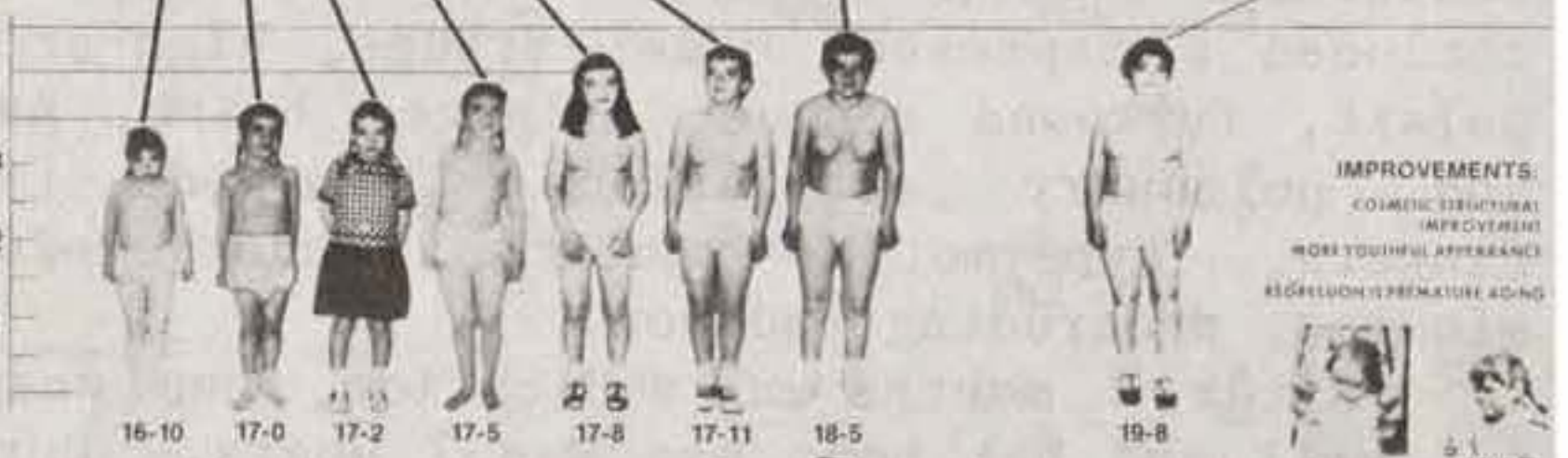
INCREASE IN ANOMALIES

MEDICINE

NO MEDICINE

1956 1957 1958 1959

10-0



16-10 17-0 17-2 17-5 17-8 17-11 18-5 19-8

IMPROVEMENTS:

COSMETIC STRUCTURAL IMPROVEMENT

MORE YOUTHFUL APPEARANCE

REGRESSION IN PREMATURE AGING

2Y 10M

10/4年
10Y

14-10

8-56 9-56 4-57 7-58

8/54
14Y 10M

7/56
16Y9M

16-9
40.5"

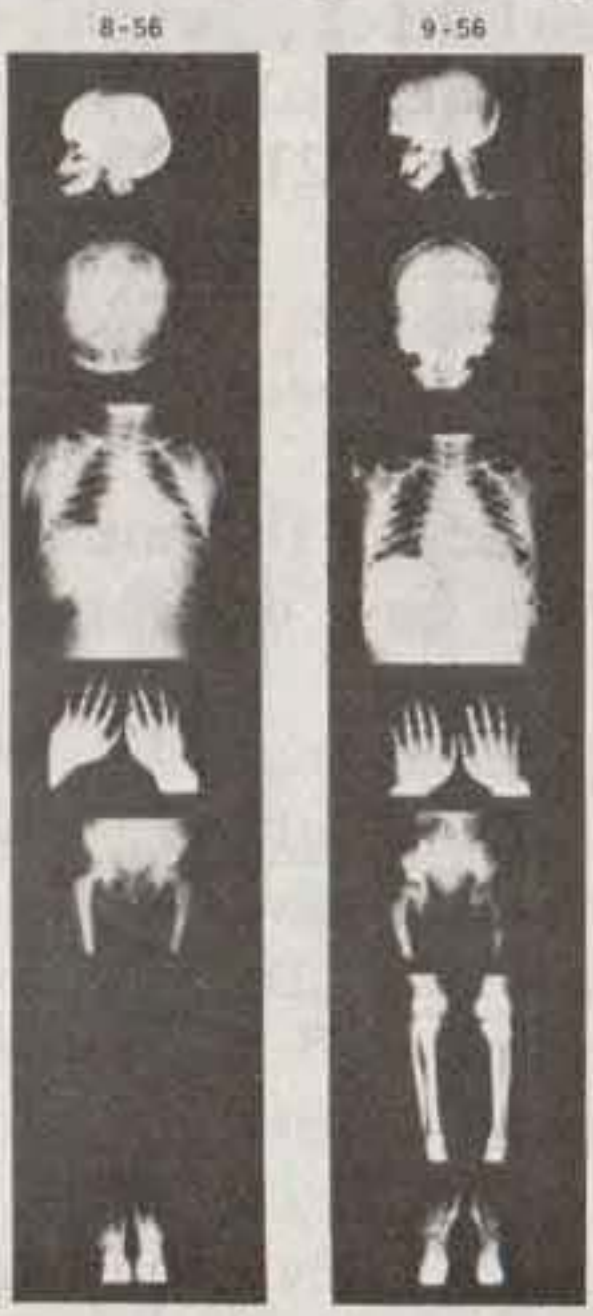
7/56
16Y9M

8/56
16Y10M

8/56
16Y10M

10/56
16Y11M

16-9



11/56
17Y

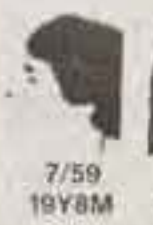
1/57
17Y2M

1/57
17Y2M

7/57
17Y8M

7/57
17Y8M

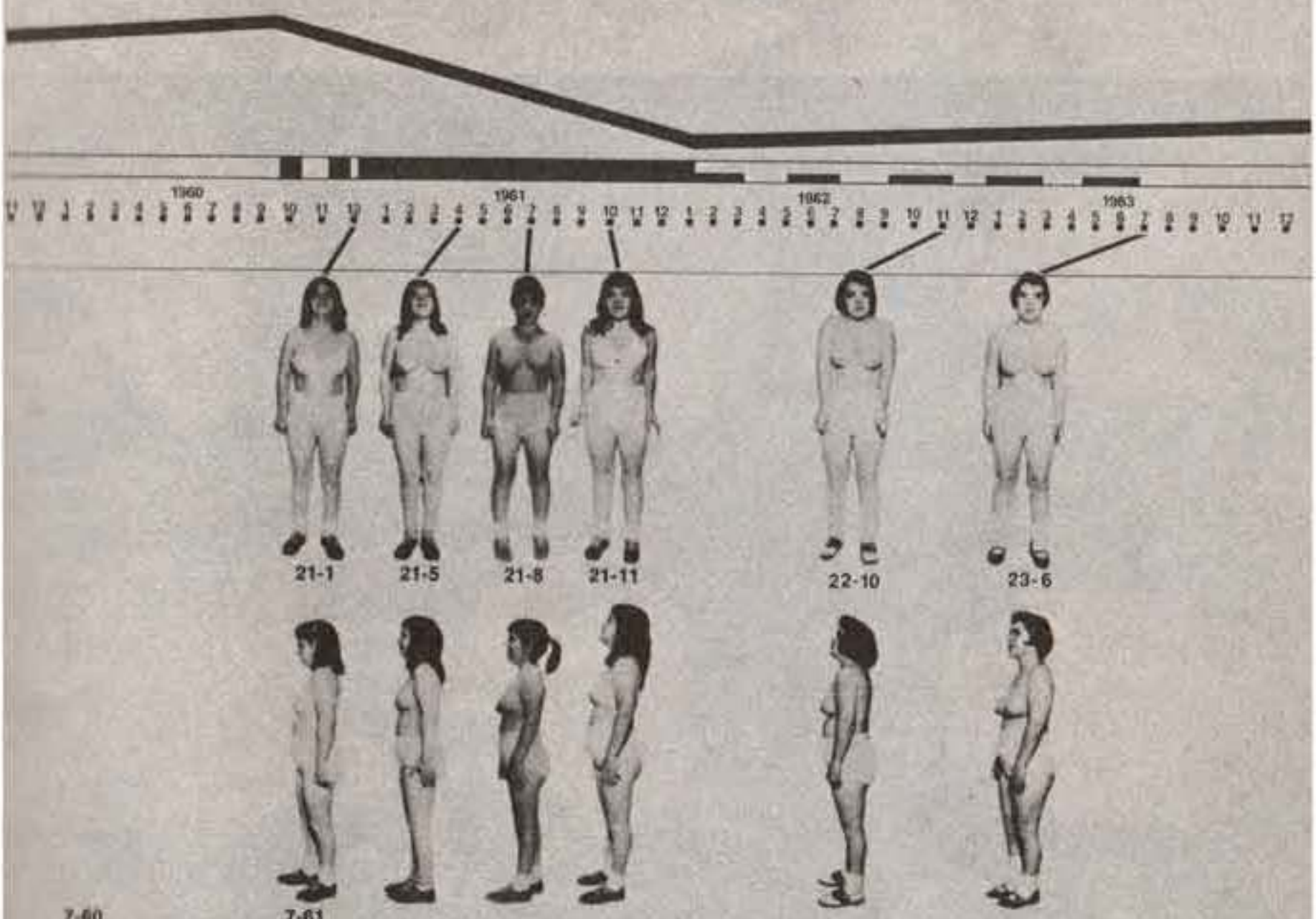
7/59
19Y8M

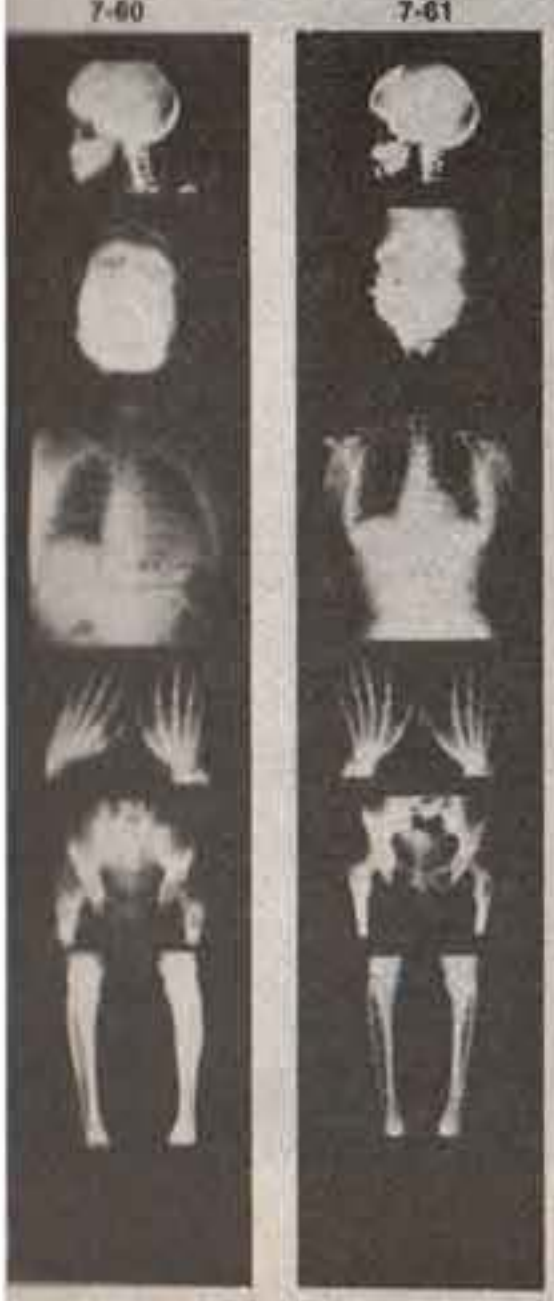


7/59
19Y8M

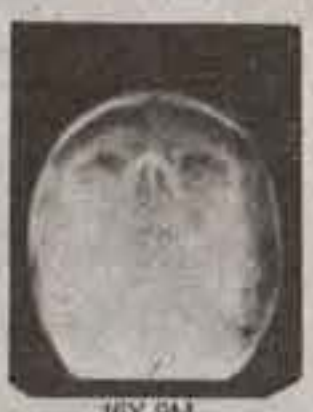
4/61
21Y5M

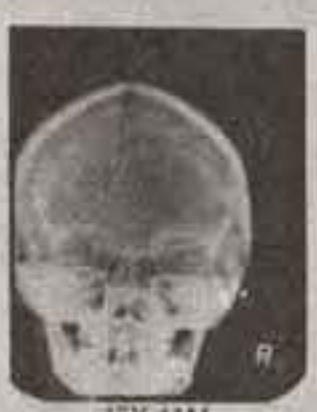
EFFECT OF "U" SERIES OF DRUGS



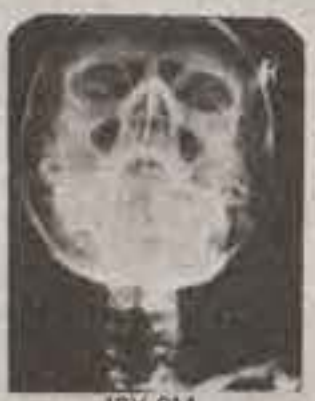


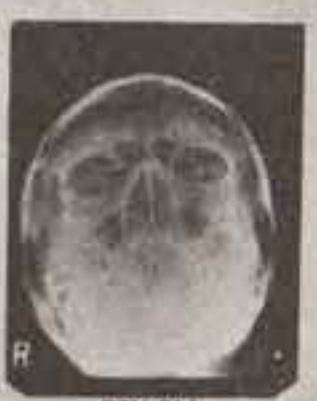
'U' SERIES DEVELOPS RETARDED ORGANS AND TISSUES I.E. FRONTAL SINUSES


16Y 9M

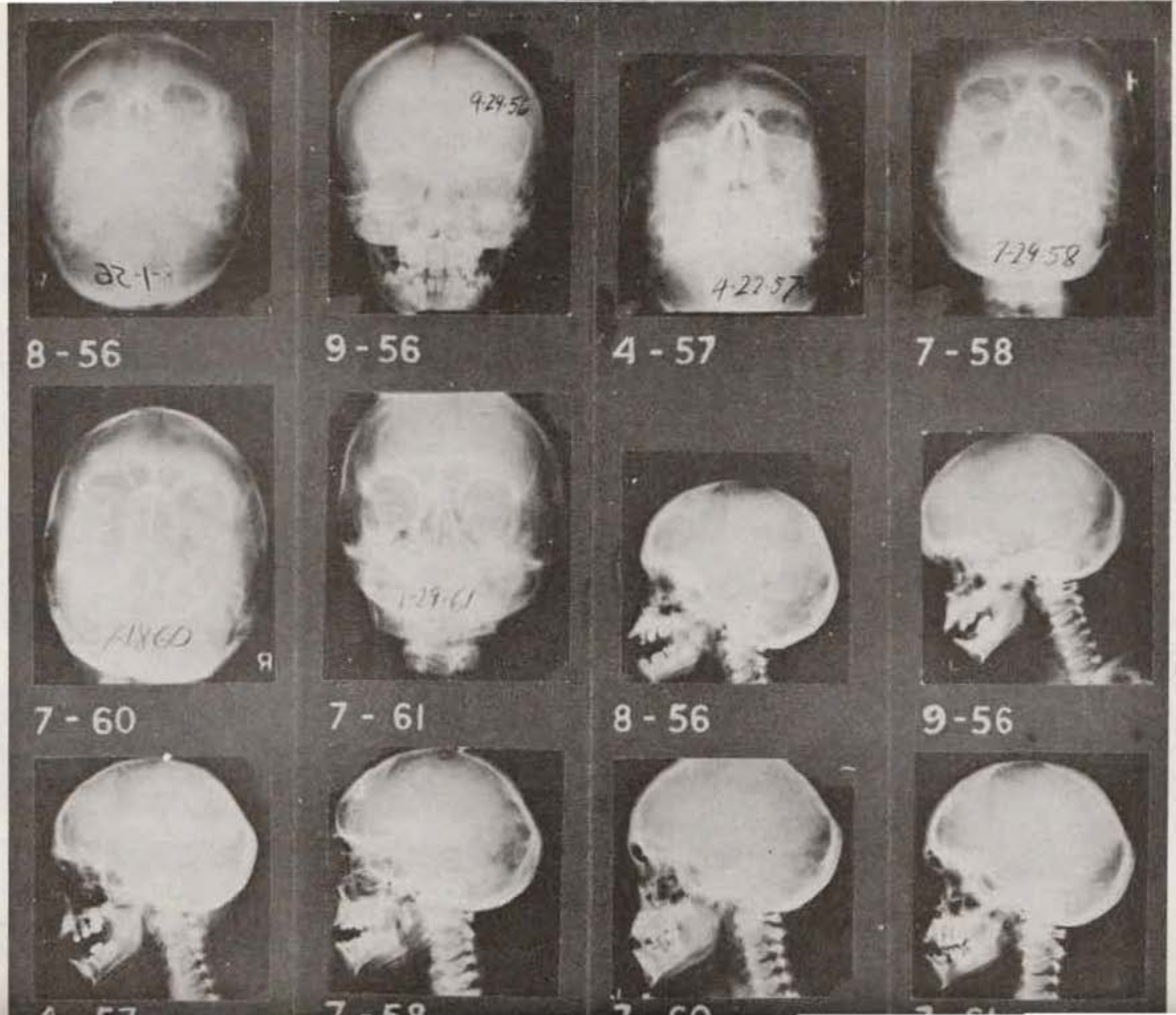

16Y 11M


17Y 6M


18Y 9M


20Y 9M


21Y 9M

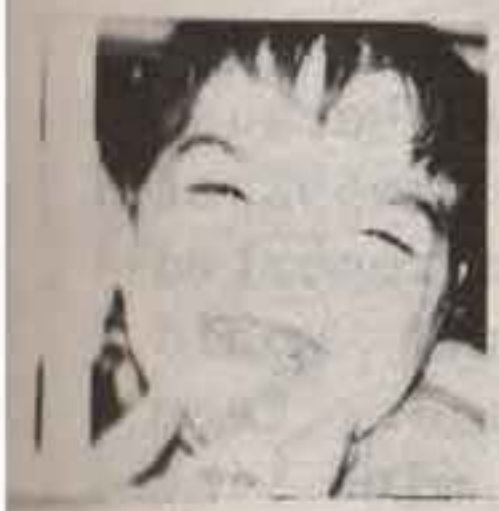

8 - 56
9 - 56
4 - 57
7 - 58
7 - 60
7 - 61
8 - 56
9-56

8/1942 age 2.10

10/1949 age 10

8/1954 age 14.10

7/1956 age 16.9



7/56 age 16.9

8/56 age 16.10

8/56 age 16.10

10/5/56 age 16.11

11/1/56 age 17

1/57 age 17.3

1/57 age 17.3

6/57 age 17.8

6/57 age 17.8

7/59 age 19.9

7/59 age 19.9

4/61 age 21.6

CHAPTER II

The "nutritional teamwork principle" has been defined by Drs. Roger J. Williams and James Heffley as the body's normal utilization of all nutritional elements simultaneously every day. In a study of the principle in action, they discussed the regression of galactose-induced cataracts in rats.[15]

Their studies are pertinent to the treatment of patients with Down syndrome because fine-lens opacities have been reported in 59% of these patients, and cataracts have been reported in 1.3%.[16] A study of older patients would possibly reveal an even higher incidence. Even fine-lens opacities would interfere with the person's ability to see and to learn.

Nutritional studies have demonstrated that a low-carbohydrate diet is capable of reducing levels of sorbitol, which causes cataracts when it penetrates the lens in hyperglycemia. Dulcitol similarly accumulates in galactosemia. Aldose reductase, the enzyme associated with development of cataracts, can be inhibited by a number of methods. For example, the presence of ketones, as well as certain anti-allergy compounds, flavonoids, and sorbinil, was found

[15]Heffley, J.D. and Williams, R.J.: The Nutritional Teamwork Approach: Prevention and Regression of Cataracts in Rats. Proc. Nat. Acad. Sci. USA, 71:4164-4168 (October) 1974

[16]Smith, D.W.: Recognizable Patterns of Human Malformation - Genetic, Embryologic and Clinical Aspects. 2nd Ed. W.B. Saunders. Phila. 1976.

to inhibit its actions.[17]

The study of Dr. Ruth Harrell and co-workers, who tested Dr. Williams' genetotrophic concept with high dosages of vitamins and minerals (GTC formula),[18] further confirmed findings that a type of human cataract responds favorably to nutritional therapy.[19] Alternatively, high levels of glucose or galactose in susceptible individuals produce

[17]Malaisee, W.J. et al. Influence of Carbohydrate Intake upon Plasma Sorbitol Concentration in Normal Subjects. Am. J. Clin. Nutr. 34 (Sept.) 1981.
Cogan, D.G., moderator: Aldose Reductase and Complications of Diabetes. Annals Int. Med. 101:82-91 (July) 1984.

[18]Harrell, R., Capp, R., Davis, D., Peerless, J., and Ravitz, L. (1981) Proc. Natl. Acad. Sci.,USA 78,574-578.

[19]Atkinson, D.T. (1952) The Eye, Ear, Nose and Throat Monthly, 31:79-83. 1952.

cataracts.[20] [21] [22] [23] New techniques have permitted more thorough investigation into the role of sorbitol, dulcitol, and other water-soluble substances as related to cataract formation.[24]

Despite general medical agreement that only surgery can remove cataracts, if an enzyme activated by high levels of sugar starts the process of deterioration in metabolic cataracts, **prevention of the harmful metabolic step by use of the inhibitors of that enzyme may be helpful.** Although most healthy patients with mature cataracts require surgery for rapid resolution of their problem, patients for whom surgery is contraindicated can be treated nutritionally, because this treatment is safe and they may benefit. Patients with metabolic disorders often associated with cataracts, such

[20]Van Heyningen, R.: Formation of Polyols by the Lens of the Rat with Sugar Cataracts. Nature 184:194-5. 1959.

[21]Kinoshita, J.H, Kador, P., Catiles, M.: Aldose Reductase in Diabetic Cataracts. JAMA 246:257 (July 17) 1981.

[22]Lorand, L., Hsu, L.,Siefring, G., Jr., and Rafferty, N.: Lens Transglutaminase and Cataract Formation. Proc. Natl.Acad.Sci.,USA. 78: 1356-1360 (March) 1981.

[23]Garner, M.H.; Roy, D.; Rosenfeld, L; Garner, W.; Spector, A.: Biochemical Evidence for Membrane Disintegration in Human Cataracts. Proc. Natl. Acad. Sci.,USA 78:1892-1895 (March) 1981.

[24]Kinoshita, J.H. Merola, L. Satah, K., Dikmak, E.: Osmotic Change Caused by the Accumulation of Dulcitol in the Lenses of Rats fed with Galactose. Nature. 194:1085-7. 1962.

as diabetes, may be given the "U" Series to help prevent the formation of cataracts.[25] [26] [27]

[25] Turkel, H.: Medical Amelioration of Down's Syndrome Incorporating the Orthomolecular Approach. Journal of Orthomolecular Psychiatry 4:102-115 1975.

[26] Turkel, H.: Treatment of a Mucopolysaccharide Type of Storage Disease with the "U" Series. Jrl. Orth. Psych. 10:239-248 1981.

[27] Turkel. H.: In Second Internat'l. Congress on Mental Retardation. Vienna. 1961. Ed. Stur, O. (S. Karger, Basel) 1963 pp. 409-416.

Larry, a Down syndrome patient, was born May 23, 1959, by cesarian section. A septal defect was diagnosed at birth. Cyanosis and pneumonia led to hospitalization at 6 months and again at 17 months. At 18 months he learned to walk. He was reported to be speaking at the age of 3, but he gradually lost all verbal comprehension. He was toilet trained and started school at 4. The same year, he underwent open-heart surgery: an aortic and a ventricular defect were corrected.

When he was 6, his mental age on the Cattell Infant Scale was 10 months. At the chronological age of 7-9 his mental age on the Cattell Infant Scale was 11 months. When he was 8, he was placed on Mellaril. Reevaluated at the age of 9-8 8 months on the Cattell Infant Intelligence Scale, his mental age was 15 months, and his developmental age was 18 months. He succeeded only at tasks requiring the grasping or manipulation of objects, and had no understanding of language. He rocked, kicked, dropped test materials on the floor, grunted, made unusual noises, and was extremely distractible and hyperactive throughout the testing. Most likely, he was visually impaired by the developing cataract from an early age.

When Larry was 10, his mother was told by the Ohio Medical College ophthalmologist that for all practical purposes, her son was blind because of bilateral cataracts. He was examined at the Ohio Medical College Eye Clinic regularly thereafter.

From the records of Ohio Medical College.

June 11, 1971: Intumescent cataract of right eye diagnosed. July 2, 1971: Cataract of the left eye noted. February 25, 1971: Right eye intumescent cataract; left eye cataract moderately advanced. September 6, 1973: Right eye - dense cataract; left eye maturing

cataract. June 6, '1974: Bilateral cataracts, intumescent right eye. Left eye, probable posterior subcapsular cataract. "Plan no surgery until cataract, left eye, becomes mature."

He entered Columbus State Institution at the age of 15. Shortly thereafter, his mother learned about the "U" Series therapy. I examined him April 28, 1975. In addition to the bilateral cataracts, Larry had a slight heart murmur and serious facial tics, probably related to the many years that he had been given Mellaril. Even on Mellaril, his behavior was wild and alarming. Mellaril was discontinued before the "U" Series could be given. The "U" Series was first given July 7, 1975, to be dispensed at Columbus State Institution. Treatment started July 28, 1975.

November 10, 1975: He grew 2 inches and lost 10 pounds. His head circumference grew almost 4 cm. His left eye was clearer and reacting to light. The cataract of the right eye remained unchanged. Cataract surgery was postponed.

January 30, 1976: Reexamined at Ohio Medical College: "Dense mature cataract, right eye. Posterior subcapsular cataract, left eye.

"Cataract extraction recommended on right eye since left eye will follow suit in time.

"July, 26, 1976: Cataract apparently improving, right eye," vision improving, mentality improving. Larry was scheduled for speech therapy.

Although the "U" Series was not dispensed regularly at Columbus State Institution, he continued to grow taller. His left eye was clearer, right eye less cloudy. He was given additional B_{12}, 500 mg., three times daily; additional nicotinic acid, 40 mg., twice daily; and additional bromolain, 40 mg., and papaya enzymes, 10.67 mg., six times daily.

August 29, 1977: The ophthalmologist reported: "Dense cataract right eye; nuclear

cataract left eye. Mother thinks he is seeing better recently."

November 18, 1977: Larry was experiencing fewer tics and spasms. Vitamin E helps prevent some of the problems experienced by patients like Larry who have taken Mellaril.[28] Photographs demonstrate that the cataracts are less dense.

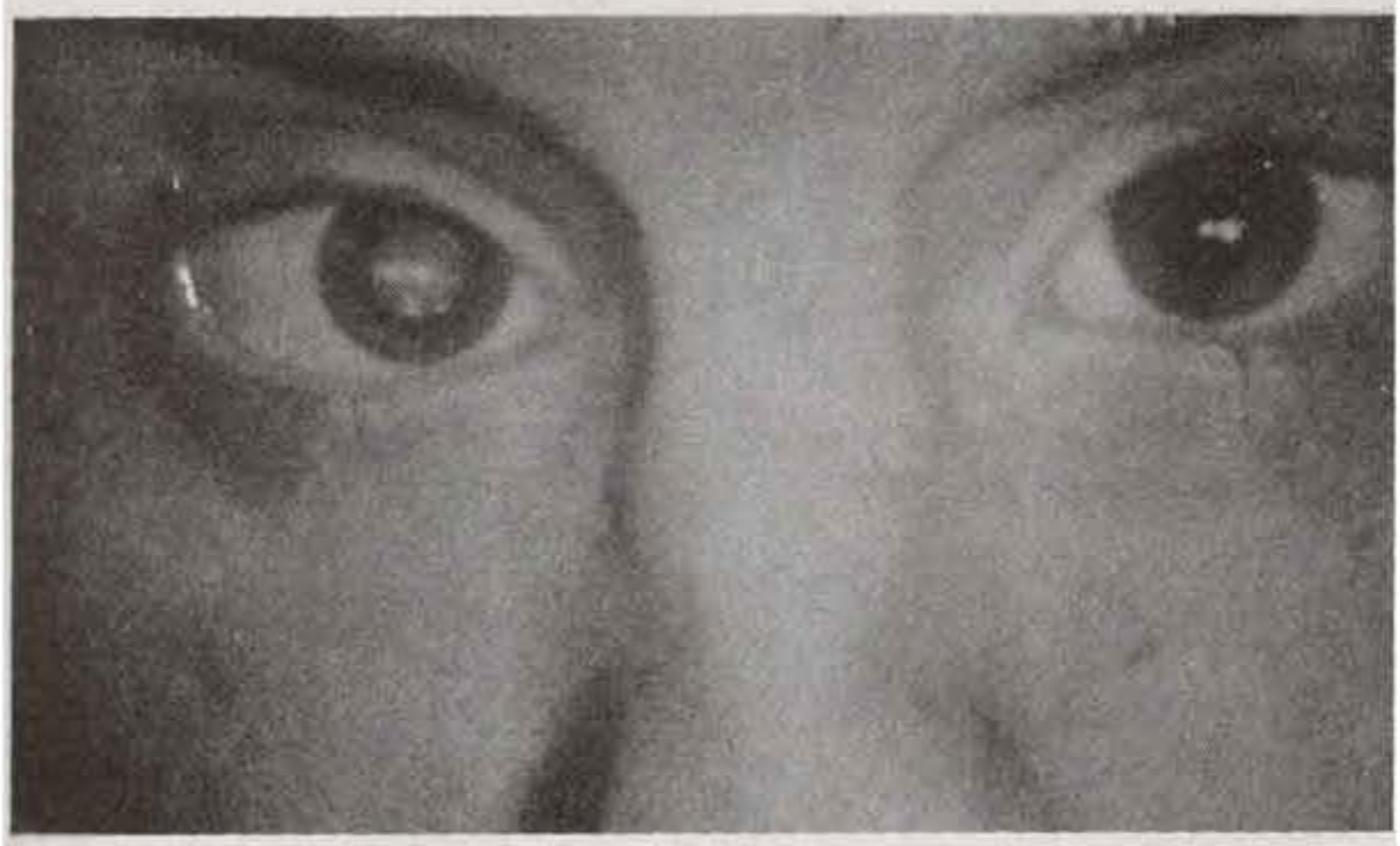
February 5, 1979: He had not received medication for nine months. During this time he gained 10 pounds and became irritable and hyperactive. Medication for six months was dispensed. During the following months, there was little physical change, but he began to develop essential self-help skills. June 4, 1980: The school nurse noted that Larry's right cataract was gone and advised that he be reexamined at the Medical College of Ohio Eye Clinic.

From the ophthalmologic report: Visual acuity of the right eye: 20/20; left eye 20/100. Impression: Rupture of mature cataract OD ?traumatic? Cataract OS.

There was no trauma or sign of rupture.

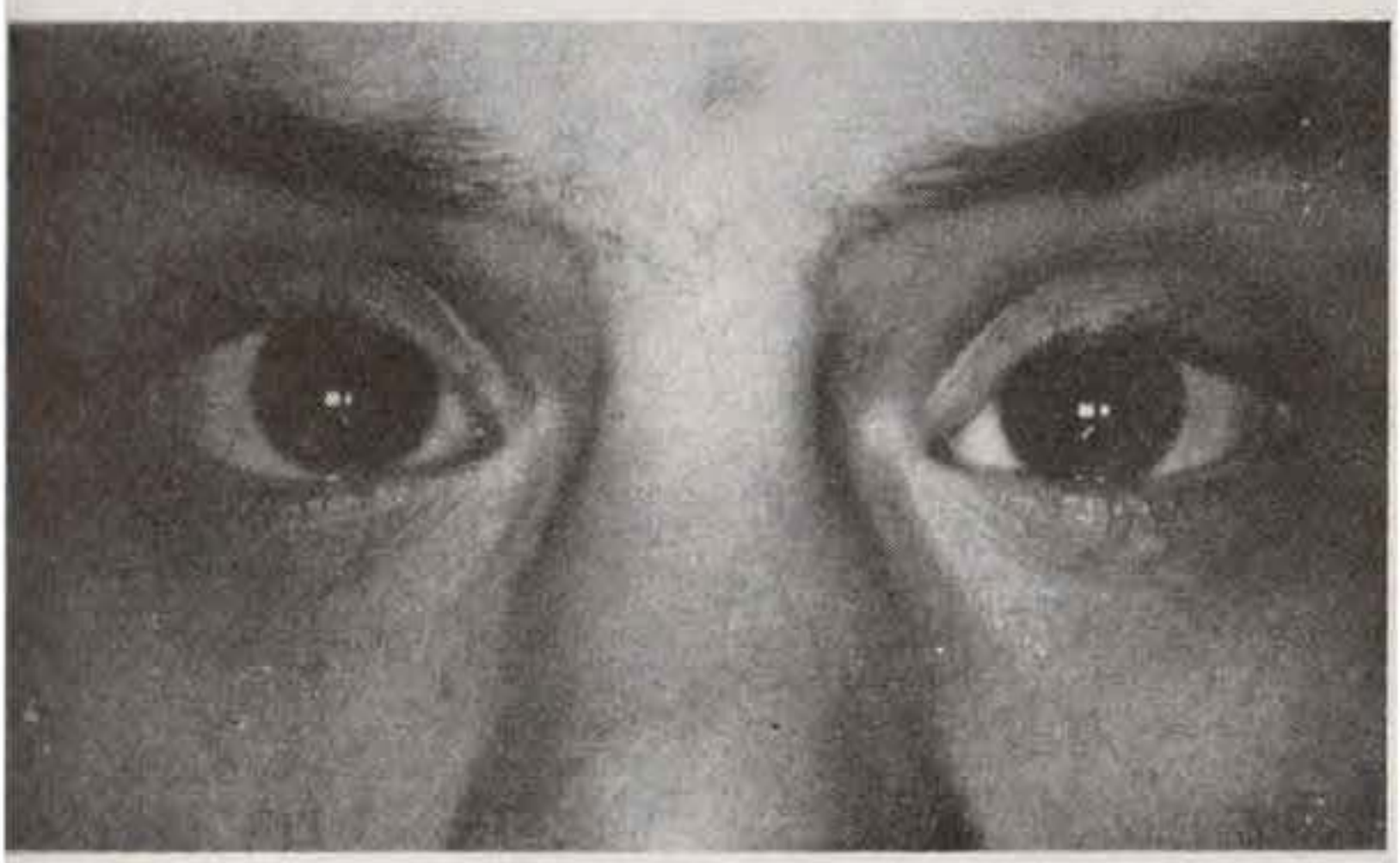
September 28, 1981: The ophthalmologist reported that the right lens appeared to remain intact following the resorption of the cataract, and that the left eye revealed an early posterior subcapsular cataract.

[28]Tkacz, C. and Hawkins, D.R.: Journal Orthomolecular Psychiatry 10: 119-123. 1981.

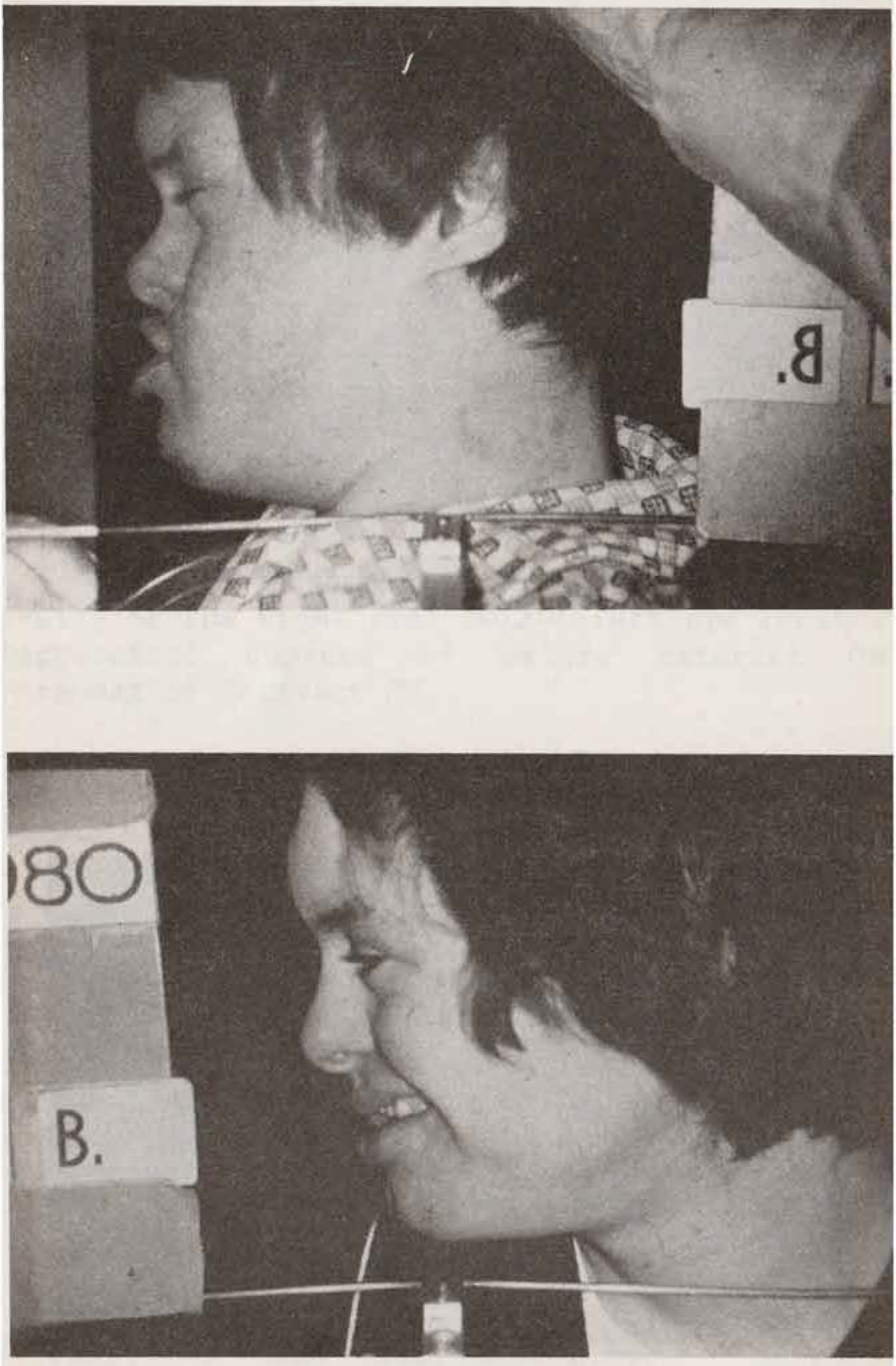


Top 11-10-75

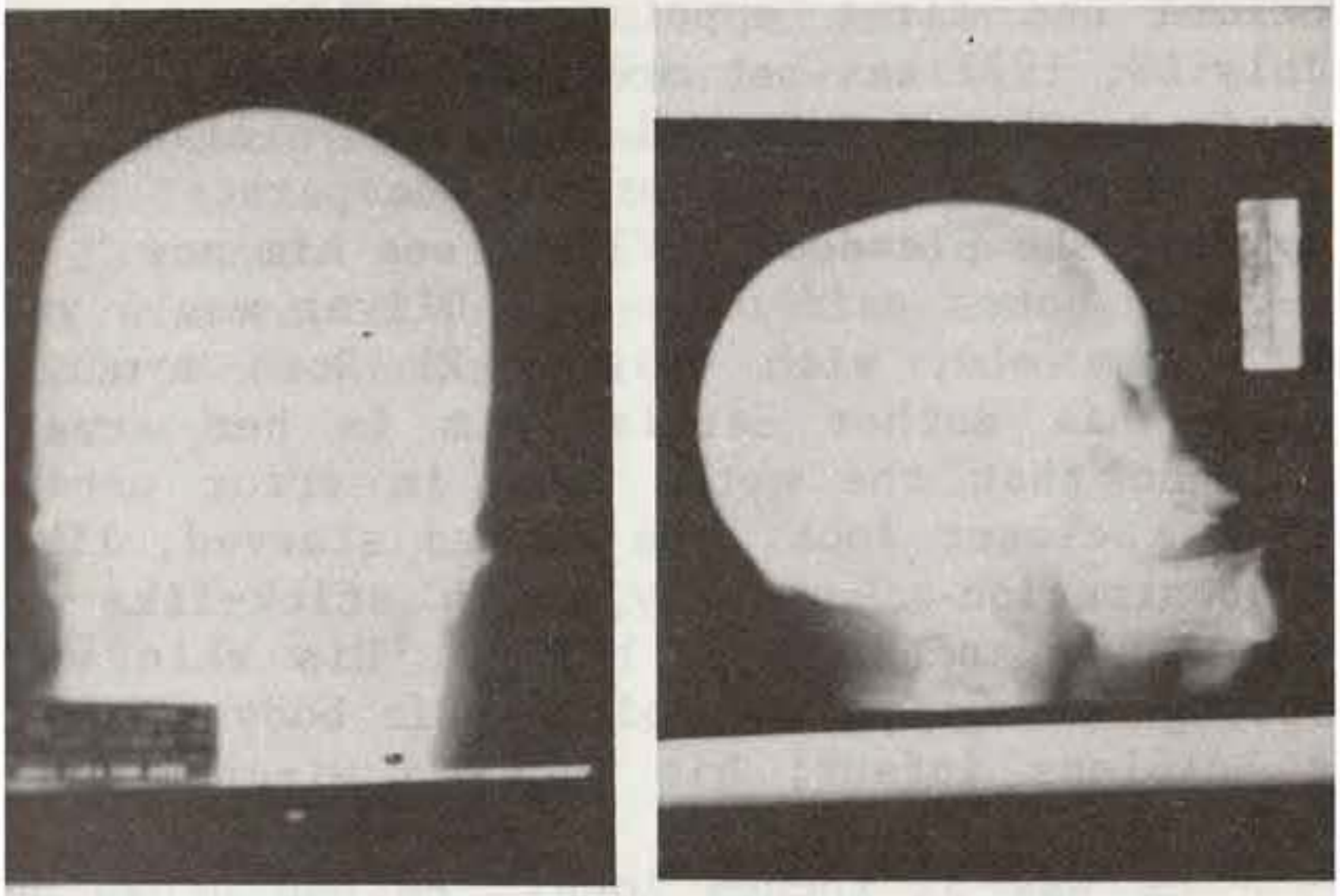
Bottom 3-27-80



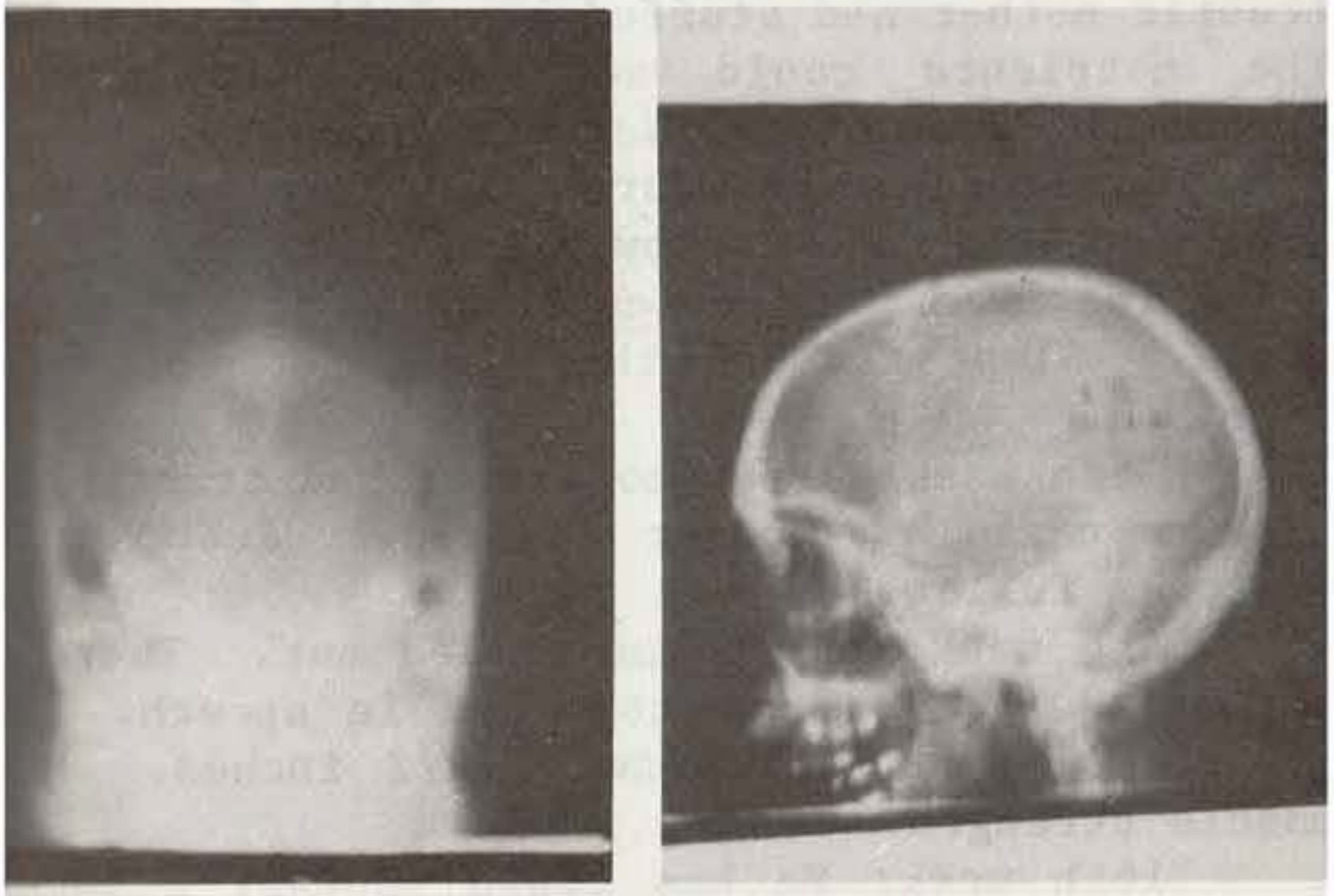
development of nasal bridge



X-rays at start of treatment 4/28/75



X-rays 10/29/81



CHAPTER III

Oliver

Ordinarily, patients' records are sent before the first appointment. The morning of July 10, 1971 was not ordinary, however. The new patient, Olver, referred by his physician, lived in Detroit. His mother was desperate: "He's dying," she pleaded. "Please see him now."

My notes said only that Oliver was 6 years 3 months old, with trisomy 21 Down syndrome. Since his mother carried him in her arms, I thought that the notes were in error until I took a closer look. He seemed starved, like a concentration camp baby, with stick-like arms and legs, and bloated belly. His skin was a strange orange-yellow color. His body resembled a helpless infant; his face, a wizened little man.

He was 32 inches long. He had grown only 15 inches in 6 1/4 years. He weighed 16 pounds, a gain of 12 pounds since birth. His bone age was 24 months at chronological age 75 months. He had to be carried, fed, diapered. His frantic mother had stuffed him full of vitamins. The nutrients could not enter his starved tissues because of the accumulations.

Oliver's progess during the first months of treatment was recorded by his mother:

"1st week: He no longer cried before meals. Slept through the night for the first time.

"6th week: Feet no longer had crusty skin -- toe nails no longer layered. Feet, legs, buttocks fuller.

"8th week: Chest has filled out. There is a change in play with toys and in speech. Has gained 4 pounds and grown 1 1/2 inches. More muscle strength.

"16th week: He has grown another 2 inches and weighs 26 1/2 pounds. His facial expression appears more youthful. He is interested in his surroundings.

"7th month: Oliver is 36 inches tall and weighs 29 pounds. Still gaining strength."

May 27, 1971, X-rays were repeated. During the first 10 1/2 months of treatment, Oliver had gained 18 months in bone age, almost twice the normal rate of develoment. He had grown from 2 to 38 inches, and had doubled his weight from 16 to 32 pounds.

The rapid development of Evelyn, Judy, and Oliver coinciding with the treatment prove efficacy.

BORN 4-12-64
7-65 1 3/12 Y
17" 3#2'
43 CM 1.42 KG

7-10-70 6 3/12 Y
B.A. 2Y
32" 16# 81 CM

SKELETAL SURVEY: 7-10-70

THERE IS A MILD SHORTENING OF THE BASE OF THE SKULL. NO OTHER CRANIAL VAULT ABNORMALITY IS IDENTIFIED.

CHEST SHOWS THE HEART TO BE SOMEWHAT PROMINENT. THERE IS PROMINENCE OF THE PULMONARY VASCULARITY. THIS MAY BE RELATED IN PART TO THE PATIENT'S SUPINE POSITIONING, HOWEVER CLINICAL CORRELATION WOULD BE NECESSARY TO EXCLUDE AN INTRACARDIAC SHUNT. THE LUNGS APPEAR FREE OF AN ACTIVE DISEASE PROCESS.

7-15-70 32" 81 CM 7.26 KG

THERE IS GENERALIZED MILD BONE ATROPHY. THE CORTISES OF THE BONES ARE THIN. THERE IS GENERALIZED DIMINUTION IN THE SIZE OF THE BONES. THE COMPARATIVE VIEWS SHOW THE PATIENT'S SKELETAL AGE TO BE THAT OF AN INFANT OF 2 YEARS OF AGE. THERE IS FLARING OF THE ILIAC WINGS. FLATTENING OF THE ACETABULA IS PRESENT. BILATERAL COXA VALGA. CLINODACTYLY OF THE FIFTH DIGITS OF THE HANDS IS PRESENT.

IMPRESSION: FINDINGS COMPATIBLE WITH MONGOLISM SKELETAL AGE IS TWO YEARS. THE GENERAL OVERALL FINDINGS ARE THOSE OF GENERALIZED PARESIS WITH SOFT TISSUE AND BONE ATROPHY.

INCREASE IN PULMONARY VASCULARITY SUGGESTS THE POSSIBILITY OF AN INTRACARDIAC SHUNT.

8-11-70 6 4/12 Y

5-21-71 38" 32# 97 CM
7 1/12 Y

BODY SURVEY: 5-27-71

THERE HAS BEEN SIGNIFICANT INTERVAL ENLARGEMENT OF OSSEOUS STRUCTURES SECONDARY TO GROWTH. FRONTAL SINUSES ARE ABSENT. PRIMARY TEETH ARE STILL DEMONSTRATED. THERE HAS BEEN NO INTERVAL CHANGE IN THESE FINDINGS AS COMPARED TO PREVIOUS STUDY. COMPARATIVE VIEWS OF THE PATIENT'S WRISTS SHOW THE SKELETAL AGE TO COMPARE CLOSEST TO THE STANDARDS FOR MALES OF 3 YEARS AND 6 MONTHS. CARDIOVASCULAR SHADOWS ARE SIMILAR TO THE PREVIOUS STUDY AND THERE IS AGAIN SUGGESTION OF INCREASE IN PULMONARY VASCULARITY.

IMPRESSIONS: SIGNIFICANT INTERVAL INCREASE IN SIZE OF THE CHILD WITH INTERVAL IMPROVEMENT IN SKELETAL AGE RADIOGRAPHICALLY. THE CONFIGURATION OF THE CARDIOVASCULAR STRUCTURES IS STILL SUGGESTIVE OF INTRACARDIAC SHUNT.

10-72 8Y6M
39½" 33½# 101 CM

4-12-73 9Y
40" 36# 102 CM

3-74 9Y11M
41" 44# 104 CM

4-12-75 11Y
44½" 49# 113 CM

6-18-76 12Y2M
48" 53# 122 CM

12-76 12Y8M

5-77 13Y1M
50¼" 56#

Jimmy

9/77

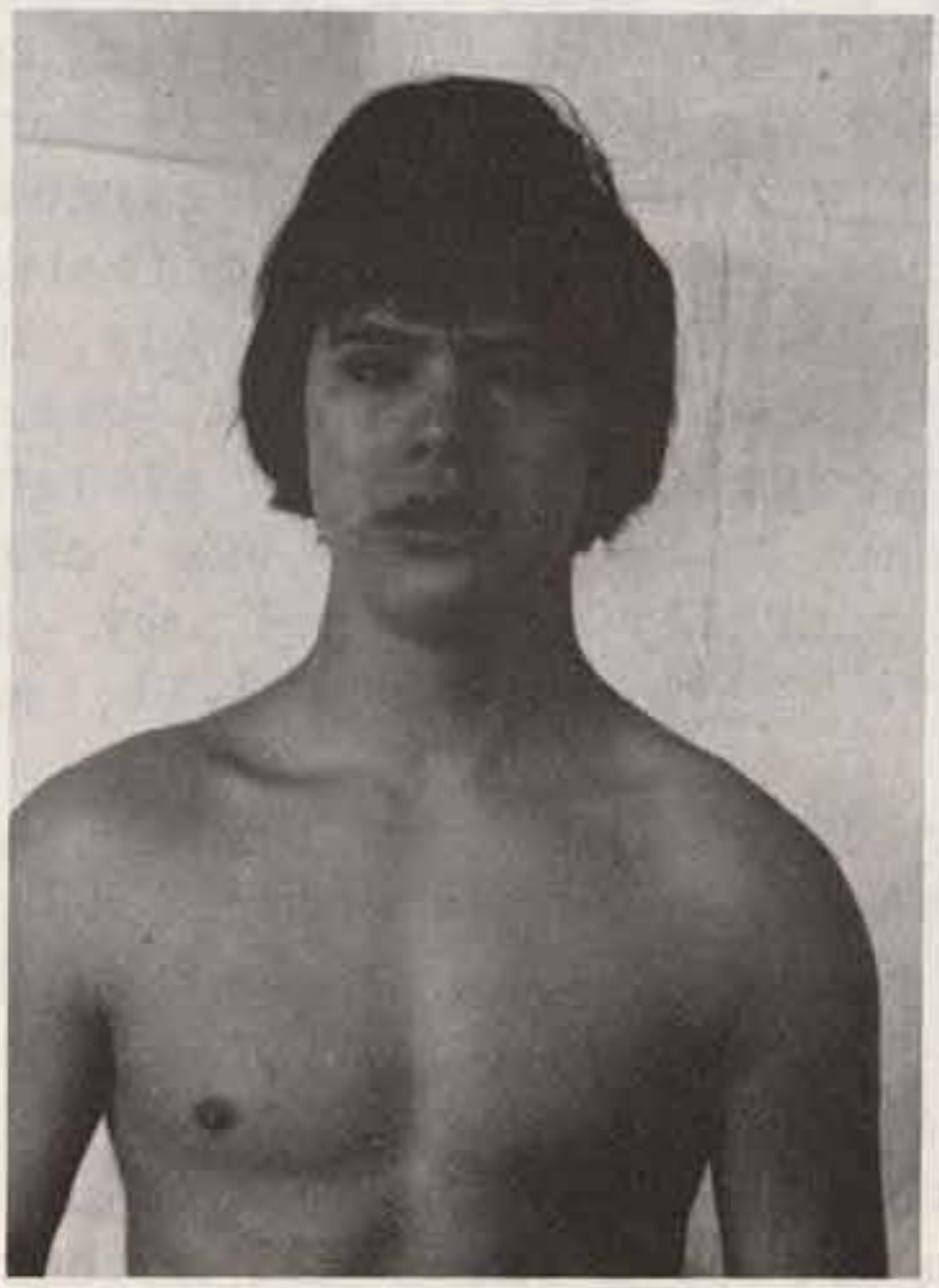
AGE 11-7

Jimmy was born February 4, 1966. The diagnosis of Down syndrome was confirmed by the Genetics Clinic of the Children's Hospital in Columbus, Ohio. Treatment with the "U" Series began September 7, 1977 when he was 11 years 7 months old. He was 54 1/2 inches tall and weighed 84 1/2 pounds, placing him in approximately the 10th percentile for height and the 50th for weight. His head circumference was 19 1/2 inches. Characteristic features of Down syndrome included epicanthal folds, curvature of the spine, protruding abdomen, overly flexible joints. His palate appeared elevated, with a thick dental ridge. He was classified as trainable mentally retarded by the school system. His mental age was 3.11, and his I.Q. was 41.

In addition to the full-size dosage of the "U" Series, he was prescribed additional calcium pantothenate, pyridoxine, zinc, dolomite, niacin, pangamic acid, and multiple chelated minerals as well as Cytomel and Lasix. Within two months, he lost 8 pounds. His abdomen appeared flat. His mother reported:

"There have been few times anyone noticed eye crossing. Classmate's mother says he seems less 'hyper.' Grandmother from out of town said, 'He has certainly matured.'" Interestingly, this is a frequent observation, despite inclusion of thyroid, cytomel, and phenylpropanolamine in the "U" Series.

At the time of the second examination, March 3, 1978, his height was 56 1/2 inches, weight was 79 1/2 pounds, and his I.Q. was 51. By August 31, 1978, he was 57 1/4 inches tall, weighed 87 1/2 pounds; his mental age was 6.1 and his I.Q. was 56. At this time, he was promoted from the trainable class to the educable. February 6, 1979, he was 60 inches tall and weighed 88 pounds -- almost average height and slightly below-average weight-for-height. His mental age was 7-5, I.Q. 66. He was doing well in the educable class. September 14, 1979 he was 60 1/4 inches tall, weighed 99 pounds, had a mental age of 8-2, I.Q. 68. This type of mental development in a Down syndrome patient is totally unexpected (See charts):



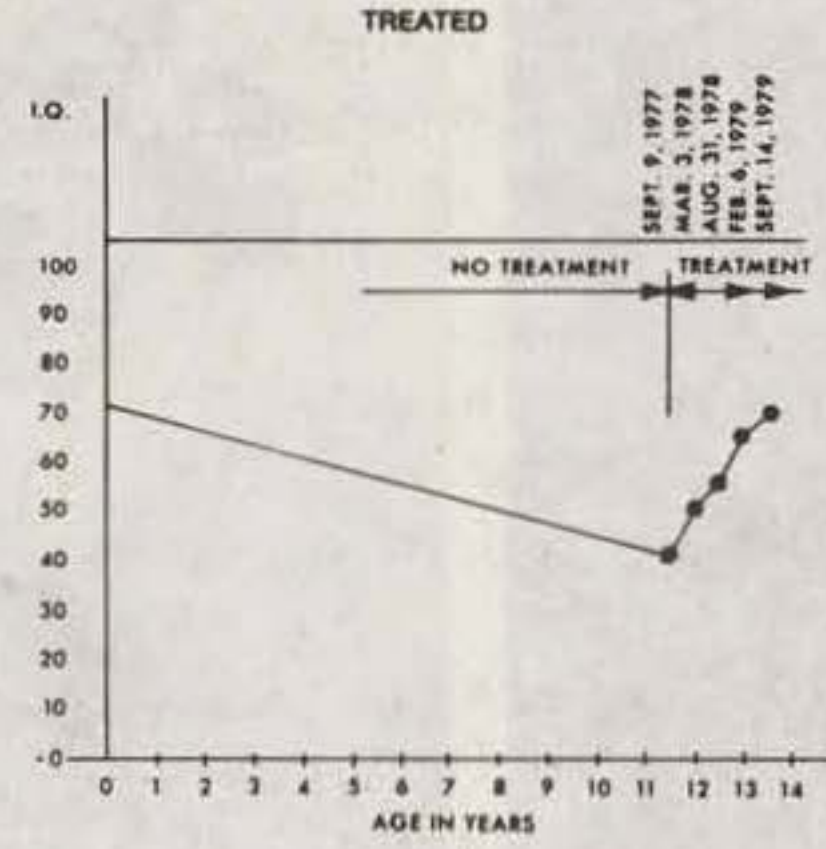
5/81

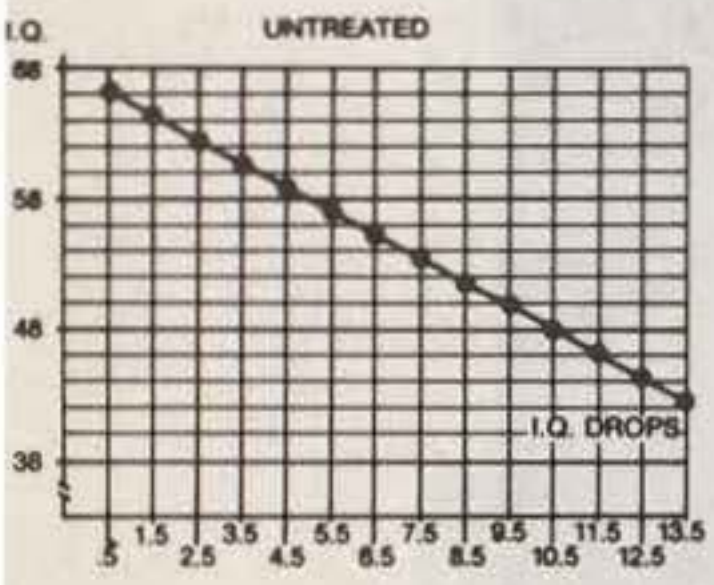
AGE 15-3

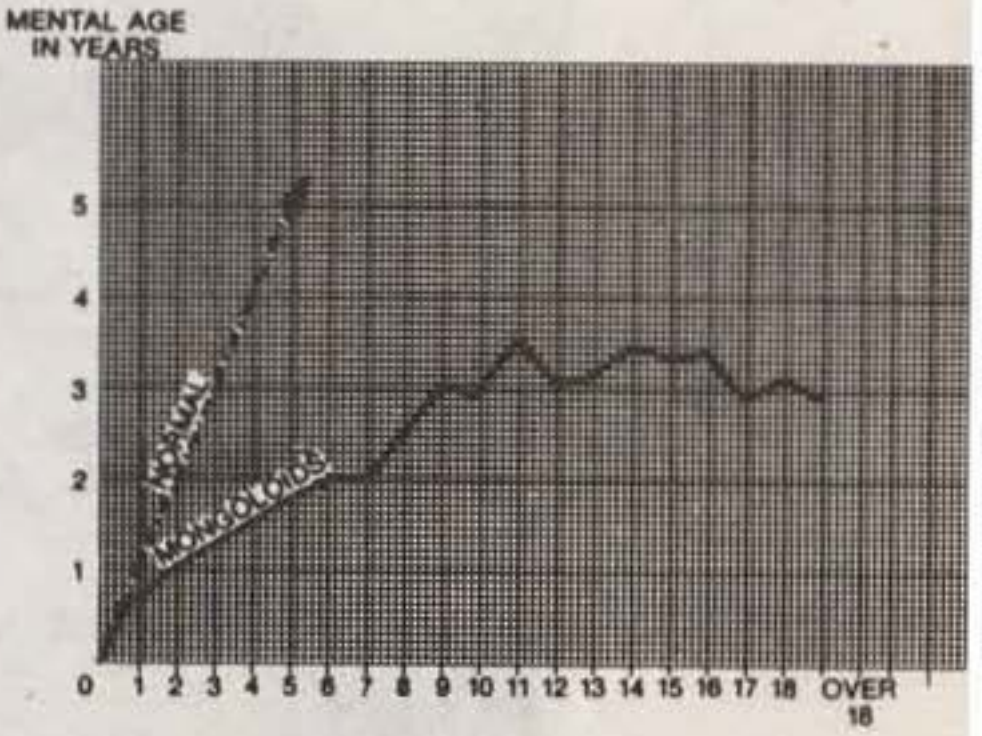
September 1977

August 1979

I.Q. RATINGS


TREATED
I.Q.
SEPT. 9, 1977
MAR. 3, 1978
AUG. 31, 1978
FEB. 6, 1979
SEPT. 14, 1979
NO TREATMENT
TREATMENT
100
90
80
70
60
50
40
30
20
10
0
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14
AGE IN YEARS


I.Q.
UNTREATED
68
58
48
38
I.Q. DROPS
.5 1.5 2.5 3.5 4.5 5.5 6.5 7.5 8.5 9.5 10.5 11.5 12.5 13.5
AGE (YEARS)


MENTAL AGE IN YEARS
5
4
3
2
1
0 1 2 3 4 5 6 7 8 9 10 11 12 13 14 15 16 17 18 OVER 18
CHRONOLOGICAL AGE IN YEARS

Stevie

I wish that everyone with a negative attitude toward patients with Down syndrome could meet Stevie. His personality is charming, and he is gifted in certain specific learning abilities.

Stevie was born January 22, 1976. His first examination was November 1, 1979. At that time, he was described as "a typical child with Down's syndrome." He suffered from frequent bouts of middle-ear infections. His developmental profile, assessed by the Santa Barbara, California school district, indicated that at the chronological age of 41 months, his gross motor development ranged between 20-23 months, fine motor 24-27 months, self-help 24-29 months, cognitive 24-29 months, social/emotional 24-27 months, and language 28-31 months.

Two-and-a-half years later, his first-grade progress report (April 8, 1983) read as follows:
READING - finished approximately 40 short children's books. Currently has read 82 pages of a 225-page book.
GEOGRAPHY - learned names and general locations on map of all states of the United States and their capital cities; all countries of North, South, and Central America, including the Antilles and their capitals; all countries of Europe and their capitals; some African nations including Morocco, Algeria, Tunisia, Libya, Egypt, Mauritania, Western Sahara, Mali, Niger, and Chad; most nations of the Middle East and Asia including Turkey, Cyprus, Lebanon, Israel, Syria, Jordan, Iraq, Saudi Arabia, Yemen, FDR Yemen, Oman, Iran, India, Pakistan, China, Mongolia, Burma, Thailand, Laos, N. Viet Nam, S. Viet Nam, Malaysia, Sumatra, Korea, Japan, and the Philippines; the Great Lakes; the Atlantic Ocean; the Pacific Ocean; the Gulf of Mexico, and the Gulf of California."
SCIENCE - learned the names of all the PLANETS; knows one characteristic about each planet except Neptune & Uranus; learned the days of the week and seasons of the year; recognizes names

of months from a calendar; can tell time on the hour or half hour; learned to differentiate between hotter & colder, heavier & lighter, liquid & solid, bigger & smaller, etc.; learned senses of man; performed simple experiments and described his observations.
MATHEMATICS - learned to count; learning difference between odd & even; learning numeric relationships; learning to add two single-digit numbers together; learning to refer to tables in order to find correct answers; can print multi-digit numbers.
PRINTING - can print all capital letters; can print most lower-case letters; prints name and address; copies from flash cards; starting to spell & print some words.
HEALTH - learning personal hygiene; learning internal organs of body; learned external parts of body; learning the dangers of taking medicine without supervision; improving his posture.
GRAMMAR - learning plurals of words; learning past tense of some verbs; learned comparative degrees of some adjectives; learning to construct simple sentences.
GEOMETRY - can identify most common figures /square, triangle, etc./; learned to construct a square from two equal right triangles.
MUSIC - learned to play a few children's songs on the xylophone; learning to identify musical instruments by their sound; learned to identify some compositions played from recordings; learning to play on the electronic organ
ART - learning to color within lines of coloring book figures; draws simple pictures; fingerpainting; working with clay.
SOCIAL SKILLS - ties his shoes; closes snaps; buttons pajamas (large buttons); learning to button small buttons; cuts; cuts paper with scissors.
PHYSICAL EDUCATION - throwing, catching, bouncing, kicking, and hitting a ball; he also runs, skips, hops, and jumps; he's learning to jump rope.

David

Born September 18, 1955, David was first examined on August 5, 1977. His height was 63 inches; weight 187 pounds, head circumference, 21 1/2 inches. His body development was obese and edematous, despite the careful nutritious attention of his concerned mother. He had slight epicanthal folds, some strabismus. His palate was elevated and narrow. He had single-palm lines on both hands. Evaluated on the Stanford-Binet, L-M on July 20, 1977 at California State University, he attained a mental age of 6-6, I.Q. 40. His mental age on the Peabody Picture Vocabulary Test was 8-4, and his social age on the Vineland Scale was 8-9.

During the 4-year course of treatment, he lost 40 pounds. Reexamined with the Wechsler Scale at two-year intervals, following the start of treatment, by Dr. Enid Reed in California, his verbal score rose from 47 to 59, performance score from 63 to 78, for a rise in his full-scale I.Q. from 51 to 65.

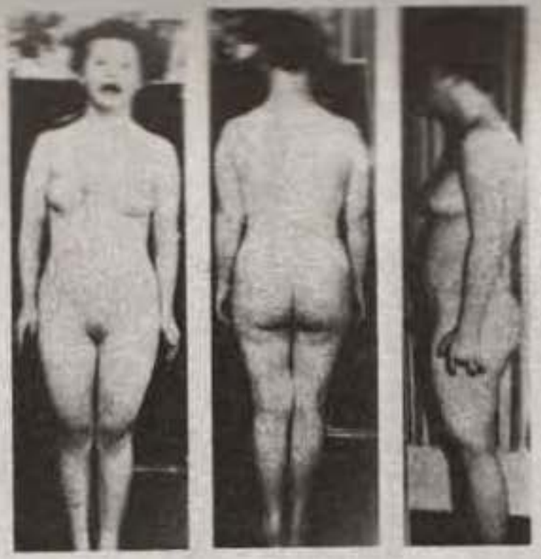
BEFORE TREATMENT

AFTER TREATMENT

Deseee

BORN 6/9/47

8 YRS.



1/2/61 BEFORE TREATMENT 13½ YRS.

MEDICATION DISCONTINUED BY ORDER OF FDA COMMISSIONER GEO. P. LARRICK

NO "U" SERIES GIVEN

5/69 22Y

"U" SERIES RESTARTED

10/24/70
23Y5M

11/25/71 1Y1M Rx
24Y6M

11/25/71

1Y1M Rx

24Y6M

6/72 1Y8M
Rx 25Y

3/73 2Y5M
25Y9M Rx

10/15/62 1½y4m

1/24/63 1½y7m

12/63 1½y6m

10/73 3YRX 26Y4M

M.G. - 1

SOUTHFIELD RADIOLOGY ASSOCIATES, P.C.

DIAGNOSTIC RADIOLOGY
[illegible] WEST NINE MILE ROAD SUITE [illegible]
NORTHLAND NINE MILE MEDICAL BLDG
SOUTHFIELD MICHIGAN [illegible]
TELEPHONE [illegible]

March 24, 1980

SKELETAL SURVEY

There was some rotation of the head on the lateral study, but generally, the cranium appears somewhat small. There is underdevelopment of the frontal sinuses. The remainder of the sinuses are within normal limits. There is minimal asymmetry of the left greater wing of the sphenoid, compared to the right. This may again be due to minimal rotation.

There is minimal scoliosis of the lumbosacral spine, which is not significant and compensated scoliosis is noted in the lower lumbar spine. There is no significant flaring of the iliac wings. The left acetabular angle is normal. There is deformity of the right femoral head and right acetabulum compatible with congenital dislocation of the right femoral head with formation of pseudoacetabulum. There is noted coxa valga. The long bones of the legs are normal otherwise.

Studies of the hands revealed the middle phalanges of the fifth finger to be at lower normal limits. The bone age according to Greulich and Pyle standards is 16 years.

There is noted minimal redistribution of the pulmonary vasculature. The cardiac size is normal. There is no other evidence of active cardiovascular or pulmonary disease.

IMPRESSION: 1) No definite finding of mongolism. There is minimal scoliosis of the thoracolumbar spine, coxa valga, congenital right hip dislocation with pseudoacetabulum, and some minimal redistribution of the pulmonary vasculature.

2) The bone age is not retarded.

Shahzad Sadiq, M.D.

SS/ckh
4/23/80

M.G. - 2

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November 20, 1981

CHEST/BONE SURVEY

The previous study of 3-24-80, was reviewed. The bone age, according to Greulich and Pyle standards is seventeen years. Again note is made of hypoplastic development of the frontal sinuses as well as some deformity of the right femoral head and acetabulum compatible with congenital dislocation of the right hip. No significant scoliosis of the thoracic or lumbar spine is demonstrated. The heart is not enlarged and the lung fields appear clear of an active process. The pulmonary vasculature is within normal limits.

IMPRESSION:
1) Hypoplastic development of the frontal sinuses sometimes associated with Down's syndrome.

2) Deformity of the right acetabulum and right femoral head, consistent with congenital dislocation.

3) The bone age, according to the Greulich and Pyle standard is that of a male seventeen years of age.

John E. Temple, M.D

JET/bjh
3/19/82

X-ray reports - spine normalizes

figure 17

E.N.

E.N. was 26 years old at the time of his first examination on January 24, 1961. Previous medication included 1 1/2 gr. thyroid, anterior pituitary, testosterone, and glutamic acid. His height was 59 3/4 inches, weight 151 pounds, blood presure 120/70. Many features of Down syndrome were present, including absent frontal sinuses. All epiphyseal centers were closed; no additional growth was possible.

After three months of treatment, he had lost 1/2 inch in girth, though height and weight remained the same. His tongue appeared smaller. His attention span increased. He suddenly expressed the desire to paint.

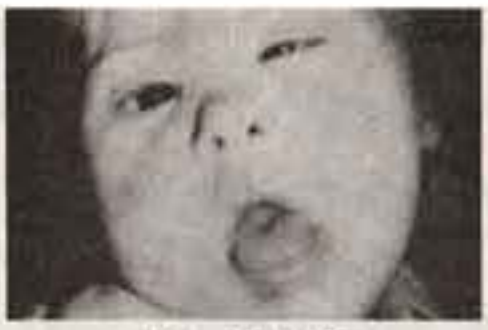
Within the year, he had produced a number of original paintings that were exhibited and sold. By early 1963, the sale of his paintings was contributing substantially to the household income.

J.B.

J.B. was born December 24, 1948. He was referred for treatment by his physician in Colorado March 23. 1965: "J.B. is typical of mongolism; is about fifteen years of age; and is mentally somewhere beyond eight years." According to the history, he was lethargic and slept 11 to 12 hours daily. Previous medication included thyroid and glutamic acid. He was 64 inches tall and weighed 128 pounds.

October 18, 1966, after 18 months of treatment with the "U" Series, his physician wrote: "J.B. is not the typical child of this medical diagnosis. He is well-coordinated, muscular, and motivated to perform." He also required substantially less sleep.

After 3 years of treatment, he was 65 inches tall, weighed 142 pounds, and was gaining initiative in a number of areas. He was a helper in his father's car wash. Treatment ended in 1970. Since that time, he has been a steady worker, paying his own way, helping to support his mother after his father's death, and traveling alone on vacations.



10-19-72

10-19-72

6-20-73

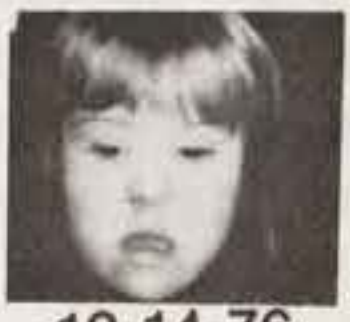
6-20-73

10-29-74

10-29-74

8-22-75

8-22-75



12-14-76

12-14-76

10-78

RACHEL

12-78

1979

1979

OUTSOL CALIF 800 4. 3 3146

BIO-METRIC SERVICES INC.
ATTENTION: LABORATORY
757 PACIFIC STE BL
MONTEREY, CALIF. 93940

SOURCE #06551

COLLECTION DATE: 09-10-79
RECEIPT DATE: 09-11-79
REPORT DATE: 09/28/79

CYTOGENETIC REPORT

Patient JEANNE L. Ref. A.J.KANTER

TEST REQUESTED:

- [X] ROUT'NE
- [ ] EXTENDED STUDY
- [ ] PHILADELPHIA

SPECIMEN TYPE:

- [X] BLOOD
- [ ] BONE MARROW
- [ ] AMNIOTIC FLUID
- [ ] TISSUE
- [ ] OTHER _____

(Please include clinical information and specimen type with your request)

CHROMOSOME STUDIES

RESULTS:

TOTAL CELLS COUNTED 5

DISTRIBUTION: 5 cells with 47 chromosomes

* DATA CODE: 47,XX,+G

NOTES:

Life Science Laboratories

[illegible]

This test may be important in determining an inherited condition, but other factors may need thorough evaluation as well. Consultation with experts at genetic counseling centers, medical centers or at other facilities with experience in this specialty is recommended if any question exists. Address of such centers will be provided on request.

Peter S. Nose

Peter S. Nose, M.D., Ph.D.
Director

* Based on Paris Conference Standardization in Human Cytogenetics. Birth Defects: Original Articles Series 9:7, 1971, Supplement, 11:8, 1975. The National Foundation, New York.

› Interpretation.)

208088

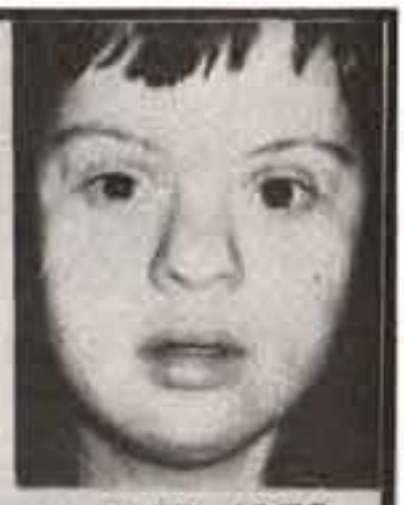
JEANNE

6-28-1972

7-5-1974

11-28-1975

7-22-1977



7-30-1979

7-30-1979

DOWN'S SYNDROME PATIENT GRADUATED FROM REGULAR HIGH SCHOOL, ON THE HONOR ROLL, WITH A 3.30 AVERAGE, AT AGE 21, WITH ONLY 11½ YEARS IN PUBLIC SCHOOL FROM KINDERGARTEN THROUGH GRADE 12. SCHOOLING WAS DELAYED BY HER CONTINUOUS ILLNESSES AND LACK OF COOPERATION BY EDUCATORS, WHO CONSIDERED D.S. CHILDREN UNEDUCABLE.

TREATMENT BEGAN WHEN SHE WAS 14. HER VISION IMPROVED, HEARING IMPROVED, SPEECH IMPROVED, SCHOOL PROGRESS IMPROVED. SHE PARTICIPATES IN ATHLETIC AND MUSICAL ACTIVITIES (BASKETBALL, BICYCLING, SWIMMING, GYMNASTICS, VOLLEYBALL, CHURCH CHOIR, HIGH SCHOOL CHORUS, COMMUNITY COLLEGE CHORUS). SHE PLAYS CELLO AND GUITAR; IS AN AVID READER, GOOD SPELLER; AND TYPES ACCURATELY. SHE HAS PASSED HIGH SCHOOL DRIVER EDUCATION AND WILL ATTEND COMMUNITY COLLEGE.

Lower Lake High School

Lower Lake, California

This Certifies that

Jeanne Louise

Has satisfactorily completed a Course of Study prescribed for Graduation from this School and is therefore awarded this

Diploma

Given this month of June, nineteen hundred seventy-nine

JEANNE

Dale

Dale was born July 20, 1966. Although characteristic features such as congenital heart disease, single-palm line, and epicanthal folds were noted at birth, the diagnosis of Down syndrome was delayed, in order to "spare" his parents. He was not expected to live beyond the age of 2. January 9, 1967, hospitalized with pneumonia, he contacted tuberculosis. The diagnosis of Down syndrome, trisomy 21, was confirmed while he was in the hospital. Dale survived, but failed to thrive.

He was one of the four youngsters scheduled for examination February 10, 1974.† The other three were Alan, Gino, and Brad. At the age of 7 years 7 months, Dale was 44 3/4 inches tall and weighed 50 pounds. His head circumference was 50 cm., with partial alopecia. His nasal bridge was depressed. His upper lip had a raised center, with fissures. His tongue was large and fissured. He had a high, narrow palate with a wide gum line. His skin was marbled. His abdomen protruded. His testes were undescended. He had extremely hypermotile joints. Congenital heart disease was seen on the X-rays, and I could hear a murmur. He was sick, as usual: he had vomited on the plane, was running a fever, and was congested, coughing and wheezing. His mental age was under 2 years 6 months; however, this assessment was considered inaccurate because of his illness.

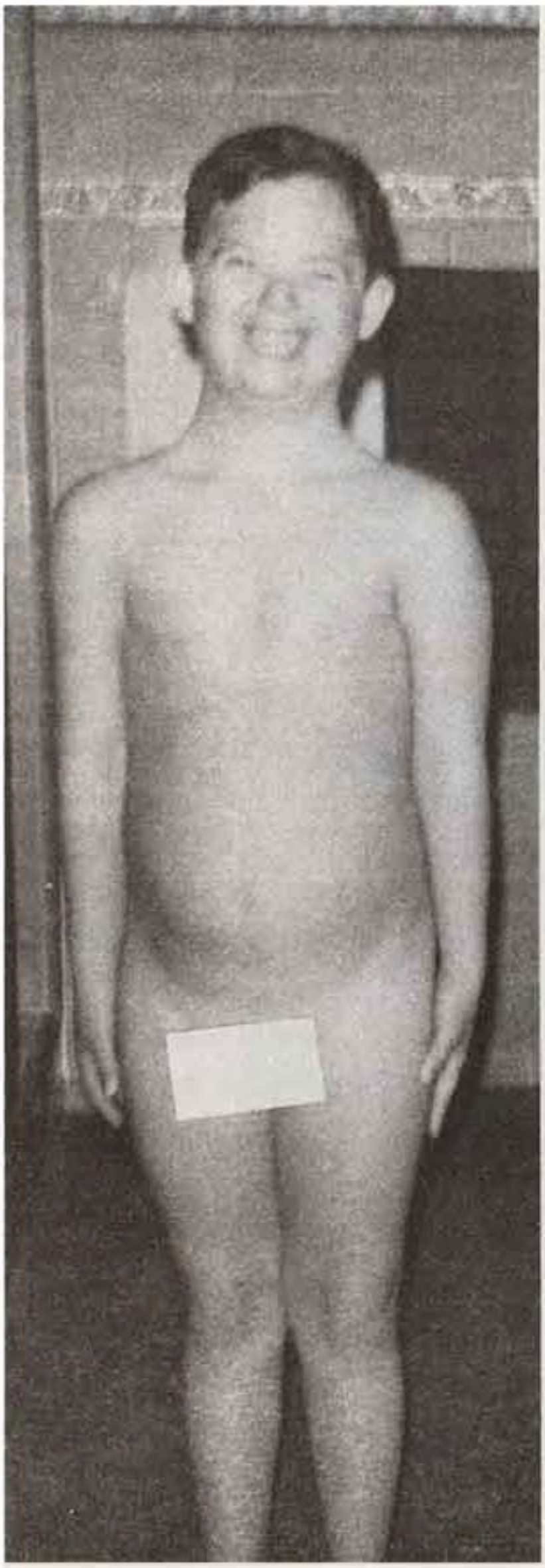
†I was spending much time in Switzerland, where I was licensed to treat Down syndrome patients at an institution for the retarded. I practiced abroad for 9 months during 1973, returning to Michigan between November 13 and December 17, and then was out of the country until February 9, 1974. To reduce the waiting list of patients, our previous policy of scheduling no more than two patients a day was set aside.

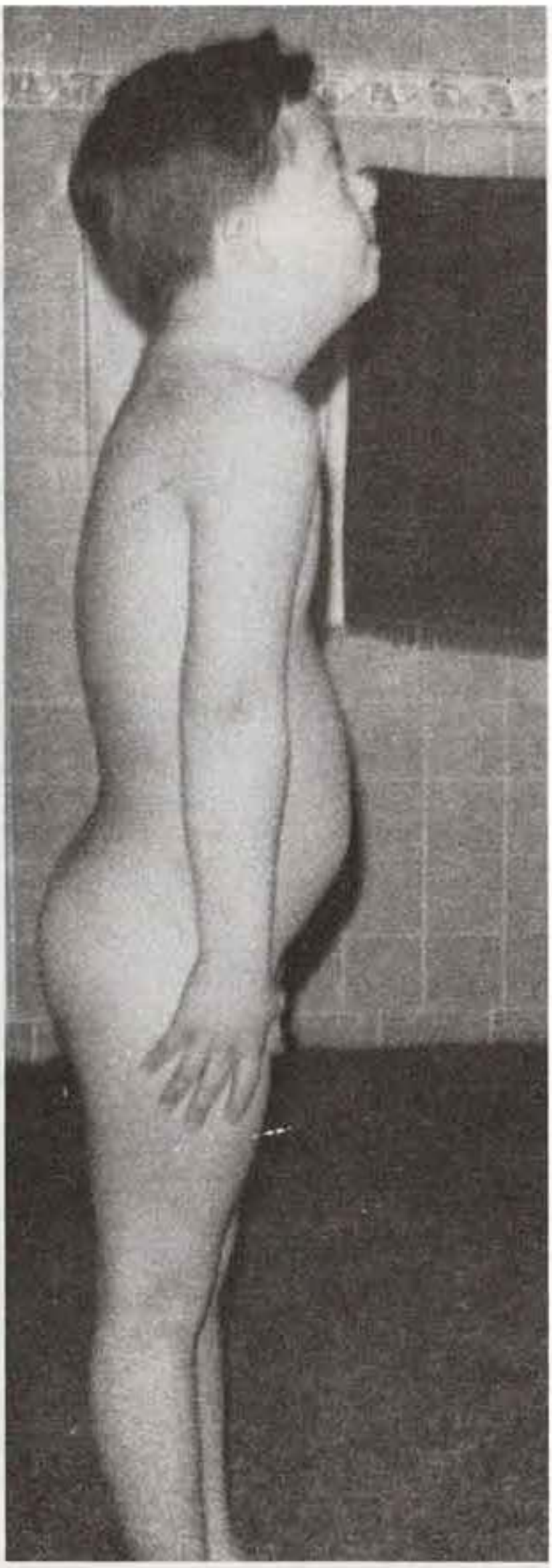
During the following 8 months, Dale grew almost 2 inches and gained 7 pounds. His mental age was 5 years 3 months. This dramatic increase was partly attributed to his greatly improved general health since beginning treatment with the "U" Series. His growth and development enabled him to function at a much higher social and mental age.

July 30, 1975, Dale was 46 3/4 inches tall, weighed 47 1/4 pounds and had a head circumference of 48 1/2 cm. His skull obviously did not shrink; the smaller circumference was due to the loss of edema. His skin was less marmorated, but he remained edamatous and obese.

As the years passed, his nasal bridge developed, Down syndrome features lessened, his testes descended, and the curvature of the spine seen on the 1974 X-ray was no longer evident. His growth rate remained steady. By January 12, 1982, he was just under 5 feet tall and weighed 128 1/2 pounds. He became an excellent swimmer, a skill he was originally never expected to attain because of his very poor health and congenital heart disease. His I.Q. was 86. Later that year, he celebrated his Bar Mitzvah. According to his 1984 school report, "Dale is capable of so many more things than he does. He must feel familiar with the person he is dealing with and needs a lot of motivation."

Dale

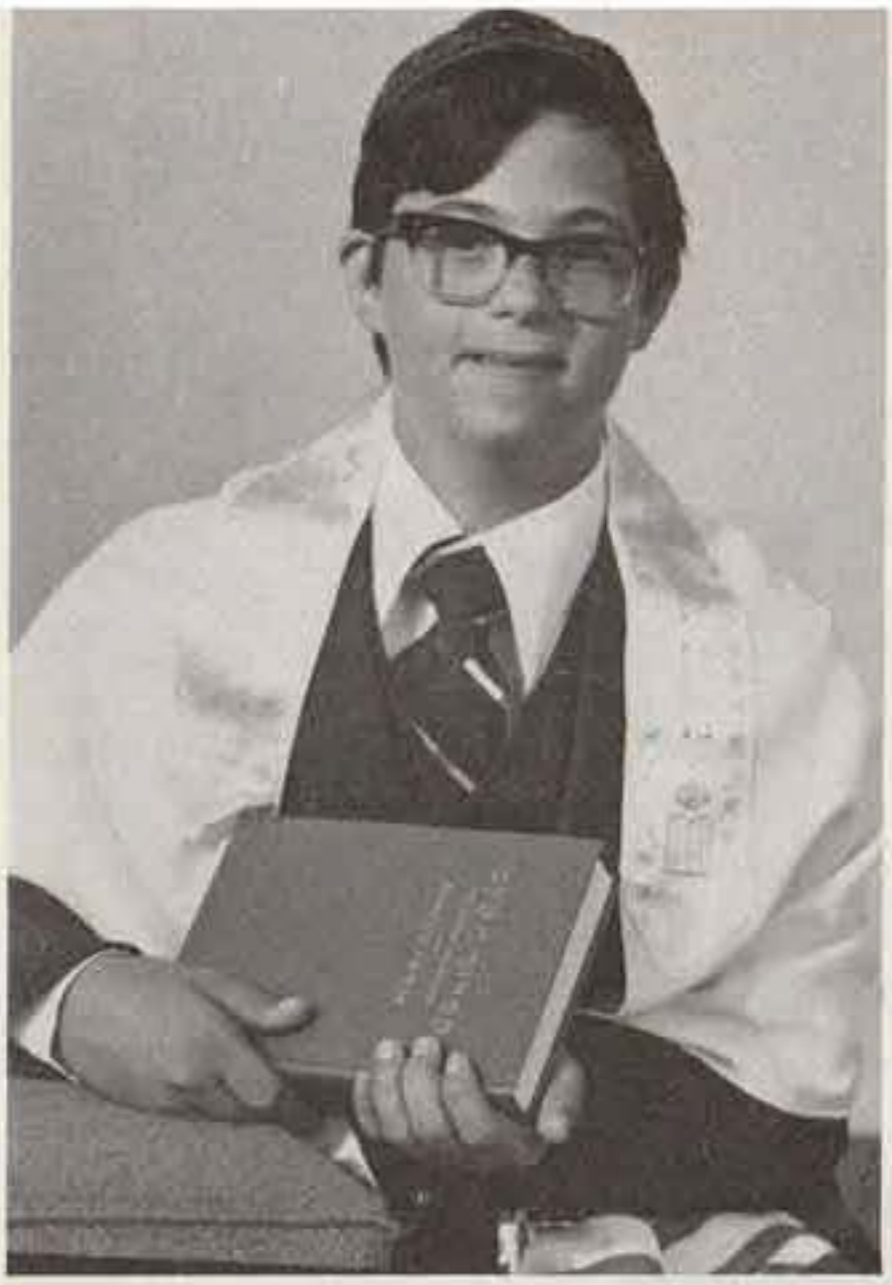




Brad

Brad

Brad



Brad has graduated from high school. He attends regular courses (no special education) with normal classmates and participates in normal extra-curricular activities

BRAD

Alan

12-24-1973
17 YRS. 8-¾ M.
BEFORE Rx

5-2-1974
18 YRS.
Rx STARTED
2-11-'74
Rx 2M 3 WKS.

8-12-1974
18 YRS 3-⅓ M.
TOTAL Rx 6M

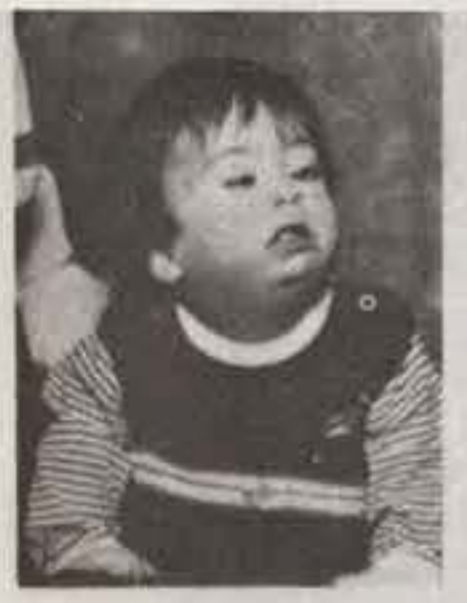
4-24-1975
18YRS. 11¾ M.
6 WKS. NO Rx

5-2-1975
19YRS.
Rx RESTARTED
4-27-'75

12-23-1975
19 YRS. 7¾ M.
TOTAL Rx 21M.

Alan said only 2 words at the start of treatment (age 18). He was institutionalized. Within a year after start of treatment, he began to communicate and was awarded the most improved resident certificate in the institution. His weight loss and the change in his features, especially the development of the nasal bridge, demonstrate treatment efficacy. When medication was discontinued, he reaccumulated fluids. After 3 years of treatment, he left the institution and worked in his mother's flower shop.

Gino



12-1972
16M

TREATMENT STARTED

2-1974
2Y 8M

3-1975
3Y 9M 1YRx

2-1976
4Y 9M 2YRx

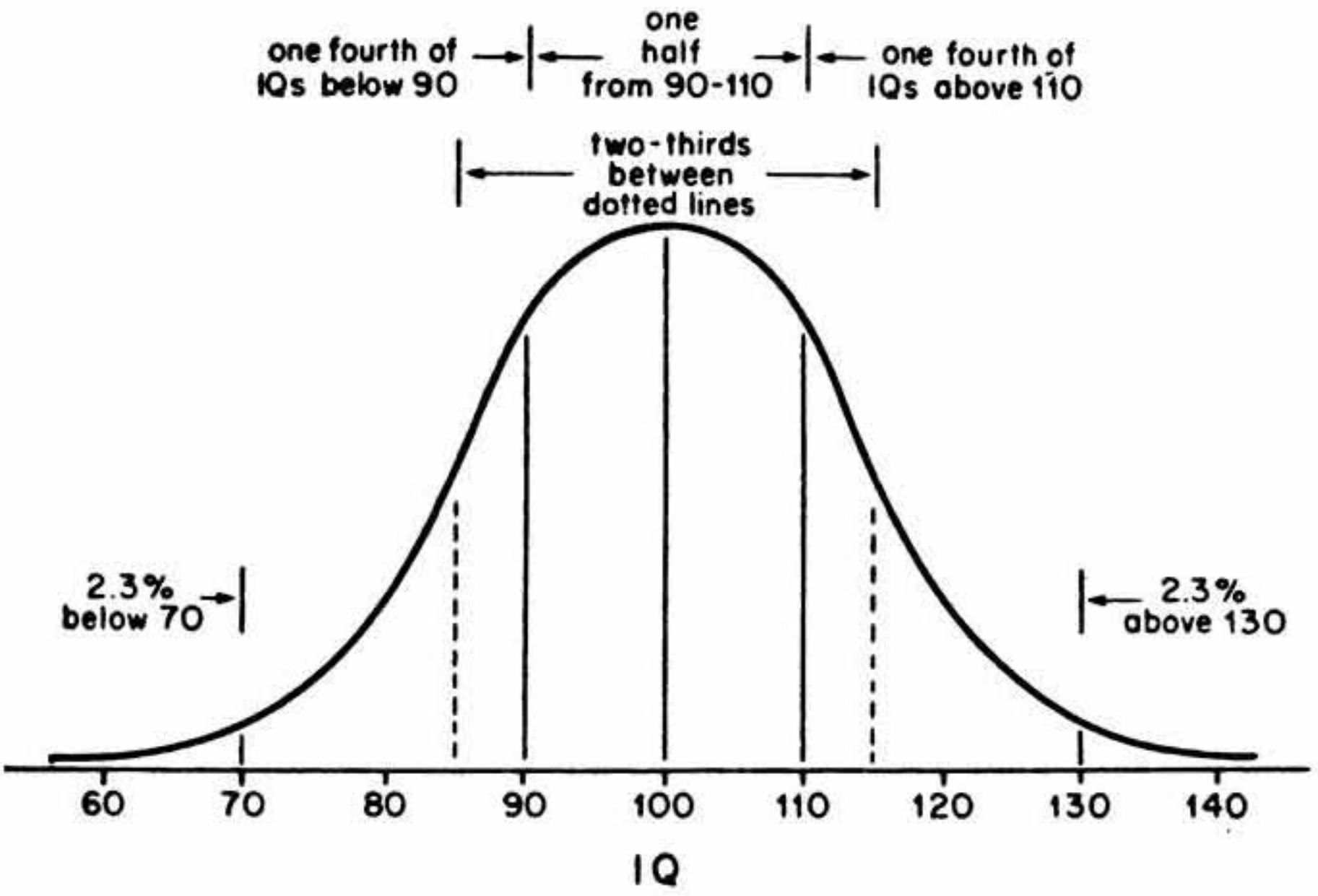
2-1977
5Y9M 3Y Rx

2-1978
6Y 9M 4YRx

SURVIVING MEMBER OF TWIN SET, THIS CHILD AT START OF TREATMENT, WAS UNABLE TO SIT UP ALONE WITHOUT SUPPORT. HE WAS LETHARGIC, WEAK, SHORT ATTENTION SPAN, POOR APPETITE. AT THE TIME OF THE FIRST PROGRESS REPORT (3-11-74) MOTHER REPORTED THAT HE WAS STRONGER, MORE ALERT, AND HAD A BETTER APPETITE. THEREAFTER HIS MENTAL PROGRESS WAS RAPID. BY 10-23-75 HIS I.Q. (PPVT—A) WAS 69, AND REMAINS AT THAT LEVEL, WHICH IS A BORDERLINE—TO—MILDLY RETARDED. HE LEARNED TO READ AT AGE 5, AND RECEIVED FIRST COMMUNION AT AGE 8.

Additional information about Gino appears in the "Dear World" section. His rapid and steady development proves efficacy of the "U" Series.

Normal Distribution of IQs



The scores illustrated have a standard deviation of 15 points. With a standard deviation of 15, 2/3 of IQs fall 15 points above and below the mean of 100. On the Stanford-Binet, with its standard deviation of 16, the cognate numbers are 84 and 116. The diagnosis of mental retardation begins 2 standard deviations below the mean (I.Q. 70). However, if we consider the very real problems experienced by schoolchildren with I.Q.s as high as 90, we can state that fully 25% of schoolchildren are slow learners or borderline retarded.[29]

[29] Baird, P.A. and Sadovnick, A.D.: Mental Retardation in over Half-a-Million Consecutive Livebirths. AmJMD 89:323-330 (Jan.) 1985. See also our chapter, "Treatment of the 'Slow Learner,' in Hippchen: Ecologic-Biochemical Approaches to Treatment of Delinquents and Criminals. 1978.

CHAPTER IV

Wendy[30]

At the age of 3 years 6 months, Wendy had features that are often associated with retardation, such as a narrow, elevated palate and edema. Wendy was examined on her fourth birthday at Case Western Reserve University (6/14/67). Results of blood chemistry, urinalysis, and chromosome studies were all within the normal range. The reason for the retardation was unknown. However, patients like Wendy may, in fact, be undiagnosed mosaic Down syndrome patients (cf. page 166). The Cattell Infant Intelligence Scale was used to determine her mental development. She scored an I.Q. of 44, and was classified as moderately retarded, with a mental age of 21 months.

Wendy's parents were informed that while improvement was unlikely, all testing has a possibility of error in measurement, and that for Wendy's score of 44, this error was ±15. It is, however, the standard deviation, not the range of error, that spans ±15 points. The standard deviation indicates the percentage of people who fall within a certain distance from the mean, not the measure of the possible range for any individual's test score. A corrected score range would have diagnosed Wendy as having a 44 ±6.7 I.Q.

In 1967, Wendy's parents enrolled her in a class for children within the I.Q. range of 50-80. In 1968, Wendy was tested with the Stanford-Binet Intelligence Scale. She was 4 years 9 months old. She scored a 49 I.Q.,

[30]Turkel, H., Nusbaum, I., Baker, S.: Intellectual Improvement of a Retarded Patient Treated with the "U" Series. Jrl. Orth. Psych. 13:4. 1984. Also, Foreword by Dr. A. Hoffer.

with a· 44-54 I.Q. range. This score again placed her within the moderately retarded category.

I examined Wendy on February 14, 1969. At her chronolgical age of 5 years 8 months, Wendy's X-ray examination established her wrist bone age at 3 years to 3 years 3 months, which was approximately 50% of her chronological age. Her femur and tibia bone ages were at the 3 year 6 month to 4 year levels, approximately 75% of her chronological age. She was 38 1/4 inches tall. She had not spoken a complete sentence to that date and was still very distractible, with an attention span of 10-15 seconds, at nearly 6 years of age. Wendy was attending the school for the mildly retarded, but remained at the moderately retarded level verbally, socially, physically, and in motor development.

The physical and mental effects of the "U" Series therapy on Wendy were immediately apparent. Her attention span increased from 10-15 seconds to 10 minutes within two weeks of starting treatment with the "U" Series. Within 3 months she began speaking in complete sentences, something she had never done before. Wendy's father noted the reduction in her body edema within 3 months. He said the child slept better than she ever had. Within 4 months, Wendy's rate of growth increased by 3 times her pretreatment rate.

She was tested with the Wechsler Intelligence Scale for children in August, 1969 after six months of treatment. She was 6 years, 2 months old. Her Full Scale Score on the Wechsler was 72, an increase of 23 I.Q. points in a little more than one year's time. On this test, Wendy advanced from the retardation to the non-retardation group of children, though her intellectual capacities were still below those of a normal child.

The psychologist suggested that the rise in I.Q. was due to Wendy's advancement in age. He explained that Wendy's I.Q. could vary from 62 to 82. As a result of this interpretation, together with his interpretation that the Cattell score could have been as low as 29 or as high as 59, he stated that the results overlapped. However, the ±10 point variability figure is not intended as a measure of test score error; that measurement is ±4.25 for the Full Scale score. Wendy's range for the 1969 Wechsler testing was 67.5 - 76.25.

The rise in I.Q. cannot be attributed to Wendy's advancement in age. Retarded children, especially those with features of Down syndrome, are more likely to test lower on I.Q. tests as they grow older (see also pp. 196-198).[31]

Improvements in all of Wendy's areas of development increased dramatically within six months of treatment with the "U" Series. Dr. Shapiro's prediction that Wendy "may never adapt to regular public school classes" was tested the following year when she was accepted into regular kindergarten at the age of seven.

At the age of 7 years 1 month, she attained a mental age of 4 years 10 months on the Stanford-Binet, Form L-M, for an I.Q. of 65. Wendy was again tested in 1971 at the age of 7 years 11 months, using the Stanford-Binet, Form L-M. She scored an I.Q. of 64 with a range of 55-73 I.Q., placing her in the mildly retarded category with possible overlap into the borderline category. Comparison of the 49 I.Q. (moderate retardation) with the 64 I.Q. (mild, almost borderline intellectual functioning) shows a very significant increase, especially in only a three-year period. The Wechsler was again adminstered to Wendy when she was eight.

[31]Øster, J.: Op. Cit. 1953.

She had scored an overall ability level of 85±3.25 I.Q., a range of 81-88 I.Q., borderline or low-average ability. It is unusual for a child to attain so dissimilar a score on the Stanford——Binet Form L-M and WISC-R.

Reading skills were taught with the Word Rummy cards which I invented. She read at the fourth grade level in the second grade. Her attention span doubled from 10 minutes to 20 minutes in approximately two years. Analysis of Wendy's abilities confirmed that her verbal and perceptual abilities were relatively high, but that her motor ability was low.

Wendy also developed physically. Her strabismus improved from the "severe" level to the "scarcely noticeable" level. The change in Wendy's palate from "greatly raised" to "nearly normal" over the years was considered significant. By 1974 her bone age growth rate had increased to an 86% normal rate. In 1977, her bone age was 94% of normal. The combination of mental growth and physical growth can be explained only by some treatment that could improve both variables.

The "U" Series treatment has apparently achieved both goals in Wendy. She was retarded in her physical and mental development for six years before treatment. She improved dramatically in both these areas within months after treatment began, and she continued to gain progressively in both areas over the long term. She has been able to remain in the regular classroom throughout her school life doing average work, graduating from high school in 1983.

BORN 6-1963

6-14-67 — AGE 4 — I.Q. 44
AGE 5 — I.Q. 49

TREATMENT STARTED 2-14-69
BONE AGE 53-62% OF NORMAL

8-69 AGE 6 I.Q. 72

6-71 AGE 8 I.Q. 85
BONE AGE 72%

2-19-75 AGE 11.8 I.Q. 80
BONE AGE 86%

TREATMENT ENDED 4-75

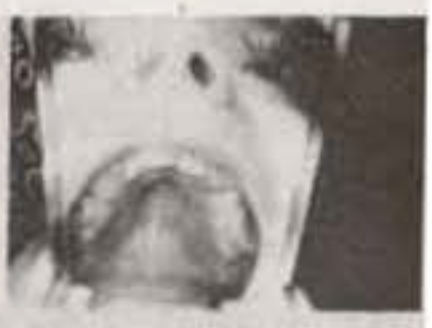
11-18-77 AGE 14.5 I.Q. 80-85
BONE AGE 93.6

9-79 ENTERED HIGH SCHOOL


2-20-69


9-19-69


3-3-73


3-3-73


6-16-70


10-12-70

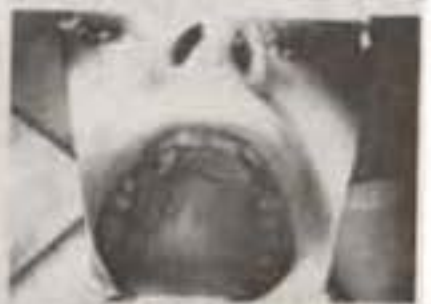

2-17-75


2-19-75

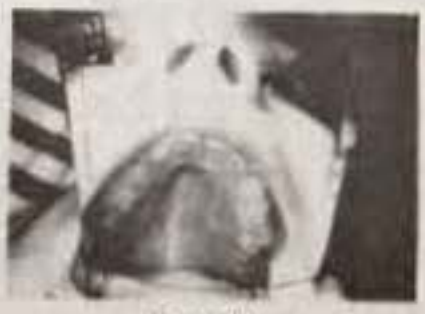

10-29-71


10-29-71


8-29-78


8-29-78


6-27-72


4-1-72


6-1970


11-2-78

Lakewood High School

Wendy Sheila

has completed a Course of Study
approved by the Lakewood Board of Education
and is hereby awarded this

Diploma

Given at Lakewood, Ohio
this sixth day of June, nineteen hundred and eighty-three

Eleanor A. Chapman
PRESIDENT OF BOARD OF EDUCATION

Richard A. Boyd
SUPERINTENDENT OF SCHOOLS

William Murray
TREASURER OF THE BOARD OF EDUCATION

PRINCIPAL

Tommy

Tommy, half-brother of a Down syndrome patient, was given the diagnosis of "minimal cerebral dysfunction" at Massachusetts General Hospital. When he was 8 years 5 months old, his I.Q. was 78, and his bone age was 72% of normal. Characteristics consistent with a diagnosis of mosaic Down syndrome included hypermotile joints, hypotonic muscles, raised upper lip, and fluid retention. However, unlike the Down syndrome patient, who excretes no abnormal chemicals (as far as we can tell with present tests), he began to excrete lysine and cystine after treatment. His behavior deteriorated. His bone age during the first 19 months of treatment developed an impressive 38 months, twice the normal rate. Before the end of the second year's treatment, Tommy's behavior improved, and he was retested at our office. Because his mental ability appeared to be normal, he was referred back to the psychologist in Massachusetts who had originally reported that "test scatter does not suggest a higher potential." When tested there again, his verbal score on the WISC was 99 with a full-scale I.Q. of 102.

Marcie

Marcie G., born November 2. 1958, was examined at the Cleveland Clinic at the age of 4 years 2 months. The following information was sent to her pediatrician at University Hospital in Ann Arbor, Michigan:

To prevent vomiting during the early months of pregnancy, Mrs. G. ingested large amounts of Dramamine. There was frequent spotting during the last two weeks of pregnancy. Labor was medically induced and lasted about seven hours. Marcie's birth weight was 7 pounds, 4 ounces. Mrs. G. required readmission to the hospital because of a retained placenta. Marcie suffered from colic during her first 6 months, slept poorly for at least a year, and continued to sleep poorly until the age of 4. She sat alone at 8 months, walked at 13 months, spoke in monosyllables at 3 1/2 years, and had a vocabulary of 15-20 words at 4 years. Although some superficial characteristics of autism were present, such as rocking and bruxism, she was affectionate and outgoing. PKU studies were negative. Her behavior was hyperactive. Her appearance suggested Down syndrome or hypercalcemia. The chromosome count was 46, and calcium was in the high-normal range.

Urinary amino acid output was highly abnormal, with large amounts of taurine, serine, 1-3 methyl histidine present, and small amounts of leucine, isoleucine, and valine "and many others present, most which she has no business having," according to a Cleveland Clinic report. Amino acids may be excreted because of enzymatic defects. When the digestive organs are developed and can function efficiently, some of these may be digested.

Her EEG was also abnormal, with excessively slow activity present. Her I.Q. was 51, and her social age on the Vineland Scale was 2 years 6 months. It was suggested that some of the depression in the I.Q. could be attributed to emotional factors. Her bone age at 4.2 was 3.6, or 84% of normal. There was flaring of the iliac wings and flattening of the acetabular angles. She was placed in an institution until 1968.

Treatment began in 1972. Examination at that time revealed the following characteristics suggestive of Down syndrome: slight epicanthal folds of both eyes, strabismus of the left eye, Brushfield spots, both eyes; raised center of the upper lip; high-arched palate, broad base of the nose with slight depression of the bridge, rhinorrhea; small jaw; irregular dentition; excessive cerumen; hypotonicity of muscles and hypermotility of joints; severe scoliosis and lordosis; slightly incurved fifth fingers; flat arches. Her I.Q. on the Peabody Picture Vocabulary Test at my office was 79, which corresponded with bone age retardation.

From 1974 to 1978 a Milwaukee Brace was prescribed; however, it caused such discomfort that Marcie could not cope with daily routines, including taking her medications. Therefore treatment was sporadic until 1978, at which time I suggested that she be examined at the Department of Pediatric Genetics, University Hospital, in Ann Arbor, in order to determine whether treatment had normalized the urinary output. The report was as follows:

CLEVELAND CLINIC

Date: Jan. 17, 1973

To: Henry Turkel, M.D.
8000 W. Seven Mile
Detroit, Michigan 48221

Name of Patient:

Cleveland Clinic Number: 950-773

In reply to the request of recent date, we are enclosing medical reports on the above named patient. We hope that this information will be of assistance to you.

If additional information is necessary, please contact us.

950 773 December 12, 1962

George Lowrey, M.D.
Department of Pediatrics
University Hospital
Ann Arbor, Michigan

Re:

Dear George:

This is to report to you on I believe you saw this baby about a year ago. She is now 4 years 1 month of age and her mother brought her here because of delayed speech.

The urinary output of amino acids was abnormal. The total was within normal ranges at 11.4 mg./100 ml. However, the chromatogram showed large amounts of taurine, serine, 1-3-methyl histadine; small amounts of leucine, isoleucine, and valine were present. However, this is not the pattern for maple syrup urine disease. She has many others present, most of which she has no business having. However, aside from the classification of a generalized amino-aciduria these abnormalities do not fall into a pattern which I can classify.

The electroencephalogram was also abnormal. There was excessive slow activity present. Most of this was anterior symmetrical in the range of 4 to 5 per second. No focal abnormalities or paroxysmal discharges were noted.

Psychological testing was done. The Stanford-Binet Form L-M was used. The chronological age 4years 1 month, mental age 2 years 2 months yielding an I.Q. of 51. Her basal age accomplishment was at 2 years with effort through 2½ years. The Vineland Social Maturity Scale yielded a social age of 2 years 6 months.

Sincerely yours.

Medical Record Librarian

Robert D. Mercer, M.D.
Department of Pediatrics

UNIVERSITY HOSPITAL

from the Section of Pediatric Genetics
Department of Pediatrics
(313) 764-0579

December 13, 1978

Henry Turkel, M.D.
19145 W. Nine Mile Road
Southfield, MI 48075

Re:
Reg #: 0988-769-6

Dear Doctor Turkel:

On October 25, 1978, we had the pleasure of seeing your patient, , in our Birth Defects Clinic. is a 20 year-old girl you referred to us for metabolic evaluation. , as you know, was identified at approximately three years of age as having some psychomotor retardation when it was noted that she was not talking.

Evaluation done at approximately four years of age at the Cleveland Clinic indicated that she may have some metabolic abnormality but we have no records to substantiate this. has also been hospitalized in Coldwater but for the last nine years, she has been cared for at home. stated that for the last several years, she has placed under your care and feels that she has done quite well.

An amino acid screen done here was completely within normal limits. We could find no evidence of elevated amino acids or metabolites in urine. This screen was done by Dr. Jess Thoene who coordinates the State Metabolic Screening Program. The amino acid screen was done by high voltage paper electrophoresis. In addition, we tested urine for the presence of mucopolysaccharides and organic acids and found none.

At the present time, we can find no recognizable metabolic etiology for problem and none that we would recognize that would benefit by vitamin and mineral therapy. We spoke with the mother and realize that she desired her child to undergo your treatment. We stated that we had no evidence that such therapy was beneficial and that the high cost of treatment was not warranted in our opinion.

Sincerely,

John R. Waterson, M.D., Ph.D.
Fellow, Pediatric Genetics

Roy D. Schmickel, M.D.
Director of Pediatric Genetics
Department of Pediatrics

JRW:RDS:mab

METPATH Hospital Reference Laboratory Services

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SEX F AGE E4 PROVIDENCE CTR-NOVI
ATT. REF PHY/LAB
39500 W TEN MILE RD.
NOVI MI 48050

TURKEL
A30174 42702 ND
HOSPITAL NO 6E4252

TEST NAME	RESULT	UNITS	REFERENCE RANGE

SPECIAL REPORT

AMINO ACID FRACTIONATION

AMINO ACID FRACTIONATION (URINE - 24 HR. VOLUME) 2210 ML
NORMAL LEVELS (MAXIMUM) IN MICROMOLES/24 HRS

AMINO ACID	CHILDREN	ADULTS	RESULT	
TAURINE	100	2350	461	-
ASPARTIC ACID	37	550	69	
HYDROXYPROLINE			NONE	
THREONINE	250	400	66	
SERINE	540	700	182	—
ASPARAGINE		700	38	
GLUTAMIC ACID	100	70	17	
GLUTAMINE	600	700	46	
PROLINE	100	90	NONE	
GLYCINE	1420	1320	1211	
ALANINE	440	600	61	
CITRULLINE	TRACE	50	NONE	
ALPHA-AMINO BUTYRIC ACID	80	60	7	
VALINE	50	100	NONE	-
CYSTINE	250	400	223	
METHIONINE	95	70	13	—
ISOLEUCINE	56	210	4	—
LEUCINE	83	160	20	—
TYROSINE	166	270	35	
PHENYLALANINE	100	190	29	
BETA-AMINOISOBUTYRIC ACID			NONE	
TRYPTOPHAN		200	132	
ORNITHINE	36	50	269	+
LYSINE	642	330	977	+
1-METHYL-HISTIDINE	270	800	1079	+
HISTIDINE	1300	2060	439	
3-METHYL-HISTIDINE	2480	700	379	-
ARGININE	30	60	NONE	

COMMENTS - INCREASES IN VARIOUS FRACTIONS MAY NOT INDICATE ANY ONE PARTICULAR METABOLIC DISORDER.

PAUL A KRIEGER M.D. JOSEPH E. O'BRIEN M.D.

Ronna

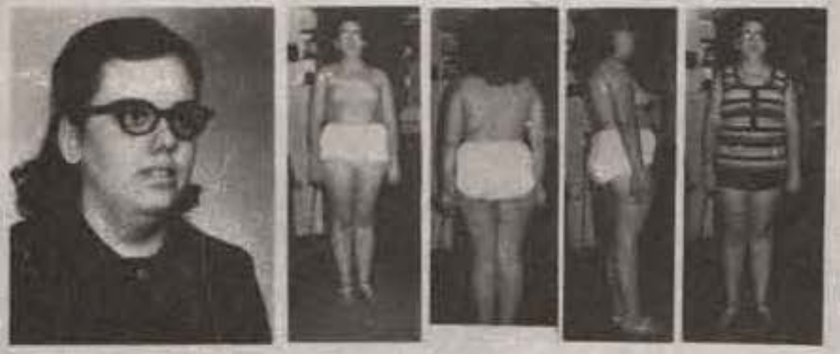
Ronna and Beth were friends, and also acquaintances of a Down syndrome patient in Florida, who took guitar lessons from Beth. That was how they came to know about my work. Ronna was considered to be a slow learner in high school. Her problems included an intractable weight disorder (metabolic obesity). She had been sent to health resorts but remained unable to lose weight on strictly supervised diets. She was eventually referred with the clinical diagnosis of Down syndrome on the basis of epicanthal folds and Brushfield spots. These characteristics are not confined to Down syndrome patients, but can be seen in patients with other diseases, including hyperkinetic syndrome.[32] Her physical improvement and weight loss were accompanied by an equivalent improvement in mental attitude and ability. She has graduated from high school, drives a car, works in a bank, and leads an active and happy social life.

[32]Hyperkinesis: Opinions Vary on Cause and Treatment. Mod. Med. 46:82 (Apr. 15) 1978.

TREATED WITH "U" SERIES

BORN 12/14/54

TREATMENT WITH "U" SERIES STARTED 7/1/71 16Y6M 158# 60¼"



16Y6M 158# 60"

6/73 1Y11M Rk 18Y5M 125# 62"

8/1/72 1Y1M Rk 17Y7M 136# 61"

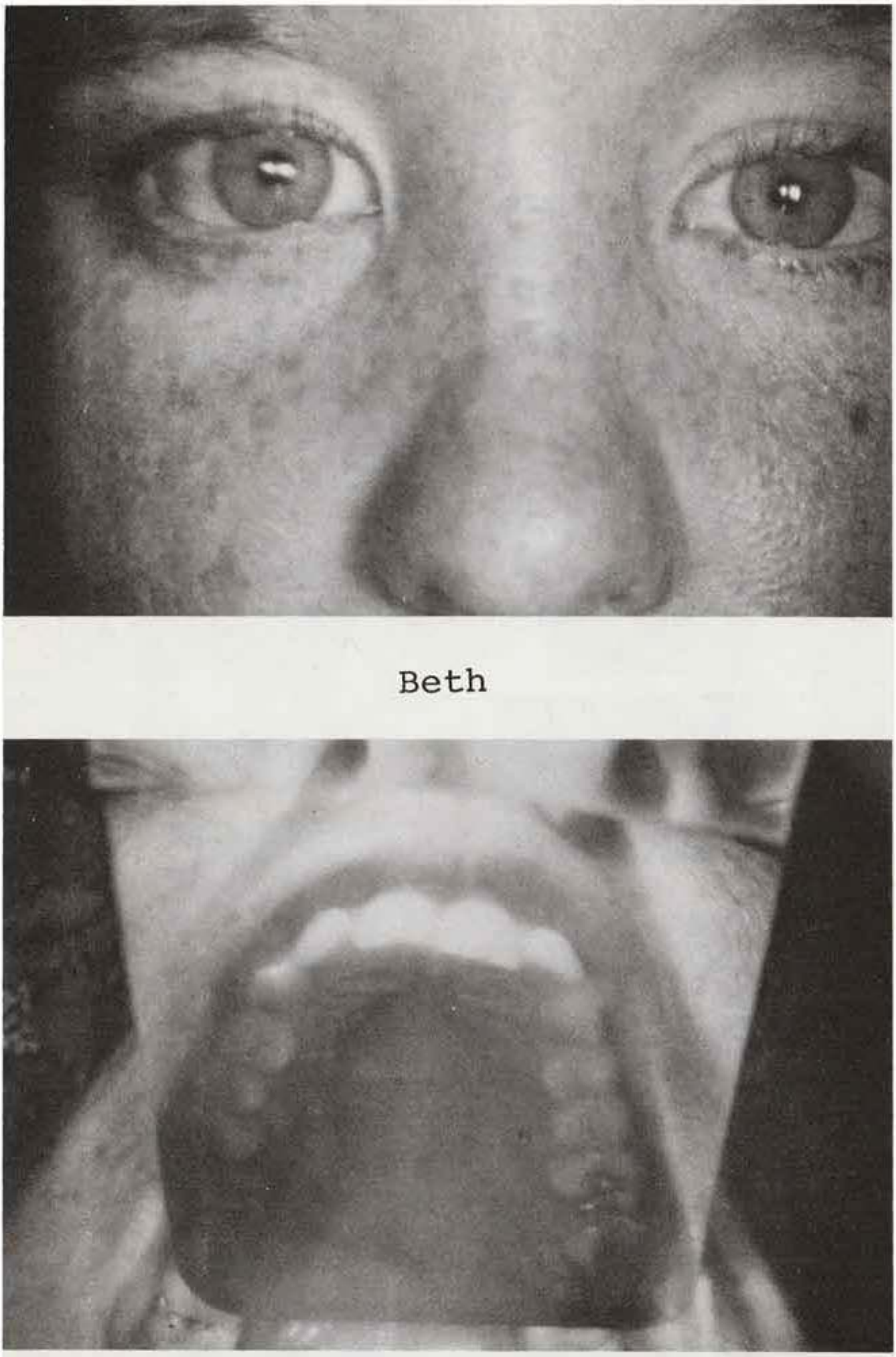
8/74 NO Rk 19Y7M 121# 62"

RONNA—BORN 12/14/54—TREATED WITH THE "U" SERIES FROM 7/1/71 TO 6/1/73 (23 MONTHS). HAS WORKED SINCE GRADUATING FROM HIGH SCHOOL (REGULAR, NOT SPECIAL), FIRST PART-TIME AT A NEWSPAPER, THEN, SINCE FALL OF 1973, FULL-TIME AT AN OFFICE TO WHICH SHE DRIVES HER OWN CAR. SHE IS A RECEPTIONIST AND HAS NOT MISSED A DAY'S WORK ALTHOUGH 2 YEARS EARLIER SHE WAS CONSIDERED RETARDED.

Beth

When Beth saw the changes in Ronna, she, too, came for treatment. I accepted her as a patient on the basis of the physical examination, which revealed epicanthal folds, depressed nasal bridge, marmorated, edematous skin, and an elevated palate with thick gum line. Her problems were obviously due to a genetic disorder associated with metabolic accumulations.

Therefore, she was accepted without a diagnosis of Down syndrome. After all, the "U" Series was not originally developed for treatment of Down syndrome, but for removal of accumulations seen in numerous genetic diseases. As expected, she lost weight. Both academic and social life improved considerably.



Beth

Mary

Mary was born November 26, 1935, an only child. By the time she came for treatment (July 1956), she did not have Down syndrome features, although she had been diagnosed as Down syndrome when younger. Her height was 62 inches, weight 116 pounds. She had a few fissures in her tongue, rough skin, and coarse hair. She was very myopic, and strabismus was present. X-rays revealed an elongated heart but no other abnormalities. She had attended school for retarded children until she was in the sixth grade, but she did not participate in school activities. Her academic education ended at the age of 16. Because she was legally blind, she was sent for training to an institute for the blind. She was apathetic and avoided other people.

Two months after starting the "U" Series, she became socially aware and participated in conversations. Her vision improved dramatically. There was little change physically, except that she began to take pride in her appearance. After two months' treatment, medication was withheld for two weeks. Reversal was immediate. Mary once again became solitary and sullen. At that point, she resumed treatment until June 1957.

Gradual changes in Mary's facial expression and appearance were noticed. Her hair became softer and thicker. She was legally blind prior to treatment. At the end of only six months of treatment, her vision improved so much that she was able to sew on a sewing machine. She refused to return to the institute for the blind. Instead, with the help of a social worker, she moved to another city, rented a room, did her own housework and cooking, and found a job as a seamstress. She supported herself and even sent money home to her mother.

While at the institute for the blind, she had met a young man, also visually impaired. Ten months after Mary started treatment, and four months after treatment ended, they married. She worked and kept house, shopping, cooking, caring for her blind husband. Though her first baby was born too prematurely to survive, she subsequently had two normal children who are doing well.

Mary

E. C. GALSTERER, M. D.
601 - 603 FIRST SAVINGS AND LOAN BUILDING
SAGINAW, MICHIGAN

June 5, 1956

Henry Turkel, M.D.
8000 W. Seven Mile Rd.
Detroit 21, Michigan

Dear Dr. Turkel, Re: [redacted]

I attended Mrs. [redacted] at the time of delivery, it was obvious the baby showed evidence of mongolism. I have not seen the child in many years therefore, I am not in a position to make a diagnosis.

Eric

Eric, born July 9, 1944, was referred to me because he was a "slow learner." His I.Q. was approximately 85 when he started treatment October 1, 1957. His bone age was 11 years at a chronological age of 13 years 3 months. His height was 53 1/4 inches, and he weighed 85 pounds. After a year's treatment there was "slight advance in the progress of ossification" which was closing the gap between bone age and chronological age.

There was equivalent advance in educability. After two years of treatment, his grades were still fairly low in the tenth grade. Two months after that report (1/15/60) he began to improve academically, and thereafter continued to improve steadily until June 6, 1963, when he was graduated from high school with high honors. The Columbus College of Art and Design awarded him a scholarship. After art school, he worked as an illustrator for a commercial art company. He later joined the army and attained the rank of SP 5 after 2 1/2 years of service. Honorably discharged after 3 years, he returned to work as a commercial artist on a trial basis.

A trial basis was considered because he had served overseas as a mechanic and senior plumber, and his employers worried that he might have lost the skills needed for commercial drawing. However, he did so well that 6 months later he was promoted to an executive position as director in charge of 10 illustrators. As a new company executive, he was eligible for the company-paid insurance program and needed a physical examination. He was in excellent health and led a happy and normal life.

CHAPTER V

Mental retardation is a symptom of inadequate development and function of the brain that occurs before the age of 18. The term refers to an impairment in behaviorial and intellectual functioning below I.Q. 70. About 2.5 or 3 percent of the population is mentally retarded, for the most part, mildly retarded (I.Q. 50-70). About 25 percent of the population functions at an I.Q. level below 90, and may experience problems in school. These schoolchildren can be defined as slow learners. Once they are out of school, however, they may grow up to be perfectly normal adults.

In producing the symptom of mental retardation, genes and environment interact. The environment includes prenatal as well as postnatal factors. Harmful prenatal agents are called teratogens. The mother's nutritional status and, since hormones respond to stress, her emotional well-being are part of the prenatal environment. Injuries can be chemical or physical, occurring before as well as during, or after birth. A congenital defect can be hereditary, mutational, or completely environment.

Maternal infections that can cause mental retardation in the unborn child include German measles (rubella), chicken pox, and toxoplasmosis. Toxins, such as lead and mercury can harm the fetus. Alcohol can produce a number of congenital disorders identified as fetal alcohol syndrome. Other risk factors include X-rays, nitrites, toxic wastes, toxemia of pregnancy, and maternal diabetes. The very low birthweight infant is also at risk for mental retardation. Maternal smoking can lead to low birth weight even at term birth.

Genetic and chromosomal diseases are responsible for a large proportion of cases of mental retardation. Phenlyketonuria, galactosemia, mucopolysaccharide diseases, and Tay-

Sachs disease are well-known examples. Phenylketonuria, galactosemia, and congenital hypothyroidism are among genetic diseases that can be be treated after birth. Down syndrome, as we have seen, can also be treated.

For 40 years, I have used the analogy of the unripe grape to assure parents of Down syndrome children that they did nothing "wrong." I have pointed out that the "green" grapes have stems that are normal in size, but for unknown reasons are unable to absorb and utilize available nutrients. The following chapter will outline the scientific background that helps explain the source of malnutrition in the Down syndrome fetus.

The placental weight in Down syndrome was found to be "similar to that of normal newborns of the same gestational age."[32] The problem does not lie with the parent or the placenta (analogous to the stem of the grape), but rather with the child's inability to utilize the nutrients, which are in normal supply.[33]

At the level of mild mental retardation, there may be no discernible "cause." There is normal human variation, as seen on page 73. In some cases, the test results may be inaccurate: the child may be frightened or the examiner may be unsympathetic. Economic or sociological factors may intervene. As pointed out in the 1972 edition of New Hope for the Mentally Retarded, our government is not supportive of family life, especially in the area of preschool child-care services. This neglect returns to haunt us in the form of illiteracy, welfare, and crime.

[33]Breg, W.R.: Down's Syndrome (Mongolism). In: Endocrine and Genetic Diseases of Childhood and Adolescence. 2nd Ed. (Ed. Lytt I. Gardner). W.B. Saunders. Phil. 1975.

[34]Horwitz, S.: Prenatal Diagnosis: Daring Therapy, Dilemmas. Med. Trib. 21; 1/13/82.

CHAPTER VI

Parents who have read about the "U" Series have asked whether it can benefit patients with other genetic diseases. In actual fact, it may be difficult to determine whether a disease is genetic. Some inborn errors of metabolism do not become apparent until late in life, Huntington disease, for example, and probably Alzheimer, but the genetic predisposition existed in the fetus. These hereditary or mutational abnormalities are not foreign to the affected individual, and therefore resist cure. Many, however, can be ameliorated.

If the defect is congenital but not caused by a genetic or chromosomal defect, it may be related to events that occurred during the pregnancy: infections, maternal use of toxins, alcohol, teratogens. Whatever their origin, biochemical defects often result in accumulations of unmetabolized normal metabolites, alternate metabolites, degradation products and/or unexcreted wastes. These substances accumulate all over the body, adversely affecting the circulatory, digestive, respiratory, biliary, lymphatic, cerebro-spinal, excretory, and other systems.

Postnatal environmental factors, including long-term stress, can also alter metabolic processes in susceptible people. Some of these disorders respond favorably to "U" Series therapy.

The prefixes eu- and ortho- have similar meanings: eu- means well, or good; ortho- means straight, normal, correct. Eubiotic (Ubiotica) is similar in meaning to orthomolecular. Both treatment methods rely on provision of correct concentrations of vitamins and other substances for proper physiological function. The "U" Series was developed to remove accumulations and to provide "optimal nutritional support, especially of those nutrients, such as niacin,

pyridoxine, and ascorbic acid, that participate in numerous metabolic processes."[35]

Treatment with the "U" Series in the 1930's

1. Respiratory allergies Allergies were successfully treated before development of antihistamines by a combination of theophylline, or aminophylline, ascorbic acid, phenylpropanolamine HCl, and rutin.

An edematous, asthmatic patient was admitted to Wayne County General Hospital unable to breathe. His eyes were swollen shut. His condition was considered terminal. Previous therapy with adrenaline had been unsuccessful. Aminophylline, phenylpropanolamine, ascorbic acid, and diuretics were dispensed. Hydrochloric acid with lactated pepsin was given to remove salts from the body. Within an hour, he began to excrete fluid at the rate of approximately one quart an hour, about 32 pounds within 4 hours. His asthma improved, he was taken off the critical list, and he was discharged after a week.

2. Premature aging[36] A 22-year-old patient crippled with calcinosis universalis was treated with dessicated thyroid, iodine, carotene, lactated pepsin with hydrochloric acid, a vegetarian diet especially high in barley and oatmeal. Before treatment, his joints were stiff and virtually immobile. Calcium extruded from skin folds and skull. After three months of

[35]Turkel, H.: Letter. Journal of Orthomolecular Psychiatry. 11:198-203. 1982.

[36]Correspondence: Carpenter (Major, USAF).: "Another point that pleased me was that nowhere in your work was there a conflict with gerontological research efforts just completed here. In fact, there was information confirming our approach as well as supporting some of my previous work." USAF Academy, Colorado (Jan. 28) 1968.

treatment, he was able to walk out of the hospital.

3. Non-insulin dependent (Type II) diabetes

One of the first conditions treated with a prototype of the "U" Series was maturity-onset diabetes. Type II diabetics have too much insulin. Insulin circulating in the blood stream[37] may be of normal or abnormal structure.[38] [39] The normal insulin may not be activated.[49] I attributed the contradiction of high blood insulin with high blood sugar to the presence of the fatty infiltration of the liver typical of Type II diabetes. With the "U" Series, fat-soluble substances can be excreted. High-density lipoprotein (HDL) cholesterol levels that protect against hardening of the arteries are abnormally low in diabetics. With use of the "U" Series, oral hypoglycemics or injected insulin can be reduced, and sometimes eliminated, for patients with Type II diabetes.

A diabetic patient with gangrene, who had previously undergone amputatation of five toes, was brought to Wayne County General Hospital for uncontrolled hyperglycemia. I dispensed bile, liver, and digestive enzymes. I ordered a diet consisting of six small, low-carbohydrate meals, not a common treatment in those days. Vasodilators improved blood circulation to the lower limbs, healing the gangrene.

[37]Levin: Still in Question: Primary Cause of Diabetes. Upjohn News Letter 2:2 (Feb. 1) 1965.

[38]Thompson and Thompson. Op. Cit. 1980.

[39]Haneda, M., et al.: Familial Hyperinsulineamia due to a Structurally Abnormal Insulin. New Engl Jrl Med 310:1288-1295 (May 17) 1984.

[40]Glucose Tolerance Test Criticized. Am Med News (Sept. 1) 1978.

Inborn diseases

1. Cystic Fibrosis is a congenital defect that affects the entire body. There is a deficiency of pancreatic enzymes (and possibly production of abnormal enzymes) in about 10% of patients. The sweat of patients with CF is salty. All organs are affected, especially the lungs. Penny, my only CF patient, improved when the "U" Series removed some of these accumulations. Pancreatic enzymes were supplemented to the "U" Series. Similar nutritional treatments have helped other patients with cystic fibrosis.[41]

2. Ataxia telangiectasia. Following a lecture in Las Vegas, I was approached by the parents of a 9-year-old child, Kent. He was dying of ataxia telangiectasia,[42] an autosomal recessive disease that includes among its problems severe immunodeficiency. Two years before, his parents had already lost one child, Kent's 11-year-old sister, to the same disease. Kent was deteriorating. He was lying on a slant bed to drain his pulmonary accumulations and was covered by a plastic tent for oxygen and steam inhalation therapy. He was no longer attending school, but was bedridden. Desperate, his parents contacted me. I requested his hospital records and X-rays. Before "U" Series treatment, Kent's bone age was 66% of normal, he was mildly mentally retarded, and he was extremely susceptible to pneumonia. At the start of the treatment, his parents sent the following Christmas message to their friends:

> Christmas, this year, will have a special meaning for us with our Kent

[41]Nutritional Aspects of Cystic Fibrosis - Mini-Guide to Lung Disease. HEW - CCD 69-50

[42]Delany: On and Off the Record. Las Vegas Sun (Oct. 23, 24, 29, Nov. 4) 1967, (Mar. 11) 1968.

recently recovering from a month's siege of double pneumonia.

It is pneumonia that is usually fatal to children with Kent's problem. We are further encouraged with the doctor's report that his lungs have never before appeared clearer and felt that the medication he is now on has a lot to do with his recovery.

For about six months we have had Kent on a rather controversial medication treatment prescribed by a Dr. Turkel from Detroit, Michigan.

Jan [Kent's mother] had to take Kent to Detroit for the treatment and will have to make another trip there sometime in January for another six months of medications since the Food and Drug Agency will not allow the doctor to ship medicine outside Michigan. Lately they have gone even further and have cut off his supply of medications.

There is to be a Senate hearing regarding this in January and we will probably fly there to appear and testify on Dr. Turkel's behalf.

As it turned out, there was no Senate hearing, but the word of Kent's treatment evidently spread to Washington. He weighed only 34 pounds at the start of treatment and was expected to deteriorate until his inevitable death. Instead, he gained 11 pounds and improved. His parents received word from Washington, the National Institutes of Health. They were told that a new treatment had been

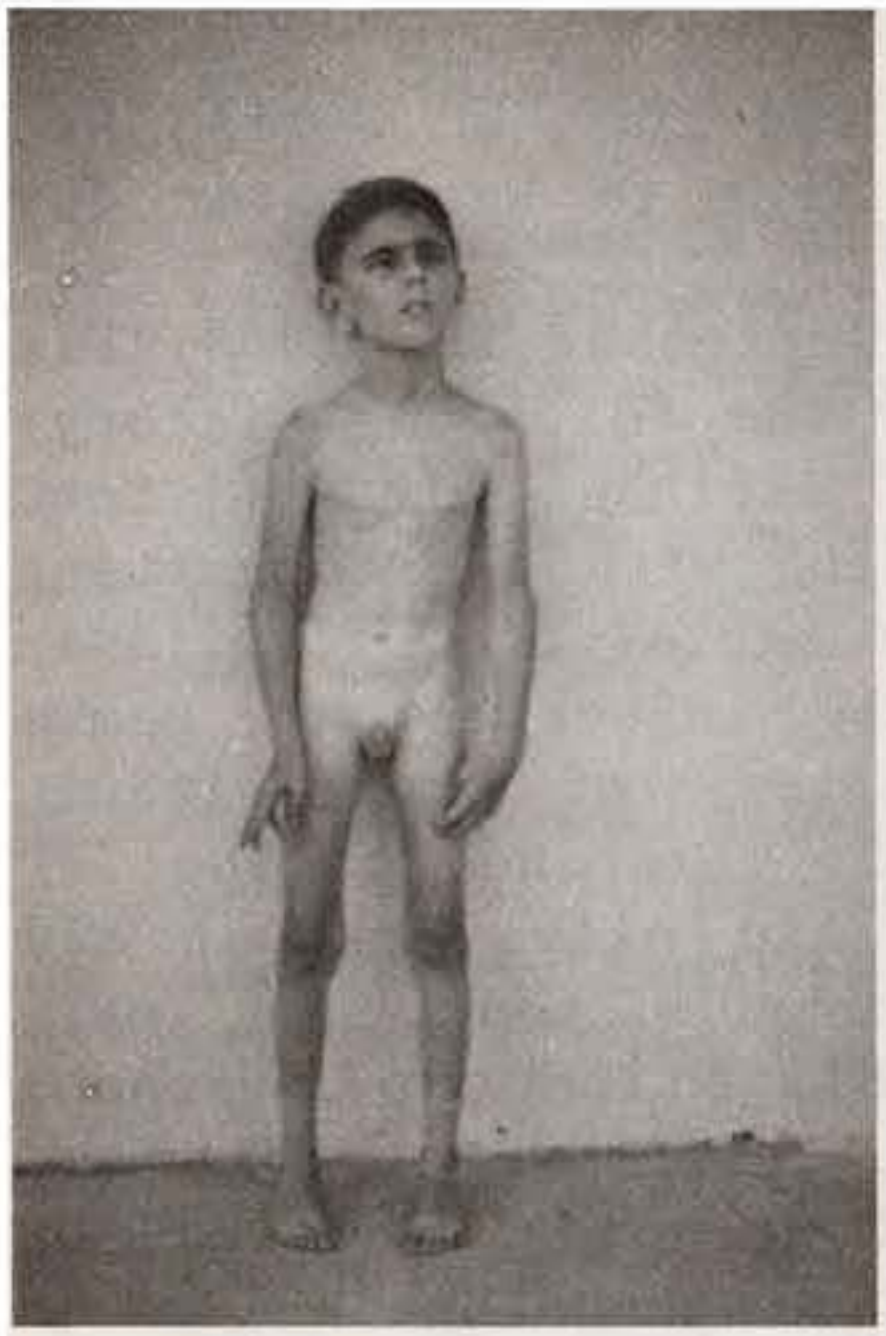
developed by the NIH that would make it unnecessary for Kent to use the "U" Series and that they should bring Kent to Washington for therapy.

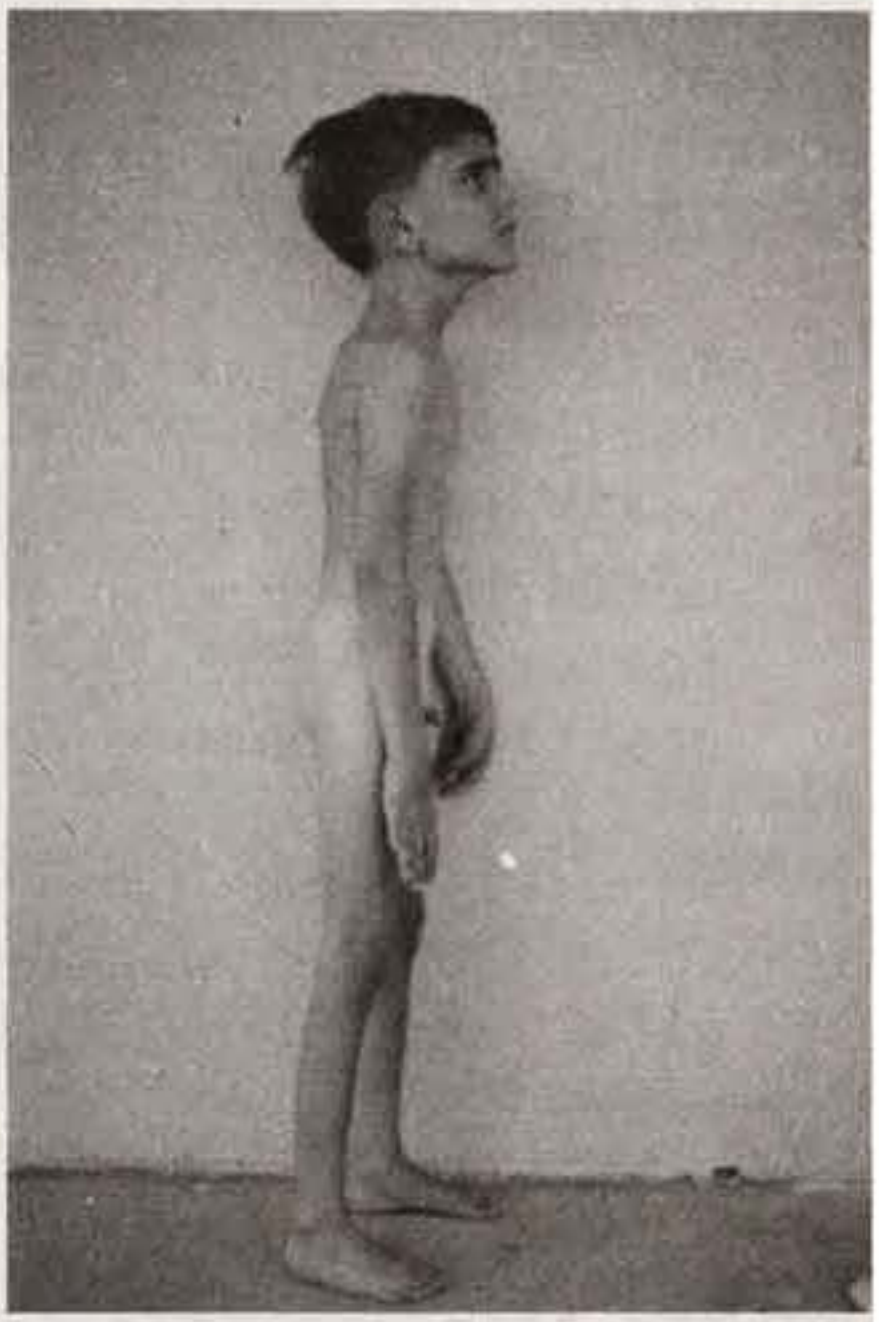
He was admitted September 18, 1968. His clinical record included the following history: "Current medications include intermittent positive pressure breathing with a decongestant agent, an expectorant, a series of multivitamin preparations, and monthly injections of gamma globulin." The "series of multivitamin preparations" was the sole reference to the "U" Series, which had kept him alive against all expectations for more than a year. Not only that, but he had been able to return to school with improved scholastic performance. His bone age went from 66% to 73% of normal. He was not only holding his own, but progressing.

He had been summoned to Washington for a newly developed treatment, but the admission record stated that he was there for "Diagnostic evaluation for ataxia telangiectasia." The "U" Series was discontinued by the NIH, in accordance with the protocol of his admission to the NIH. As the record states:

> This child has ataxia-telangiectasia. His chronic bronchitis will be treated with the same type of regimen the child has been on previously, that of postural drainage and intermittent positive pressure breathing.
>
> Investigation into the metabolic and immunological abnormalities associated with ataxia-telangiectasia will be carried out.

In other words, there was no new treatment. Kent had been admitted into the NIH to allow the doctors to study his disease, not to treat it.





Kent

L.V. Sun Monday Oct 23, 1967

ON & OFF THE RECORD

JOE DELANEY

A-T, Ataxia Telangiectasia, is a heriditary disorder of childhood. Ataxia: Lack of muscular coordination and balance. Telangiectasia: Abnormal dilation of the small blood vessels, particularly in the eyes. Despite their multiple handicaps, children with A-T are characteristically sweet-natured, appealing, boys and girls. A-T has been found in boys and girls of all racial, national and ethnic origins and at all economic levels. It is an inherited disease, often found in more than one child in a family. It is extremely rare. More on this tomorrow.

ON & OFF THE RECORD

JOE DELANEY

We spoke yesterday of A-T, Ataxia Telangiectasia, an inherited disease often found in more than one child in a family. One respected, selfless family in our community has lost one child to this dread killer. A second child of theirs is now afflicted. There are less than 200 known cases in the world. We intend to bring you the whole story . . . A reminder from Carl Lieb at Sherry's: "Nov. 11 is the deadline for mailing Christmas gifts by surface mail, five pounds and over, to Vietnam."

ON & OFF THE RECORD

JOE DELANEY

Dr. Bob Foster is the principal at the Helen J. Stewart School. His work with the mentally retarded is first rate. His accomplishments at the Stewart School are many and varied. Last year, the Fosters lost a daughter to Ataxia Telangiectasia, the congenital condition referred to here last Mon. and Tues. Their son, Kent, is also afflicted with this killer of children. There are less than 200 recorded cases in medical history!

Kent Foster, age 10, weighs only 34 pounds. Our daughter, Kathleen, age 2, weighs 37 pounds! A doctor in Detroit, Mich. developed a compound which has proven helpful with the mentally retarded. Kent was taken to Detroit. His improvement has been most remarkable. The Fosters found hope for the first time. The Food and Drug Administration has stopped production of this compound pending approval. The Fosters have enough to last until Christmas. More on this tomorrow.

LAS VEGAS SUN Tuesday, Nov. 7, 1967

ON AND OFF THE RECORD

JOE DELANEY

More on our local Ataxia Telangiectasia victim, Kent Foster, 10-year-old son of Dr. and Mrs. Bob Foster. A-T is a rare form of mental retardation. Children die of "old age" before they reach their teens. Last year, the Fosters lost a daughter to this killer of children. Kent has enough of the compound devised by Dr. Henry Turkel of Detroit, Mich., to last until Christmas. Dr. Turkel's compound is awaiting FDA approval.

Monday, March 11, 1968 LAS VEGAS SUN 9

Clark County Association for Retarded Children will meet tonight at 8 p.m. at the Elks Lodge. The discussion will be concerned with the need for legislative action and the development of a plan therefor. Panel participants include: State Sens. Chic Hecht and James Gibson; Assemblymen Mel Close, Flora Dungan, Marv White and Frank Young; Deputy Att'y Gen. Robert Grayson and exec director of the Nevada Ass'n for Retarded Children, Dr. Ted Johnson. This is your chance to become informed and, more important, to become a participant. Please, do so . . . Take your pen and paper and write to Sens. Bible and Cannon as well as Rep. Baring asking that Dr. Henry Turkel of Detroit, Mich. be given a fair, complete and impartial hearing by the Food and Drug Administration. Ask Dr. Bob Foster of Helen J. Stewart school to tell you the story of his son, Kent. Please write.

In fact, the one treatment that had improved his condition was discontinued, and the previous treatment, the postural drainage and intermittent positive pressure breathing, that had failed to decelerate deterioration, was resumed. The narrative summary concludes:

> Admitted on 9-18-68 to National Institute of Neurological Diseases, Medical Neurology Branch.
>
> Expired on 10-22-68 from National Institute of Neurological Diseases, Medical Neurology Branch.

3. Congenital lymphedema is associated with various deformities of the lymph pathways that may be due to inborn errors. Since the lymph accumulates, the affected parts of the body become grossly enlarged.

Nancy, born September 20, 1943, was referred February 15, 1955, for treatment of congenital lymphedema. Her right leg and right hand were involved. I gave her the "U" Series plus diuretics, meticortelone, Cytomel, and extra Upeptoid. Agobyl was given to stimulate biliary secretion. Pavex therapy (peripheral arterial-venous pressure exchange, which works like a plunger) was administered, successfully treating the disease.

4. Tay-Sachs disease is a storage disease. The affected infant seems normal at birth, and gradually loses all skills, becomes blind, and dies before the age of two or three. In 1969 at the NIH, Dr. Roscoe Brady discovered the enzymes, but they could not reach the sites where they were needed because of the massive accumulations.

A Tay-Sachs patient in Israel was treated with the "U" Series, to remove accumulations. This child was born June 27, 1965 to a 28-year-old mother and a 36-year-old father. Pregnancy and delivery were normal; she weighed 5 lbs. 15 oz. She developed normally for 5

months, except for hyperresponsiveness to noise. The anterior fontanelle was large and muscle tone was poor. The tentative diagnosis of rickets was ruled out. The child continued to deteriorate. Her tongue began to protrude. When she was 11 months old, ophthalmoscopic examination revealed a cherry red spot on the macula, establishing the diagnosis of Tay Sachs disease.

Treatment began June 24, 1966. On July 24, the mother informed me that until July 15, 1/6 of the proper dosage had been given, and the diuretic had been withheld, on the advice of the attending physician. Beginning July 15, the correct dosage level was administered. On November 15, 1966, her mother wrote:

> Regarding sight, it seems that an improvement has taken place. She seems to recognise parents and surroundings. Eating: she takes her meals with great difficulty helped by sucker. . .
>
> The nurse takes care of Daphna during the day, and in the afternoon I take over. When I come home and approach her, she changes her expression and seems to be happy. Also I find that she is reacting stronger than before. When seeing me she changes her expression to a happy one, and when talking to her it seems as if she would like to answer. I think that she is able to see, not only light and darkness. Sometimes she has tensions in her whole body and then she is frightened.

Soon afterwards, she caught a throat infection, and her condition deteriorated. A new series of infections prevented further improvement in her overall condition. By March

15, 1967, she was again blind. On April 7, 1968, she died. Her parents afterwards told me that she had been hospitalized for one of her frequent throat infections, caught pneumonia, and succumbed. Despite the tragic outcome, the improvements at the start of treatment suggest that the NIH should dispense medication to remove accumulations before and during enzymatic replacement therapy.

5. The Mucopolysaccharidoses: This group of storage diseases is caused by abnormal or a lack of normal enzymes. There is delayed turnover of mucopolysaccharides which then accumulate in cells and are excreted in urine.

A. Hurler syndrome. George H., my first MPS patient, was born January 18, 1971. The pregnancy had been complicated by two convulsions and toxemia; however, a term birth followed uncomplicated labor. The only abnormalities noted at birth were slight jaundice and an umbilical hernia. George weighed 8 pounds 1 ounce at birth and was 21 1/2 inches long. When he was three weeks old, a double inguinal hernia appeared and was repaired two weeks later. His toes turned in bilaterally. Congenitally dislocated hips were diagnosed at four months; he was fitted with a Craig splint. Five months later, congestion of the nasal passages and ear infections became serious. When he was 14 months old, his parents noticed a gibbus. He had spina bifida occulta in the lower lumbar region. He wore a brace for dislocated hips at night for several months, off and on. Corneal clouding was present. After X-rays were taken, the radiologist suggested the diagnosis of Hurler syndrome.

When George was two years old, his parents were told that an anencephalic fetus that was about to be delivered. Doctors recommended transplantation of the kidney or heart of the fetus into their child's lower abdomen to provide sufficient tissue to manufacture the

deficient enzyme. However, the parents felt that this surgery would not have been in their son's best interest at that stage of scientific knowledge. This technique is being attempted, using placental material.

In order to delay the stiffening of the joints, chiropractic treatment was instituted. The Stober cranial technique appeared to relieve the ear and respiratory infections. Thymus tissue was supplemented to aid his reticuloendothelial (RE) system. A plastic body cast was made to help protect his gibbus from worsening; however, it was worn for only two weeks because of the profuse sweating. At the end of 1974, a heart defect, a persistent opening that permitted arterial blood to recirculate to the lungs (patent ductus arteriosus) was diagnosed.

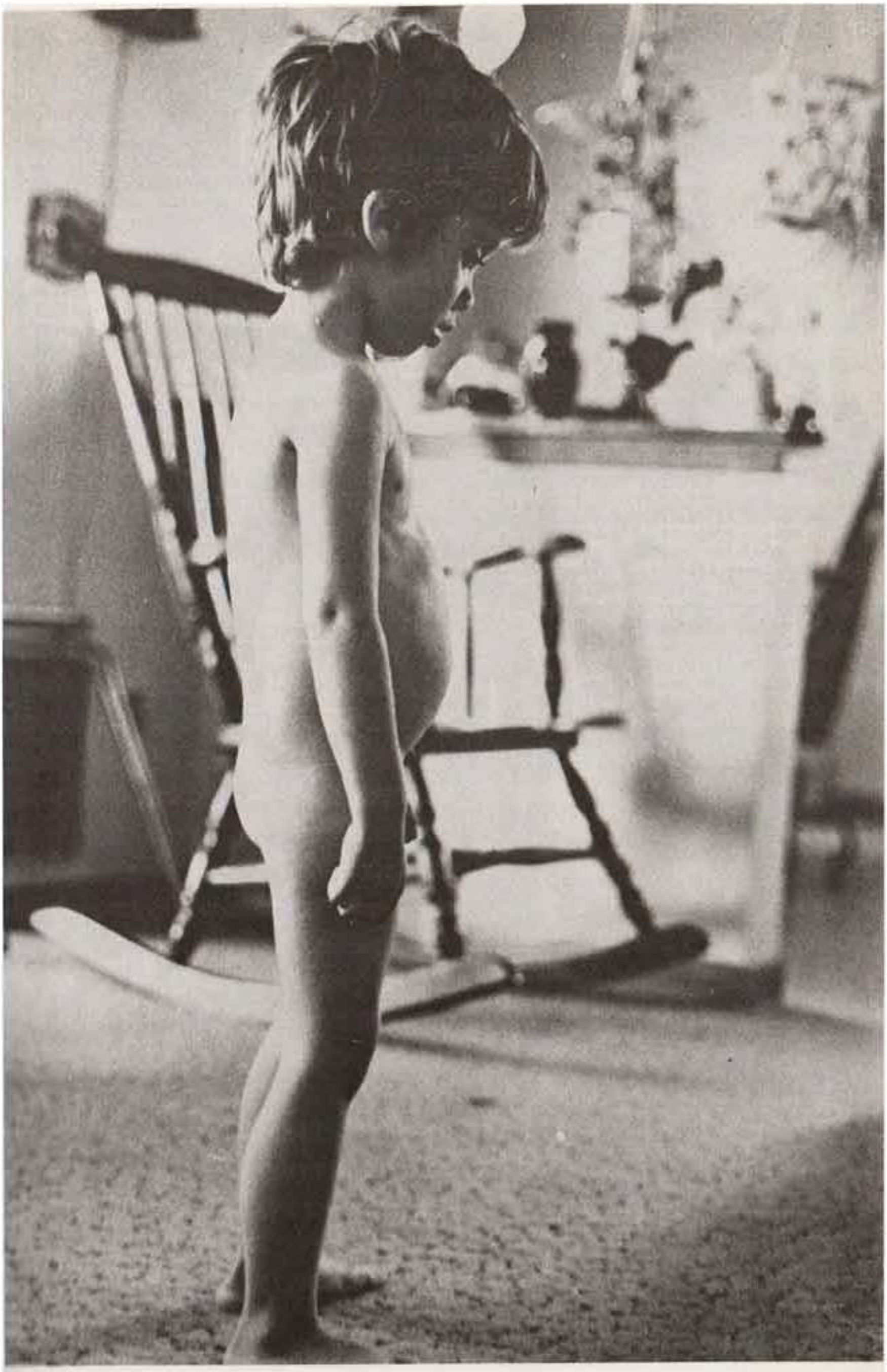
There are no known abnormalities on the paternal side until the generation of George and his first cousins. All five children of a paternal aunt were stillborn. One cousin, born with an enlarged heart and liver, no spleen, died at the age of five months; one of that cousin's sisters had dislocated hips. Another cousin had congenital inguinal hernia. In this generation there are no other diagnosed cases of Hurler syndrome. There are no known genetic abnormalities on the maternal side except for respiratory problems. One of the mother's uncles died when only two days old, of respiratory distress; an aunt has severe asthma. A niece also died when two days old, because of an unspecified breathing problem.

Developmental milestones: George rolled from front to back at six months, back to front at seven months. He crawled at approximately 7 - 8 months, and began walking at age 13 months, when the Craig Splint was removed. Just after George started walking, his mother noticed a hump in the lower region of his back. The diagnosis of Hurler syndrome was confirmed at Medical School Hospital.

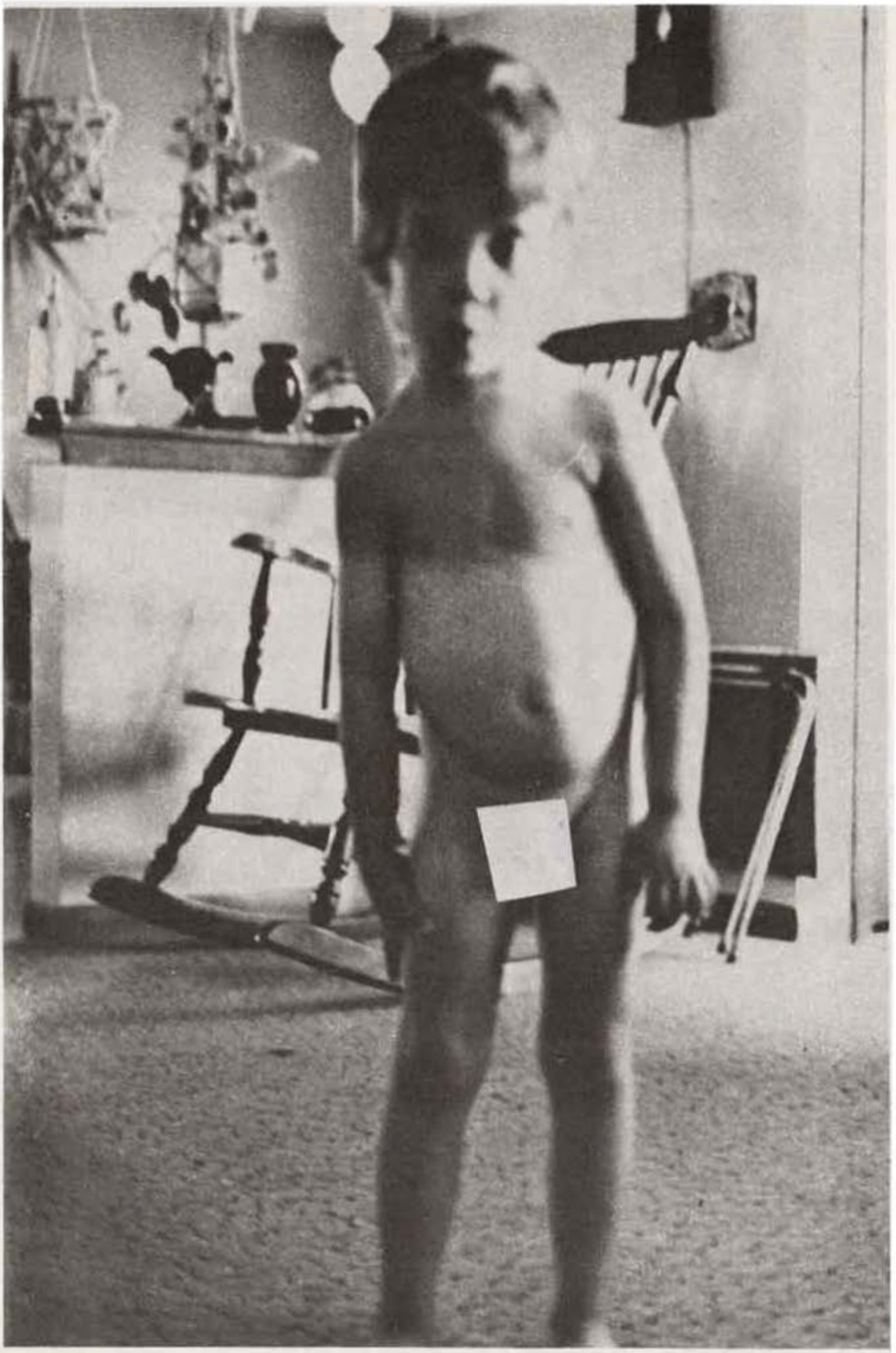
George was first examined June 17, 1976, with the intention of a therapeutic trial with the "U" Series. He was 40 1/2 inches tall and weighed 46 1/2 pounds. He spoke in 7-10 word sentences, could count to 20, read words and letters, and drew shapes and pictures. He was toilet trained during the day, and would wake up several times during the night to use the bathroom. He tired easily. At the age of 5 years, 6 months, George had a mental age of 5 years 2 months. His I.Q. was 91 on the Peabody Picture Vocabulary Test. October 8, 1976, George suffered respiratory failure and was hospitalized. He was prescribed digitalis and antibiotics, which were discontinued before he was released two days later.

General health continued to deteriorate, as expected, with the following exceptions: water retention was less, and his joints became more limber. After 6 months (12/16/76), treatment was discontinued. By the end of 1977, his parents realized that since George was once more retaining fluids, and his joints were again much more restricted, the "U" Series had been delaying the inevitable progress of the disease. He returned for a second course of treatment with the "U" Series January 30, 1978. His height was 41 1/2 inches, weight 50 pounds, bone age normal, I.Q. 97, head circumference 22 1/4 in. On March 3, 1978 it was discovered that George had mistakenly been given only one half the correct dosage of digoxin. He went into heart failure and was hospitalized for six days. Thereafter he deteriorated rapidly. He died June 23, 1978.

B. Sanfilippo syndrome Each of the subtypes of Sanfilippo syndrome is associated with a different enzymatic defect, but all are diagnosed by the typical physical features and the accumulations of heparan sulfate in the urine and cells. There are severe and mild forms of these subtypes, even within the same



"Clark"



MACOMB ORGANIZATION FOR THE DISABLED

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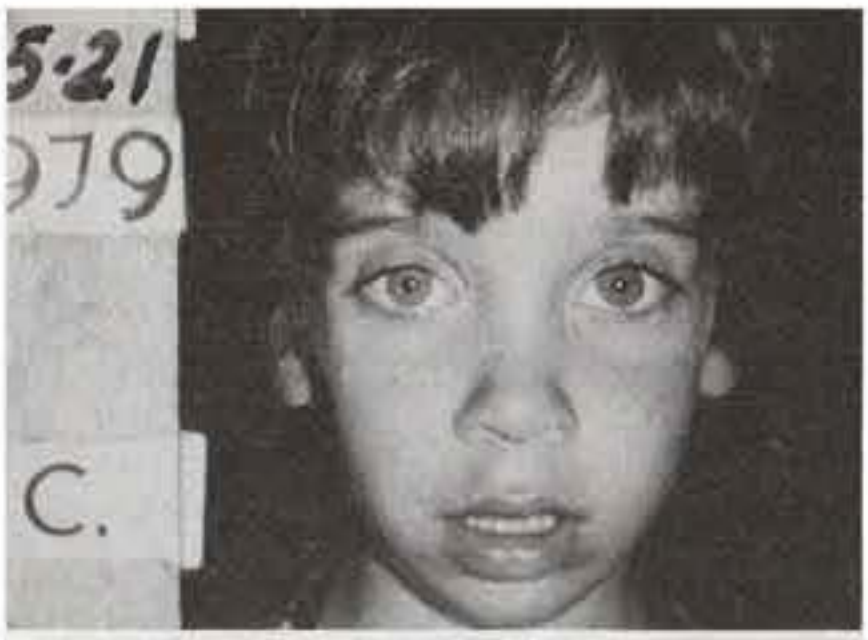
October 9, 1979

Robert Clark, of Roseville, is four years old. Robert talks, plays, laughs, cries, loves, goes to school and functions much the same as any normal healthy child. Katie Clark, Robert's mother, dreams of a full rich life and future for her young son. Katie also lives each day in fear that Robert's life will end all to soon, and unnecessarily, for reasons beyond her control.

Robert suffers from a rare genetic disease known as "mucopolysacchridosis." This disease affects the metabolism in such a manner that it prevents the body from utilizing nutrients and from filtering out wastes. The body is starved and poisoned at the same time.

Most medical experts insist the disease is terminal, with no hope of cure. Two years ago, doctors told Katie to just take Robert home and enjoy him while she could. They offered no help or hope, and told her that Robert would never develope normally but would regress to a fetal stage and die. Refusing to accept her sons "death sentence", Katie began a desperate search for someone who might hold out some hope for her childs life. She found Dr. Henry Turkel, a southfield physician, who developed a method of treatment that could be beneficial to Robert. Dr. Turkel's treatments began with a system of vitamins designed to remove all wastes from Robert's system, and supplimented with an all natural food diet. Since treatment began, Robert has regained speech, is playing with friends and is attending special education classes. In short, Robert has began to develope normally and is no longer regressing. Having visited death's door, Robert, and his mother, may once again look to the future.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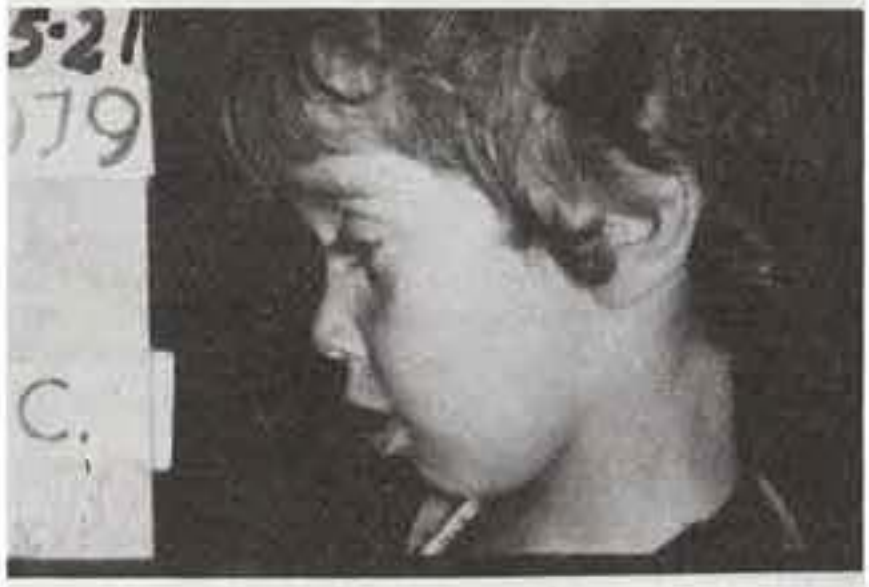
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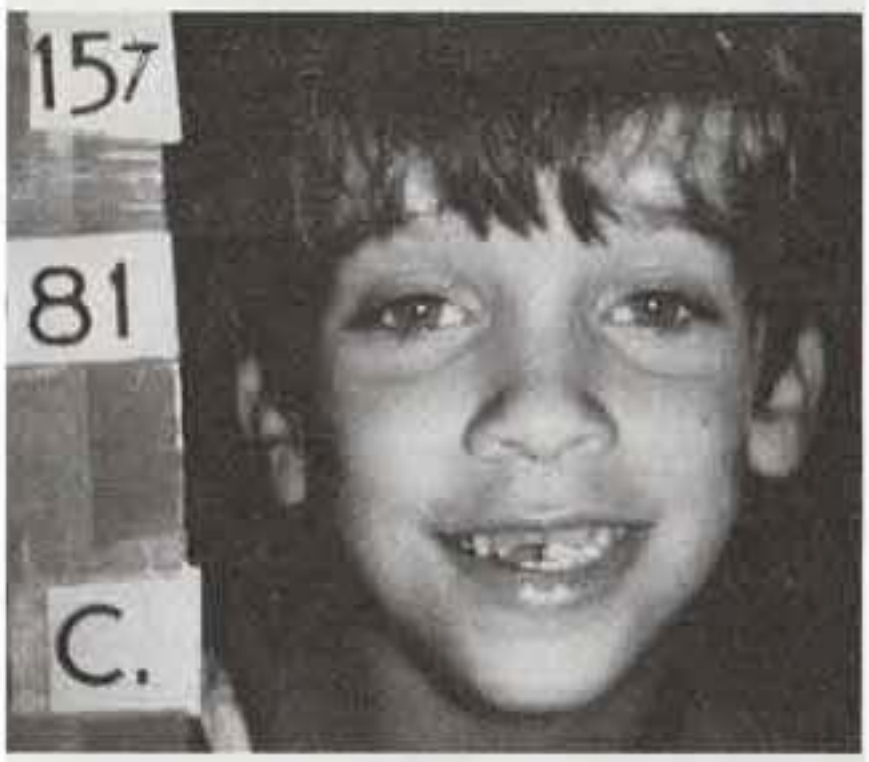
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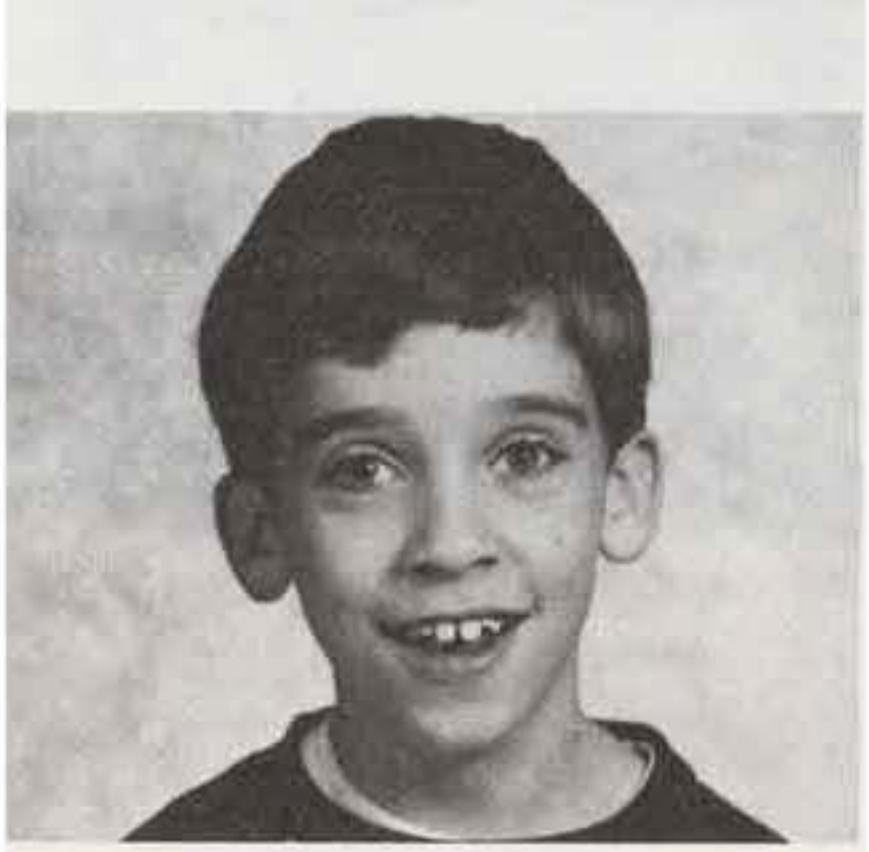


MACOMB EDUCATIONAL ASSESSMENT CENTER
REPORT OF PSYCHOLOGICAL EXAMINATION

Macomb Intermediate School District, 44001 Garfield Rd., Mt. Clemens, MI 48044

Date(s) of Examination 7/8/81 & 7/22/81

Name of Subject Robert Clark Birthdate 4/24/75

Parent or Guardian Kathleen Phone 771-9104

Address 18101 Pasadena City Roseville Zip 48066

Name of School Carlson Grade

Name of District Roseville

REASON FOR REFERRAL

Robert was referred for evaluation to aid in educational planning.

BACKGROUND INFORMATION

Robert has an extensive medical history which is documented in his file. Robert has been diagnosed as being macrocephalic. The paternal family history documents the presence of macrocephaly and multiple lipomas in several family members. In 1978, Robert was diagnosed as having Mucopoly saccharidoses and has been followed by doctors at the University Hospital in Ann Arbor. In 1979, Robert began taking the U series (treatment of massive does of vitamins and minerals) under the care of Dr. Turkel. Robert was first known to this facility in 1978 (age: three years, zero months). At that time, his I.Q. as measured by the Stanford Binet, Form L-M was 81. Robert was again tested in 1980 (age: four years, eleven months). Full scale I.Q. on the WPPSI (Wechsler Preschool and Primary Scale of Intelligence) was 113.

OBSERVATIONS

Robert is a handsome, six year, two month old male. His head appears to be enlarged. He is thin but of average height. Robert is friendly and interacts easily. He initiated conversation. Robert gave good attention to tasks and was cooperative.

TESTS ADMINISTERED

WISC-R (Wechsler Intelligence Scale for Children - Revised)

TESTS RESULTS

At the time of testing, Robert was six years, two months of age. On the WISC-R (Wechsler Intelligence Scale for Children), he attained the following summary scores:

Verbal I.Q.	107
Performance I.Q.	136
Full Scale I.Q.	123

family. Onset is noted between 1 and 4 years; life expectancy is 2 - 18 years. Urinary excretions of heparan sulfate have been known to fluctuate, ranging from very high levels to trace amounts.

"Clark" (pp. 111-115) weighed 9 lbs. 12 oz. at birth (4/24/75). His mother reported that labor was extremely difficult. She believed that, since her pelvis was small and the baby's head was large, he should have been delivered by C-section. Instead, forceps were used. As a result, Clark "looked like a battered baby." Early developmental problems were attributed to the difficult birth.

Clark's father, his paternal grandmother, and his two paternal uncles have unusually large heads. Both paternal uncles were placed in special education classes; one required speech therapy. Clark's father as well as his uncles and aunts were large babies, weighing between 9 and 11 pounds at birth. A paternal cousin was born with multiple problems, including an enlarged head. A paternal uncle died in infancy of possible hydrocephalus. An older brother died of SIDS. His half-sister, a child of his mother's first marriage, is normal. There are no known genetic diseases on the maternal side.

Although this history suggests the possibility of a dominant disorder, urinary excretions and cellular accumulations of heparan sulfate are diagnostic of Sanfilippo syndrome, a recessive disease.

His mother tells the story in her words:

"I was concerned about him right away because of his extremely large head, which was 38 cm. at birth. At three weeks, his head circumference was 41 cm.; at 7 months, it was 51 cm. According to the doctors, these measurements were far from normal. They tested him for hydrocephalus, dwarfism, and thyroid deficiency - all negative. I was in and out of the emergency room with him all the time because of the problems he had swallowing food. He could not

move his bowels without enemas. At night, his sheets were drenched with sweat that smelled peculiar, like sour pickles.

"He was late in lifting his head [8 months], rolling [18 months], and sitting alone [2 years]. He was walking clumsily by the time he was 3. His IQ was taken with the Stanford-Binet, and was found to be 81, but his gross motor development was only two years and his language ability was two years one month. When he was in the hospital with one of his choking emergencies, at the age of three, a neurologist was called in to try to determine what was causing all his problems. He looked at the unusual skeletal development and suggested that his urine should be tested for MPS. His urine was sent to Upjohn Laboratory and came back positive for MPS. A second urinalysis was done the following month, and also a skin biopsy. They were both positive.

"We were referred to the University of Michigan, and a third urinalysis was found positive for MPS, heparan sulfate. A skin biopsy showed that his cells accumulated heparan sulfate. His fibroblasts were compared with a normal control and a patient with Hurler's. In the control [normal] fibroblasts, 50% of MPS was degraded, in the Hurler patient's 20%, but in his there was no degradation of MPS. The same bad results were found in studies of the turnover of radioactive sulfate. I could tell by the doctors' concern that we were faced with a terrible disease. They were very kind but warned me that many problems lay ahead. They gave me a name for the disease: MPS III, Sanfilippo Syndrome.

"When my son was four years old, I asked his doctor at the University of Michigan about the "U" Series. He wrote a letter asking Dr. Turkel to treat my little son. He also wrote a letter to the State Department of Social Services, requesting help for our family because of the

terrible prognosis for this disease. The doctors' attitudes frightened my husband so much that he walked out on us, not to return until after Clark improved. Treatment with the "U" Series began May 21, 1979. At that time, Clark's head circumference was huge [50 cm.], his spleen and liver were enlarged, and there were other abnormal features often seen in MPS children. His mental age was under 3 years and his social age was 2 years, 2 months. He was still not toilet trained. His muscle tone was so bad that he needed enemas to move his bowels.

"Three months later, his neurologist confirmed the diagnosis of Sanfilippo syndrome. September 18, 1979, his University geneticist wrote a report stating that the organs appeared to be normal, except for the very large head, and that he seemed much more alert and vigorous. The diagnosis remained Sanfilippo syndrome, based on delayed turnover of MPS, MPS in the urine, and skeletal changes.

"During the first 9 months of "U" Series treatment, his IQ, as tested by the school district, went from 81 to 113. By July 22, 1981, the school district stated that his IQ was 123. Despite all the many studies that confirmed the diagnosis of MPS, the University stated that my son's 'excellent development over the past two years is inconsistent with the diagnosis of mucopolysaccharidosis.' No new diagnosis has been given, though Clark does not continue to do well if the "U" Series or GTC Formula is discontinued."

Mrs. C received a strange letter from the geneticist, who stated that he was happy about the child's improvement. However, had he known that all the laboratory studies diagnosing an MPS disease had been wrong, he would not have referred the child for treatment with the "U" Series - even though the "U" Series apparently does not significantly help the child with more typical Sanfilippo syndrome and did benefit Clark!

My reaction is just the opposite. Evidently children without classical Sanfilippo syndrome have similar clinical features and biochemical accumulations - as Clark did. Since this subset of patients, of whom we have seen one case, benefits, it would more sense to treat all similar patients with this safe treatment in the hope that a few will benefit than to let all suffer, including those who might otherwise have benefited.

I must point out at this time that in a letter from Holland I have been accused of being the only one who has benefited from the treatment of Patient Clark. Based on the improvements, I do not understand the accusation, particularly in view of my donation, without charge, for services and medication. However, I have benefited in the form of satisfaction in seeing the child improve. I wonder how the doctors who treat these patients while knowing that the children will not improve as a result of treatment justify their fees. At any rate, seeing that Clark improved, the University of Michigan referred him to the NIH for further examination.

After a cursory examination, the NIH stated that Clark had never had a storage disease. The diagnosis was dutifully changed by the University of Michigan. Commenting on the change of diagnosis, Dr. A. Hoffer, editor of the Journal of Orthomolecular Psychiatry, wrote: "Apparently the greatest sin in medicine is to cure a patient by using a non-established treatment."[43]

[43]Hoffer, A: Editorial - Treatment of a Mucopolysaccharide type of Storage Disease with the "U" Series. Jrl. Orth. Psych. 10:226-227. 1981.

Six other MPS patients have since been treated; one improved slightly, one improved to a greater degree, three have not improved, and for another Hurler patient, it is still too early in treatment to determine.

C. Treatment of three other Sanfilippo patients.

a. At the age of 3 1/2, patient W. was examined neurologically because of delay in speech. The child had two episodes of seizure activity and fever following his DPT injections. A severely retarded 12-year-old brother was institutionalized. A complete biochemical evaluation of both children revealed no abnormalities. An EEG of W. showed some spike activity, and he was placed first on phenobarbital, and then on Depakene. On Depakene, seizure frequency was decreased to approximately one per week. Sanfilippo syndrome, type A was confirmed biochemically by Dr. Elizabeth Neufeld of the NIH on October 18, 1979, when W. was four years old. At the same time, his older brother was also diagnosed as a Sanfilippo patient.

"U" Series therapy, without pentylene-tetrazole, was dispensed 1/23/81. Bromelain and papain enzymes, Brompheniramine maleate, and tryptophan were added. He was 42 1/4 in. tall, weighed 41 1/2 lb. and his head circumference was 50 1/2 cm. with some bulging of the anterior fontanelles. Features were slightly coarsened, with depressed nasal bridge. His gait was wide and unsteady. His abdomen protruded. Both testes were descended.

Positive changes with treatment included some reduction of abdominal protrusion, more social interaction, improvement in behavior with

less hyperactivity, and the ability to recall past events that he had previously forgotten. Six months later, at the time of the second examination, his height was 43 3/4 in. weight 40 lb., head circumference 49 1/2 cm. Because of lack of significant progress, treatment was discontinued after one year.

b. Bill, born March 29, 1969, was diagnosed as having Sanfilippo syndrome, type A by Dr. Neufeld, February 26, 1976. Early development appeared normal. He walked at 16 months, fed himself at 28 months, and was toilet trained at 30 months, but did not speak until age 3. Hyperactivity began at age 4, and previously acquired skills deteriorated. He screamed constantly. Various medications, including Thorazine, Mellaril, Ritalin, Haldol, and Dilantin, did not help. He was classified as profoundly retarded. His EEG was abnormal.

"U" Series treatment was started December 17, 1980. No pentylenetetrazole was given. Tryptophan, bromelain, papain, and brompheniramine maleate were supplemented. His height was 55 in., weight 75 lb., head circumference 55 1/2 cm. After 6 months, his height was 57 in., weight 75 lb., head circumference 53 cm., representing loss of edema. He appeared to be calmer, and was screaming less. Since progress was slow, treatment was discontinued after one year.

c. A 16-month-old child in Texas, whose diagnosis was Sanfilippo syndrome on the basis of skeletal changes, accumulations of heparan sulfate, and deficiency of N-acetyl-A-D-glucosaminidase enzyme activity, was brought to Michigan for treatment at the age of 21 months, October 28, 1981. His spleen was palpable 1 to 2 cm. below the left costal margin, and his liver was palpable 6 cm. below the right costal margin. After 18 months of treatment, his spleen and liver were no longer palpable, and urine was normal for mucopoly-

polysaccharides. He was not regressing physically, but was losing verbal skills and becoming increasingly hyperactive. The parents have been advised to consider bone-marrow transplantation to introduce the lacking enzyme into his body.

D. Hunter syndrome is a sex-linked mucopolysaccharide disease, with intellectual decline variable even among brothers.[44]

Joel was born October 8, 1971, weighing 9 lb. 6 oz., the first (and only) child of a 23-year-old mother and 21-year-old father. Labor was prolonged (48 hours), and he was delivered by cesarian section. Mild jaundice was treated with light therapy. Milk produced vomiting and diarrhea, but this problem was solved by use of milk-free formulas.

Joel sat alone at 4 months, walked at 11 months, said single words at 1 to 2 years, used phrases at 3 to 5 years, was toilet trained at 3 years. By the time he was 7 years old, he was no longer toilet trained. Clumsiness and hyperactivity were apparent from birth, but other problems appeared gradually. General health was poor, with recurrent bouts of respiratory and ear infections. Surgery for hernia repair was followed by kidney infections. Coarse facial features and skeletal changes, including macrocephaly, suggested a mucopolysaccharide disease. A skin biopsy confirmed a deficiency of iduronate sulfatase, consistent with Hunter's syndrome.

At the time of his first examination for treatment with the "U" Series, November 23, 1982, Joel's mother recorded the following observations:

[44]Murphy, J.V., Hodach, A.E., Gilbert, E.F., Deanching, M., Matalon, R.: Hunter's syndrome, Ultrastructural Features in Young Children. Arch Pathol Lab Med 107:495-499 (Sept.) 1983.

"Joel is now:
(1) Taking Isoclor antihistamine/decongestant for sinus congestion.
(2) Walking stiffly (back bent to some degree, legs bent at the knees).
(3) Having periodic bouts of muscle spasms (as far as we can tell). He will (upon rising from a sitting position), take a few steps, and then become glued in his tracks. We have to hold onto him very tightly and support him until he pulls away and tries to continue walking.
(4) He does not walk even a few steps without holding your hand. If you do not hold his hand, he will just start turning in circles.
(5) He cannot walk more than approximately 50 feet without appearing to be tired.
(6) Does not talk. If you get right in front of him (face to face) and talk or sing to him, he will move his tongue in what looks like proper movements to say the words, but no audible sound is made.
(7) I know that Joel can hear. He sometimes laughs out loud if something funny comes on TV or if you are playing with him and he thinks you are funny.
(8) Joel takes a 2 mg. Valium at bedtime to rest. The Isoclor makes him restless. Sometimes he doesn't go to sleep until after 3:00 a.m.
(9) He does not have a good deal of use in his hands. His fingers are bent.
(10) Joel does not feed or dress himself. He wears Pampers all the time.
(11) Occasionally, when Joel is eating, he seems to push the food back out of his mouth."

Joel's bone age at the time of the examination was between 5 and 6 years, at chronological age of 11 years. He was 46 to 47 in. tall, weighed 69 lb. His abdomen was 74 cm. around. His head circumference was 55 cm. Epicanthal eyefolds were present; facial features were coarse; there was hirsutism; all his joints were stiff. His heart appeared to be normal.

At the end of the first six months of treatment, his mother wrote again:
"Improvements since beginning "U" Series:
(1) Walking straighter.
(2) Smiling more.
(3) More relaxed (no valium since 3rd week on treatment).
(4) Fingers are straightening out.
(5) Stomach softer and flatter. Much less gas.
(6) Generally healthier
(7) Hair softer.
(8) He will let you touch him now. Lets you comb his hair, wash his face, holds more still for barber.
(9) Good daily bowel movements.
(10) Bones seem smaller in sides of his head above his ears.
(11) Forehead getting a normal look.
(12) Tongue getting smaller."

It was also apparent, at the time of his examination February 22, 1983, that his joints were less stiff. He measured 50 1/4 in., weighed 72 lb. He was considerably more relaxed.

Storage diseases require not only the removal of accumulations but also supplementation of the necessary enzyme. Without the enzyme, improvements are limited. What we are striving for at this time with the "U" Series is improved quality of life.

Disorders with a possible genetic component

1. In accordance with the "U" Series rationale, it should be possible to ameliorate various other inborn errors of metabolism, particularly if the lacking enzyme can be introduced into the patient's body. Dr. Johanna Blumel, specialist in cerebral palsy at Moody State School of Cerebral Palsy, in Galveston, Texas, who demonstrated that cerebral palsy may

be familial,[45] [46] suggested that the "U" Series might benefit those children in whom she diagnosed chromosomal abnormalities, cataracts, or other evidence of accumulations. Because of the difficulty of determining the underlying cause of this disease, I have been reluctant to accept patients with this diagnosis. However, the brother of a Down syndrome patient, whose diagnosis is familial spastic paraparesis is undergoing "U" Series treatment concurrently with a patterning program of the National Academy of Child Development. His first examination was April 12, 1984. He was unable to take a step without crutches. After 3 1/2 months of treatment, he was able to walk 100 feet without crutches.

2. Emphysema is a crippling disease. The patient's lungs lose elasticity because of excessive elastase, a natural digestive enzyme, which destroys foreign substances that enter the lungs. Too much elastase can attack healthy tissue and cause emphysema.

Dr. P. suffered from emphysema and psoriasis, previously treated with methotrexate. He consulted me following an almost fatal bout with iatrogenic (treatment induced) aplastic anemia. Methotrexate was discontinued. Portions of the "U" Series, including Utrophoid C, folic acid, iron, and vitamin B_{12}, were dispensed to build up his bone marrow. Upneoid, extra vitamin C, rutin, vitamin A, theophylline, and prednisone were given to improve his pulmonary function. He had been totally disabled for six months. Following treatment, he was able to teach full time at the university level.

[45]Translocation of the X-Chromosome. Med Trib (Feb. 6) 1961.

[46]Tablan, D.J. and Valdecanas-Dizon, I.: Cerebral Palsy among Filipino Twins. Jrl Philip Med. Assoc 40: 631 (August) 1964.

Whenever there is destruction of cells because of allergy, histamine is released. Therefore, antihistamines, as in Upneoid A, combined with aminophylline, phenylpropanolamine, rutin, and vitamin C, are indicated - improvement in pulmonary function).

3. Orthomolecular therapy usually refers to psychiatry. I am not a psychiatrist. I have, however, treated a patient with anorexia nervosa. Although this life-threatening disease afflicts, for the most part, young women between the ages of 12 to 25, anorexia or bulemia also affects males and cuts across socioeonomic lines.[47] The anorectic patient is hungry, and may be obsessed with food, but the body image is distorted.

The cause of the disorder is unknown; however, it is often treated as though it were a psychological problem. Dr. James Hudson, clinical instructor in psychiatry at Harvard Medical School, has said that a serious problem with psychotherapy is the assumption that a psychological problem must be due to psychological factors: "The three most common psychiatric diagnoses in the nineteenth century were epilepsy, tertiary syphilis, and tuberculosis."[48] As more is learned about the biochemical basis of a patient's behavioral problem, the presumed psychogenic influences as well as the benefits of orthomolecular therapy can be reassessed.

At the age of 15, "T" weighed almost 90 pounds. By the time she was 16 years old, and just under 5 feet tall, she weighed 70 pounds. Half a year later, she weighed less than 60

[47]Male anorectics and bulimics: Study finds evidence of sexual inactivity, homosexuality. Med World News 25: 67 (Oct. 8) 1984.

[48]Ely, Elissa: Rx for Bulimia. Harvard Magazine 86:53-64 (Nov.-Dec.) 1983.

pounds. Amenorrhea was blamed on slightly elevated levels of androgens, for which her gynecologist prescribed prednisone. Her tongue turned black. Her skin and sternum began to ache.

During her freshman year at college, she consulted a dermatologist because the infection around her fingernails would not heal. He diagnosed a yeast infection, treated topically. I dispensed Upeptoid A and B, Utrophoid B and C, vitamin B_1, vitamin C, rutin, bioflavonoids, and chlorpheniramine maleate.

In May 1982, I presented two case studies at a meeting of the Academy of Orthomolecular Psychiatry in Toronto. At the same convention, cases of anorexia nervosa and bulemia were presented by Dr. L. Gilka of Canada. She recommended that an underlying yeast infection be considered. T's history of treatment with penicillin and prednisone, cravings for mushrooms, soups containing yeast, a localized yeast infection fit the pattern described by Dr. Gilka. During her summer vacation, I added Nystatin, as pure powder, in a clear capsule, without sucrose or lactose. T's improvement has been steady. She has become healthier, has no desire to starve herself, and has lost puffy weight, while building muscle.

Body and mind.

Certain behavioral disorders are considered psychogenic. However, if the underlying problem in these diseases is a biochemical imbalance, therapy based entirely on the psychological model may be inadequate. Bulemia appears to be related to depression. A double-blind study conducted by Dr. James Hudson and Dr. Harrison Pope, Jr., assistant clinical professor of psychiatry at Harvard Medical School, demonstrated the benefits of treatment with Imipramine (Tofranil), a tricyclic antidepressant. Dr. Philip Gold and his coworkers at the NIH found abnormal and randomly

changing levels of vasopressin (antidiuretic hormone) in anorexia. Dr. Gold has considered the possibility that vasopressin, which has memory-enhancing effects, could be related to the patient's false body image and obsessions.[49] Dismissal of the medical model, as suggested by Dr. Szasz and other radical psychiatrists,[50] can be hazardous to the patient. During the past 30 years, the medical model has become increasingly important.[51] [52] Some depressed patients benefit from amino acid therapy.[53] In other patients, pharmacologically active metabolites (products of alternate enzymatic pathways) that resemble hallucinogenic drugs may be present. Urinalysis may reveal N-dimethyltryptamine or other hallucinogens.

These examples raise the question: "How does a modified "U" Series regimen differ from other orthomolecular therapy?" In his Introduction to this book, Dr. Pauling clearly includes the "U" Series as an orthomolecular treatment. However, the "U" Series differs to the extent that it was developed to remove accumulations, a common factor in metabolic disturbances in addition to supplying the necessary components of orthomolecular therapy.

[49]Hooper, J.: Continuum: Anorexia Hormone. Omni (Nov.) 1983.

[50]Szasz, T.: The Myth of Mental Illness (Revised) Harper & Row, New York 1977.

[51]Turkel, H.: Freud. JAMA 163:580 (Feb 16) 1957.

[52]Turkel, H.: Medicine and Analysis. New Eng J Med 256:764 (April 18) 1957.

[53]...and depressed patients improve with single amino acid, tyrosine. Medical World News 25:106-107

The "U" Series makes no impact on the basic cause of any disease, but like other orthomolecular medical modalities,[54] improves the patient's condition. I adapt the "U" Series to the needs of patients. Few, if any, human beings are free of all harmful genetic idiocyncracies that lead to deleterious accumulations. Since this method of treating patients is safe, different therapeutic trials can be implemented.

[54]Hoffer, A.: Latent Huntington's Disease - Response to Orthomolecular Treatment. Jrl of Orthomolecular Psychiatry 12:44-47 1st Quarter. 1983.

CHAPTER VII

Controversy over Down syndrome persists. Many medical texts still do not include it among diseases associated with biochemical disorders. However, as the imbalances and accumulations associated with the disease are gradually identified, the principles behind use of the "U" Series are being vindicated. More importantly, the results of the treatment are being verified on increasingly larger numbers of patients, especially in Japan, where Down syndrome children are treated at 80 hospitals.

In 1961, at a convention in Vienna, I met Dr. Makoto Iida of the Japanese National Institute of Mental Health. Following this meeting, various Japanese physicians attempted to duplicate the "U" Series but found it too complicated.[55] In 1964, I renewed my acquaintance with Dr. Iida at a convention of Military Surgeons in Washington, D.C. Dr. Iida told me that complications of Down syndrome were claiming the lives of 90% of these patients prior to adolescence, and that he wanted to learn how to compound the "U" Series correctly.

We discussed the formulation and manufacture of the "U" Series. For the following ten years, although I did not know it, the Japanese used and studied the "U" Series, in somewhat modified form (MD Series) because of the unavailability of several of the components.

In 1974, I received the following letter:

> I am very pleased to tell you that thanks to your kind approval we have been able to prescribe the medicine to Japanese children in several thousand

[55]Tanino, Y.: Improvement of Children with Mongolism. Ann. Paed. Jap. 12:32. [Jan-Feb] 1966).

at national or university hospitals amounting to about 60 in total throughout Japan, thus resulting in improvement of their health greatly.

On September 12, 1974, Dr. Iida and Dr. Takatsune Koishi, a biochemist and president of Kobato-Kai, the Parents' Association, visited Detroit to thank and inform me of results.[56] [57]. The mortality rate prior to adolescence had been reduced from 90% to 1%. Since then, at least 1000 additional children have been treated at 80 hospitals. While here, Drs. Iida and Koishi examined my results. Observing that the physical improvements were greater with the "U" Series than the MD Series, they decided to import it, preferably from the United States, as soon as possible.

My wife, Jeanne, and I were invited to Japan, where we lectured to about 2000 parents and doctors under the auspices of Kobato Kai, the parents' organization. Our itinerary included meetings at several hospitals where Down syndrome children were treated with the modified "U" Series. We also visited governmental officials and representatives of pharmaceutical companies.

Plans were made to treat about 250 Japanese patients under my supervision with the complete "U" Series. It was agreed that some patients

[56]Iida, M. and Kurita, I: Investigational Studies of Nutritional and Medical Treatment of Down's syndrome Children. Japanese National Institutes of Mental Health. Ichihawa City. Chiba-Ken. Japan.

[57]Tomada, A.: Studies in the Clinical Observation of Down's Syndrome and the Effects of Treatment. Takasago City Hospital. 1974.

would come to the United States, and another 250 or so would receive the "U" Series in Japan. To further these plans, Jeanne and I, accompanied by the parents of two patients, one with Sanfilippo syndrome confirmed by five laboratory studies (pp. 111-119), the other with Down syndrome confirmed by a chromosome study, attended a meeting with the Food and Drug Administration (FDA), the Federal agency that controls domestic marketing and exportation of drugs. Because the child with Sanfilippo syndrome improved, his mother was informed that he did not have the disease.[58] [59] The FDA also stated that the diagnosis of Down syndrome was unestablished in the patient with trisomy 21. Although there is no other treatment for these diseases, the FDA again refused to approve the "U" Series.

Later that year, the Japanese requested FDA permission to import the "U" Series from the United States. Considering our unfavorable balance of trade with Japan, I was certain that the FDA would approve exportation. I joined the Japanese in Washington. However, after three trips to the United States, the representatives from Japan, including an assistant to the Ambassador, were informed that they would not be permitted to import the "U" Series from the United States. Therefore, early in 1982, the Japanese, determined to improve the health, skeletal structure, appearance, and mentality of their Down syndrome children, began to import the "U" Series from Europe. On half the percentage of the gross national product spent by the United States on health care, their infant mortality rate is 64% of ours, and the

[58]Turkel, H.: A Superior Method of Treating Patients with Down's Syndrome or Other Storage Diseases. Nut. Consult. 10-17 (Oct/Nov). 1980

[59]Hoffer, A.: Editorial. Jr. Orthomolecular Psychiatry. 10:226-227. 1981.

life expectancy of women exceeds ours by two years, of men by four years.[60]

Since 1982, the "U" Series has been accepted in Norway, without a new drug application.[61] So that all physicians can treat their retarded patients, the government has cancelled import duties and other impediments to the use of the "U" Series. Reports of outstanding patient progress are being sent from both Norway and Japan.

The Problem of Research: NIH

Dr. Richard Masland, Director of the National Institute of Neurological Diseases and Blindness, stated in a letter to the President of the Valley Association for Retarded Children (Connecticut):

> A serious problem related to the evaluation of such a treatment is the fact that it requires the treatment of a rather considerable number of children observed over prolonged periods of time to achieve a valid conclusion.
>
> (January 8, 1962)

The National Institutes of Health (NIH) have not, to date, found a single investigator willing to conduct a study, even though a considerable number of children have, in fact, been treated and observed over prolonged periods of time. Since the scientific community requires studies, the NIH could be conducting them (page 134). However, the NIH have generally failed to acknowledge the existence of treatment.

[60]Time Magazine, issue on Japan, Aug. 1, 1983.

[61]Mork, T.: Vitamin/Mineral Supplementation For Down's Syndrome. Lancet. (November 26) 1983.

DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE
PUBLIC HEALTH SERVICE
NATIONAL INSTITUTES OF HEALTH
BETHESDA, MARYLAND 20014

December 21, 1976

Henry Turkel, M.D.
19145 W. Nine Mile Road
Southfield, Michigan 48075

Dear Dr. Turkel:

Thank you for your letter of December 8 and for enclosing a copy of your paper, "Medical Amelioration of Down's Syndrome Incorporating the Orthomolecular Approach."

As I indicated in my letter to you dated November 30, 1976, the National Institutes of Health, particularly the Mental Retardation and Developmental Disabilities Program of the National Institute of Child Health and Human Development, are supporting several research projects on Down syndrome. We share your concern about the lack of enthusiasm on the part of the scientific community to study the effects of the "U" Series. Despite our programming efforts, NICHD has not been able to attract a single investigator to do the proper kind of study that would be acceptable to the scientific community. Almost every year, this Institute sends a representative to the annual meetings of the National Association for Retarded Citizens and the American Association on Mental Deficiency. Since the inaugural meeting of the Down Syndrome Congress in 1973 the Mental Retardation and Developmental Disabilities Branch of NICHD has participated actively in their annual meetings in an effort to generate scientific and community support on behalf of the mentally retarded and their families. Our staff has also participated in national and international meetings in which they have presented not only our research portfolio and interesting research leads, but also gaps in our knowledge, hoping that research will be conducted in those unexplored areas. So, it is not due to Institute apathy that we have not succeeded in supporting a study on the "U" Series. On the contrary, I would like to emphasize that this Institute welcomes the opportunity to support scientifically meritorious research on Down syndrome including its amelioration using the "U" Series.

Sincerely yours,

Gilbert D. Woodside

Gilbert Woodside, Ph.D.
Deputy Director
National Institute of Child Health
and Human Development

Articles have been published in lay and professional journals about the "U" Series, and the medication has been mentioned in numerous books, in many languages,[62] particularly Japanese and Norwegian, as well as English. However, the NIH published their own bibliography[63] without mentioning The "U" Series or any of the other then-current therapies; evidently, the priorities of the Federal government do not include treatment.

The Problem of Research: PRIVATE AGENCIES

The larger voluntary health organizations have also not been receptive toward treatment of Down syndrome. The Foundation for Infantile Paralyisis - March of Dimes elected not to close shop when polio was conquered.[64] After entering the field of birth defects, March of Dimes promoted prenatal screening as the answer to the problem of Down syndrome (if the pregnant woman

[62]The contents of the entire "U" Series have also been published in France, in Le Mongolism - Edition Complete: Therapeutiques medicales et psychopedagogiques by Eugene Rethault, Les Editions E S F, Paris. 1973 229-231.

[63]Vollman, R.F.: Down's Syndrome (Mongolism) - a Reference Bibliography. HEW-PHS-NIH (1969).

[64]Wheeler, C.: Old Foundations Never Die (They Just Switch Diseases) Private Practice 61-63 (Feb.) 1982.
See also the political background and the pivotal role played by the NFIP-March of Dimes in delaying use of the safer, more effective oral vaccine and promoting the use of the more hazardous injected form in: Polio Leaders Beg to Disagree. Med. World News (Feb. 17) 1961; Salker Prizes Celebrate an End and a Beginning. Med. World News (November 15) 1965; NIH Head Says Wrong Choice was made on Polio Vaccine. Med. Trib. (Nov. 21) 1966.

is in a high-risk group). However, after a Down syndrome child is born, help to the family is insufficient. It is expensive to raise a mentally and physically handicapped child. Additional emotional and economic support should be made available.

The National Association for Retarded Citizens (NARC) has been less than enthusiastic. Immediately after informing me that they had no time to see me while we were in Texas for a convention members of the research committee of NARC (headquartered in Texas) announced that "Big Dollars" were needed to find treatment for Down syndrome.[65] None of this research was aimed at perfecting available therapy. NARC is to be commended for bringing retarded citizens into the mainstream. A less dogmatic attitude of its research teams about nutritional therapies would also be helpful to patients.

For reasons that NARC has not clarified, in 1956, when I presented my findings to Dr. Gunnar Dybwad, Executive Director of NARC, intending to give over the "U" Series without cost, Dr. Dybwad told me that NARC was "not interested." If officials of NARC believed that I was exploiting these families, they were mistaken. If they believed that I would request remuneration from the organization, they were also mistaken. My only request was that if articles about the treatment were published, my role in developing it should be acknowledged. Shortly thereafter, my medical society accused me of unethical behavior for presenting medical findings to a person who was not a physician, Dr. Dybwad. At about the same time, I was reprimanded by my medical society for refusing to present medical findings to a person who was not a physician, a nurse who attended a meeting.

[65]Menolascino, F.: Research and Demonstration. M.R. News (Dec. 6) 1975.

national association for retarded citizens
2709 Avenue E East · P O Box 6109 / Arlington, Texas 76011 / (817) 261-4961

Carol Burnett,
National Honorary
Chairman

Marion P Smith,
President

Philip Roos Ph D.,
Executive Director

July 22, 1975

Henry Turkel, M.D.
8000 W. Seven Mile Rd.
Detroit, Mich. 48221

Dear Dr. Turkel:

Thank you for your letter of June 27, 1975 offering to meet with me and my collegues when you come to Texas for a meeting of the American Society of Hematology. I will share a copy of your letter with the NARC Research Advisory Committee for discussion and review.

Sincerely yours,

Ronald Neman

Ronald Neman, Ph.D.
Research Director

RN:th

cc: Dr. Frank Menolascino
Dr. John Sterrett
Mr. Melvin D. Heckt
Mr. John Foley
Mr. Harvey Zuckerberg
Research Advisory Committ

November 24, 1975

Henry Turkel, M.D.
8000 West Seven Mile Road
Detroit, Michigan 48221

Dear Dr. Turkel:

Please forgive the delay in responding to your inquiry regard your visit in Dallas. Regretfully, we will not be able to s a meeting with you in December.

Cordially,

Ronald Neman

Ronald Neman, Ph.D.
Research Director

RN:sd

FORMERLY THE NATIONAL ASSOCIATION FOR RETARDED CHILDREN

After the "U" Series was brought to its attention by Dr. Dybwad, Wayne County Medical Society ordered me to obtain FDA approval for the "U" Series.

The emphasis that larger organizations place on basic research is easy to understand. However, through the years, some of these organizations have been particularly negative about ameliorative therapies. In fact, when questioned about the possibility of running a study, one of the Foundations informed the inquiring parent that NARC had already studied the "U" Series. NARC, of course, has never done so. Because of its negative attitude regarding the "U" Series, it was not appropriate for a Circuit Court judge who had previously received $25,000 from that Foundation to hear my case against the FDA. However, he not only refused to disqualify himself despite the fact that he must inevitably have been influenced by his ties to the Foundation; he officiated over two of my cases, ruling against the "U" Series both times.

There is a remarkable lack of scientific curiosity about medical therapies. Scientists want to find a basic solution, a method of removing the extra #21 chromosome from every cell in the body. But parents of newborn Down syndrome infants are still being told, "Nothing can be done. Institutionalize them." The handicapped infant's right to live has become controversial. During the past 10 years, in hospitals around the country, infanticide has been offered as an available alternative for parents of newborn Down syndrome infants who require surgery.

Treatment, Not Cure

Before treatment became available in Japan, Japanese parents sometimes resorted to infanticide and suicide. "It means hopelessness if we become so pessimistic that we do nothing,

without any treatment at all . . . As a result of the [MD "U" Series] I have seen many of those mothers and patients or their families who once thought to die together . . . they came with bright eyes from the second consultation, as if they were different mothers from the initial consultation. . . ."[66] The possibility of improving the overall condition of the Down syndrome patient may also alter the pessimistic view of American parents and physicians.

In accordance with my rationale, the excessive substances associated with trisomy 21, not identified physiologically as abnormal or as present in abnormal quantities, were not eliminated during prenatal development by the maternal enzymes, hormones, excretory system, or otherwise compensated for. These excessive substances take up space normally used for circulation of nutrients and removal of wastes. Therefore, the organs of the Down syndrome fetus are retarded, producing characteristic anomalies as early as the first trimester after conception. Wastes also accumulate, further retarding development and function.

Physicians who lack extensive clinical contact with these patients seem to think that the basic cause of Down syndrome must be overcome before it becomes possible to improve the patient's condition, although single-gene defects are regularly treated symptomatically. Phenylketonuria (PKU) became classified as an inborn error of metabolism in 1934 when Dr. Følling described the characteristics of certain mentally retarded children who excreted

[66]Kurita, T.: Treatment of Down's syndrome. Pediatrics of Japan (Aug. 3) 1977; pp. 224-233 herein.

phenylpyruvic acid in the urine.[67] It is the model of a physical disease with "mental" manifestations.

Phenylalanine is one of the essential amino acids: it must be ingested because it is not made within the body. Milk and many other foods contain it. If an error occurs in the genetic code regulating production of the enzyme, phenylalanine hydroxylase, phenylalanine ingested in food cannot be properly metabolized into tyrosine. It accumulates, and abnormal alternate metabolites (phenylpyruvic acid, phenyllactic acid, phenylacetic acid, phenylacetyl-glutamine) that irritate or injure the brain also accumulate.

Although tyrosine is available in food, important end products of phenylalanine needed for development of the brain and other organs are deficient. Structural and functional retardations result from these deficiencies as well as from low levels of most amino acids, excluding phenylalanine. The patients suffer from malnutrition and imbalance of amino acids, from high levels of phenylalanine and alternate metabolites that damage the brain, and from deficiencies of products along the metabolic pathway of phenylalanine, including melanin, thyroxine, and epinephrine. The result is a sickly child who appears to be mentally and physically retarded and/or mentally ill.

This situation may appear as hopeless as that encountered in Down syndrome, but physicians have not abandoned the possibility of treating the patient. On the contrary, laws have been passed requiring neonatal diagnosis, so that the disease can be treated early in life, preventing much of the damage and

[67] Følling, A.: Uber Ausscheidung von Phenylbrenztraubensaure in den Harn also Stoffwechselanomalie in Verbindung mit Imbezillitat. Z. Phys. Chem. 227:169. 1934.

retardation. Reduction of the plasma phenylalanine level is apparently accompanied by reduction of alternate metabolites. Those patients not helped by the restricted diet may be deficient in different components of the enzyme system.

PKU is an example of the fallacy of dichotomizing mental and physical disorders. This fallacy has held back progress in the treatment of mental illness and mental retardation. Down syndrome should not be classified exclusively as a "mental" disorder. The development and function of the entire body, including the brain, is delayed. Many abnormalities of the Down syndrome patient at any particular age are normal in a younger person. Treatment of this condition seemed feasible, especially because while I was in college and medical school exciting discoveries were being made about vitamins.

The link between diet and good health was clear long before the scientific aspect was known; the "growth factors" were not discovered until 1912. Vitamin C was isolated in pure crystalline form by Drs. Szent- Gyorgy, Waugh, and King between 1928 and 1932. When I worked with vitamin C and guinea pigs in 1935, I was fortunate in my selection of experimental animals. Only a few mammals, among them humans and guinea pigs, require ascorbic acid in the diet. During those experiments, I discovered that guinea pigs given large dosages of vitamin C between inoculations of sensitizing proteins did not, like their unprotected counterparts, succumb to fatal anaphylactic shock.

Knowledge of the molecular structures of some of the vitamins was gained in about 1935. The coenzyme or active forms of B-complex vitamins were not discovered until 1936. The Turkel bone-marrow biopsy instrument was used by

Dr. Thomas Spies[68] to help elucidate the role of folic acid in blood formation. It was obvious that persons with metabolic variations would require more than the "trace" quantities of the water-soluble vitamins than can be obtained from a balanced diet.

[68]Spies, T. D.: Folic Acid Therapy. Experiences with Folic Acid. 1947. p. 91.

"U" Series

FULL DOSAGE SIZE

	Brand/Generic Name	dosage per tab/cap
UMORPHOID		
one with breakfast		
1	Thyroglobulin	66 mg.
2	Cytomel	25 mcg.
3	Organic Iodide	33 mg.
	Vitamin A (Acetate)	25000 IU
6	Vitamin E Palmitate	10 IU
UTROPHOID		
one with breakfast		
	Riboflavin	20 mg.
	Thiamin HCl. as mononitrate	20 mg.
	Calcium Pantothenate	20 mg.
4	Niacin	20 mg.
	Para Aminobenzoic Acid	20 mg.
	Pyridoxine HCl	20 mg.
	Cyanocobalamin	25 mcg.
	Folic Acid	5 mg.
	Calcium as citrate or phos.	30 mg.
5	Cobalt as chloride	.1 mg.
	Copper as sulfate	1 mg.
	Iodine as calcium iodate	.15 mg.
	Iron from reduced iron	10 mg.
	Magnesium as sulfate	1 mg.
	Manganese from sulfate	1.25 mg.
	Molybdenum	.1 mg.
	Zinc from zinc sulfate	1 mg.
UNOID		
one or 1/2 with breakfast, lunch, dinner		
	L-glutamic acid	200 mg.
7	Rutin	20 mg.
	Nicotinic Acid	100 mg.
UPNEOID		
one with breakfast, lunch, dinner		
	Phenylpropanolamine HCl.	20 mg.
	Ascorbic Acid *	300 mg.
8	Pyrilamine Maleate	25 mg.
	Theophylline Na. Glycinate in a base containing calc. carb.	100 mg.
DIURETIC		
one with breakfast Wednesday & Saturday		
150	Furosemide or	40 mg.
15x	Hydrochlorothiazide	50 mg.

	Brand/Generic Name	dosage per tab/cap
UPEPTOID A		
one with breakfast and dinner		
	Betaine HCl.	66 mg.
	Ketocholanic Acid	132 mg.
11	Pancreatin	66 mg.
	Papain	66 mg.
	Pepsin	66 mg.
	Diastase	3.3 mg.
UPEPTOID B		
one with breakfast and dinner		
	Methionine	100 mg.
	Betaine HCl.	100 mg.
	Choline Bitartrate	200 mg.
12	Inositol	100 mg.
	Unsaturated Fatty Acids	200 mg.
	Liver, dessicated	150 mg.
SUPPLEMENTS		
one with lunch		
	Zinc gluconate	50 mg.
17	Calcium pantothenate	50 mg.
18	Pyridoxine HCl.	50 mg.
27	Potassium gluconate	50 mg.
	Magnesium gluconate	100 mg.
one with breakfast		
25D	Calcium	260 mg.
	Magnesium	120 mg.
	Cholecalciferol	400 IU
one with breakfast, lunch, dinner		
25	Calcium	260 mg.
	Magnesium	120 mg.
one with dinner		
26	Zinc	30 mg.
UPNEOID C		
nasal spray, daily and as needed		
	Pyrilamine maleate	.25%
	Chlorpheniramine	.125%
	Naphazoline HCl	.025%
DENTAL ANESTHETIC		
either	Lidocaine ointment U.S.P	5%
or	Benzocaine	16%
	Chlorobutanol	5%

* Additional vitamins C and E may be added at the physician's discretion.

Adults may take lecithin.

"U" Series

FULL DOSAGE SIZE - European formulation

Brand/Generic Name	dosage per tab/cap
UMORPHOID	
one with breakfast	
Thyroglobulin	66 mg.
Cytomel	25 mcg.
Organic Iodide	33 mg.
Vitamin A (Acetate)	25000 IU
Vitamin E Palmitate	10 IU
UTROPHOID	
one with breakfast	
Thiamin HCl as Mononitrate	20 mg.
Riboflavin	20 mg.
Methionine	100 mg.
Calcium Pantothenate	20 mg.
Para Aminobenzoic Acid	20 mg.
Pyridoxine HCl	20 mg.
Niacin	20 mg.
Folic Acid	5 mg.
Cyanocobalamin (B-12) mcg.	25 mg.
Calcium as citrate or phos.	30 mg.
Cobalt as chloride	.1 mg.
Copper as sulfate	1 mg.
Iodine as calcium iodate	.15 mg.
Iron from reduced iron	10 mg.
Magnesium as sulfate	1 mg.
Manganese from sulfate	1.25 mg.
Molybdenum	.1 mg.
Zinc from zinc sulfate	1 mg.
UNOID	
one with breakfast, lunch, dinner	
Pentylenetetrazole	20 mg.
L-glutamic acid	200 mg.
Nicotinic Acid	50 mg.
UPNEOID	
one with breakfast, lunch, dinner	
Phenylpropanolamine HCl.	20 mg.
Ascorbic Acid *	100 mg.
Pyrilamine Maleate	25 mg.
Rutin	20 mg.
Aminophylline Na. Glycinate	100 mg.
Diuretic	
one with breakfast Wednesday & Saturday	
either Lasix (furosemide)	40 mg.
or Hydrochlorothiazide	50 mg.
Bone Meal	
one with breakfast, lunch, dinner	
Phosphorus (bone meal)	300 mg.
Calcium (bone meal)	660 mg.
Vitamin D (Fish Liver Oil)	300 IU

Brand/Generic Name	dosage per tab/cap
UPEPTOID A	
one with dinner	
Betaine HCl	66 mg.
Ketocholanic Acid	132 mg.
Pancreatin	66 mg.
Papain	66 mg.
Pepsin	66 mg.
Diastase	3.3 mg.
UPEPTOID B	
one with breakfast & dinner	
Methionine	100 mg.
Betaine HCl	100 mg.
Choline Bitartrate	200 mg.
* Inositol	100 mg.
Unsaturated Fatty Acids	100 mg.
Liver, dessicated	150 mg.
SUPPLEMENTS	
one with lunch	
Pantothenic Acid	50 mg.
Pyridoxine	50 mg.
Potassium	50 mg.
Magnesium	50 mg.
Niacinamide	15 mg.
Thiamin	2.2 mg.
Zinc gluconate	31.5 mg.
Riboflavin	2.2 mg.
one with breakfast, lunch, dinner	
Calcium	260 mg.
Magnesium	120 mg.
UPNEOID C	
NASAL SPRAY	
Chlorpheniramine maleate	.125%
Pyrilamine maleate	.25%
Naphazoline HCl.	.025%
DENTAL ANESTHETIC	
Benzocaine	16%
Chlorobutanol	5%

* Additional vitamins C and E may be added at the physician's discretion

lecithin may be supplemented

CHAPTER VIII

The "U" Series was developed during the 1930's, in its several components, to treat patients with genetic diseases. According to Dr. Linus Pauling, who coined the terminology, "orthomolecular" therapy is the treatment of disease by "the provision of optimum molecular composition of the brain. The brain provides the molecular environment of the mind. . . the right molecules in the right amounts. . .[69] Dr. Roger J. Williams has noted that certain genetic disorders are manifested because of less-than-optimal nutrition for a specific individual.[70] The "U" Series treatment is based on the provision of correct concentrations of vitamins and other substances for proper physiological function. The "U" Series was developed empirically.[71] This chapter discusses some of the reasons why I included certain vitamins, minerals, and medications in the "U" Series.

The components of the "U" Series act synergistically to remove accumulations and accelerate development of all organs simultaneously. B-complex vitamins act as coenzymes. The "U" Series dispensed in the United States is coded by number instead of by name, and a few adjustments to components and dosages have been required by the Food and Drug Administration.

[69]Pauling, L.: Orthomolecular Psychiatry. Science. 160:265-271 (April) 1968.

[70]Williams, R.J., Heffley, J.D., Yew, M.L., Bode, C.W.: A Renaissance of Nutritional Science is Imminent. Pers. in Biology and Med. 17 (Autumn) 1973.

[71]Turkel, H. and Nusbaum, I: Rationale for Components of the "U" Series. TXu 106-193. (July 14) 1982.

Calcium balance is disturbed in Down Syndrome. Despite the presence of heavy, abnormal, soft-tissue calcifications found by Benda and others, excretion levels are below normal. Low serum calcium levels and reduced incidence of atherosclerosis and dental plaque in Down syndrome may be related to the presence of excessive superoxide dismustase on chromosome 21. On the other hand, hair analyses of 67 women with Down syndrome demonstrated below-normal concentrations of calcium, indicating that calcium is not excreted in hair. With less than the normal amount of calcium removed by sluggish organs of waste elimination, including the hair and saliva, it is not found in circulating blood or other fluids in normally high ranges, but is continually deposited in the soft tissues, as seen on X-rays and in post-mortem examination, as well as examination of fibroblasts.[72] This situation is comparable to the need for tissue examination in malnutrition states and storage diseases.[73]

In discussion of Down syndrome and the inborn errors of metabolism, the primary cellular - genetic or chromosomal - disturbance has usually been emphasized. Little consideration has been given to the fact that since underdeveloped structures function inefficiently, and that since the organs of excretion and elimination are also underdeveloped and therefore function inefficiently in Down syndrome, waste products are certain to accumulate in tissues instead of being removed.

[72]Ceder, O., Roomans, G.M., Hosli, P.: Scanning Electron Microscopy II:723-230. 1982.

[73]Baron, D.N.: Down with Plasma! Intracellular Chemical Pathology Studied by Analysis of Cells of Solid Tissues, Erythrocytes, and Leukocytes. Proc Roy Soc Med 62:945 (Sept.) 1969.

This phenomenon masks the results of standard diagnostic tests. Having discovered that the calcium level is low in hair and blood, the diagnostician may ignore the tissue-storage problem. The situation is analogous to that of stored cholesterol. At first, discovery that large doses of vitamin C raised the blood level of cholesterol, some physicians warned their patients not to take it. In actual fact, the vitamin was removing depositions of cholesterol, bringing them into circulation, and permitting their elimination.[74]

Although calcium is supplied in the "U" Series to promote bone development, the rationale underlying my use of many of the contents, especially magnesium, vitamin A, and the diet that empasizes ingestion of cereals, is to improve calcium metabolism. The result of the treatment is that tissue calcification is reduced, and bone growth and development are accelerated, as can be seen on the growth charts of Evelyn, Judy, Oliver, and other patients.

For skeletal development and for demineralization of abnormal mineral deposits: UMORPHOID - #1-2-3-6

Thyroxine and organic iodides are coded #1 and #3. Organic iodides help form triiodothyronine (T_3) and thyroxine (T_4). Although the combination of hypothyroidism and Down syndrome is thought to be rare,[75] the metabolic rate in Down syndrome and other

[74]Fletcher. Does Ascorbic Acid Lower Cholesterol Levels? JAMA 287:2114. 1977.

[75]Fliegelman, M.T. & Reisman, L.E.: Double Trouble -- Down's Syndrome and Hypothyroidism. Cutis 4:1241 (Oct.) 1968.

mentally retarded children is low,[76] and thyroid-stimulating-hormone (TSH) levels are often high, indicating hypothyroidism. A study of 151 patients has confirmed the prevalence of these results.[77] Patients clearly benefit intellectually from administration of thyroid.

Other benefits of therapy with thyroid substances are: control of water balance; normalization of ossification rates and bone age; metabolism of carbohydrates; stimulation of growth, maturation, general cell metabolism, and differentiation of tissues. The negative feedback mechanism depresses formation of thyroid by the underdeveloped glands. Dr. Benda found that newborn Down syndrome patients benefit from a dosage level of as much as 1 1/2 grains daily; he considered thyroid necessary for all Down syndrome patients. Ellman and his coworkers have suggested that thyroid may have interacted synergistically with the (GTC) vitamin/ mineral supplement studied by them.[78]

L-triiodothyronine, T_3(#2) is the biologically more potent thyroid hormone. Ismail and his colleagues found that in a number of chronic diseases, and in some stressful situations, the metabolic pathway of T_4 deiodination led to an inactive form, and that T_3 supplementation assisted patients with at

[76]Kennedy, C.: The Cerebral Metabolic Rate in Mentally Retarded Children. Arch. Neurol. 16:55 1962.

[77]Pueschel, S.M., Pezzulo, J.C.: Thyroid Function in Down Syndrome. Am. J. Dis Child. 139: 636-639 (June) 1985.

[78]Ellman, G., Silverstein, C., Zingarelli, G., Schafer, E., Silverstein, L.: Vitamin-Mineral Supplement Fails to Improve IQ of Mentally Retarded Young Adults. American Journal of Mental Deficiency 88:688-691 (May) 1984.

least one chronic disease, bronchial asthma.[79] UMORPHOID (#6) includes vitamins A and E.

Vitamin A is needed for bone development. I have included it in water-dispersible formulation to help reduce soft-tissue calcification. In normal persons, excessive vitamin A and thyroid produce hypercalcemia. In Down syndrome patients, they remove excessive calcium stored in tissues, bring it into circulation, and remove it from the body. Other benefits of vitamin A are: to dissolve fatty deposits in liver and blood vessels; to liquefy and dissolve congested dried material, as in respiratory disorders; to increase resistance against infection; and to aid night vision.

Vitamin E is included in small amounts to act synergistically with other components of the "U" Series. It is an antioxidant that helps delay aging of fibroblasts. A pigment which accumulates in the aging brain increases when the diet is deficient in vitamin E. Additional vitamin E may be used as the examining physician finds appropriate.

For vasodilation: UNOID (#7).

Pentylenetetrazole is an effective and safe vasodilator and neural stimulant. Animal tests suggest that this component may exert beneficial long-term effects on brain structure and function.[80] The Food and Drug Administration has recently removed pentylenetetrazole from the market. In countries that permit pentylenetetrazole, its use in treatment of Alzheimer's diseases should be explored. In the United

[79]Ismail, A. et al.: Effect of Triiodothyronine on Bronchial Asthma. III. Jr. Asthma Research 17:157 (July) 1980.

[80]Landfield, P.W., Baskin, R.K., Pitler, T.A.: Brain Aging Correlates: Retardation by Hormomal-Pharmacological Treatments. Science 214:581-584 (October 30) 1981.

States, lecithin or other safe vasodilators should be supplemented.[81] Niacin (nicotinic acid), a safe and effective vasodilator, is a component of Unoid, together with glutamic acid, a brain nutrient that energizes the metabolism of neural tissue and improves cerebral cellular oxidation. Because of the increased dosages of niacin in the formulation without pentylenetetrazole, flushing may be intense. It should be taken with meals.

For respiratory function: UPNEOID (#8)

Phenylpropanolamine hydrochloride (PPA) is dispensed in this series (Upneoid) as a substitute for epinephrine because the adrenal function of allergic and Down syndrome patients is often near a stage of exhaustion. Dosages are low compared with PPA products available over the counter for self-administistration to suppress the appetite or relieve sinus congestion. It is an effective vasoconstrictor, bronchodilator, and aids in elimination of bronchopulmonary accumulations. As a decongestant, it shrinks swollen mucosa of the upper respiratory tract. Because of its central nervous system effects, it is preferable to consult a physician before using this over the counter medication. Caffeine and other stimulants should be restricted when PPA is used.[82]

Pyrilamine maleate is a standard antihistamine, prescribed to counteract allergic manifestations and edema and to neutralize histamine in allergies, injuries, or infections. Pyrilamine maleate and phenylpropanolamine HCl are combined in fixed dosages in numerous

[81]McCarty, M.: Cardiovascular Benefits of Gamma-Linolenic Acid. Anabolism 2:4 (July/Aug.) 1983.

[82]Weinstock, C.: Is PPA Too Dangerous? Med Trib (Aug. 1) 1984.

products available **without prescription** because of their safety. Drowsiness may occur. Caution should be used when dispensing these products to patients with hypertension, diabetes, intraocular pressure, hyperthyroidism, or cardiovascular disease. Although antihistamines uncombined with other contents of Upneoid are not generally recommended for the treatment of bronchial asthma, pyrilamine maleate, included in several over-the-counter asthma products, is safe and effective in the physician-dispensed "U" Series.

Rutin helps prevent vascular hemorrhages, especially those associated with fatty accumulations as seen in diabetes or Down syndrome. It also decreases capillary fragility[83] and helps reduce the incidence of cataracts. Dr. Carl Pfeiffer of the Brain Bio Center has measured brain waves of volunteers given 50 mg. doses of rutin, and has found that rutin has both a sedative and stimulant effect. Rutin is dispensed in Upneoid for patients outside the United States and in Unoid (#7) for patients in the United States.

Ascorbic acid is included in Upneoid to develop resistance against allergies and infections. According to Dr. Linus Pauling, certain mammals have lost the ability to synthesize vitamin C, presumably because the evolutionary advantage exceeds the disadvantage of decreased availability of the vitamin in a changed environment. The concentration of vitamin C required for unimpeded functioning in these mammals, including humans, may exceed the quantity readily available in food. It aids in production of adrenal cortical hormones and acts as a temporary substitute for epinephrine. In addition, vitamin C is required for production

[83]Walker, B.J., Boyd, W.C., and Asimov, I.: Biochemistry and Human Metabolism. Third Ed. Baltimore. Williams & Wilkins. 1957.

of pituitary hormones; aids in utilization of iron for hemoglobin and in oxidation metabolism of phenylalanine and tyrosine; is required for formation of intercellular bone, cartilage, and dentine; aids in collagen callus formation; is needed for wound and bone healing and detoxification of the liver; and is a mild diuretic. It can prevent and treat arteriosclerosis by reducing cholesterol deposits in arteries.[84] It activates the immune system.[85] [86] [87] Like rutin, it promotes capillary integrity. It can be given in megadoses to prevent and treat viral infections and to counteract shock.

Most animals, including rats, produce their own ascorbic acid. When haloperidol, an antipsychotic drug used to reduce the syptoms of schizophrenia, was given with ascorbic acid in an animal study, it was determined that with ascorbic acid there was significantly greater improvement in the schizophrenic behaviors than with the drug alone. The investigators pointed out that since humans do not make their own ascorbic acid (AA), supplementation may be effective, and that, "in fact, megavitamin therapy, which includes pharmacological doses of AA, has been successful in treating certain

[84]Cameron, E., Pauling, L: Cancer and Vitamin C. 1979.

[85]Turkel, H. : Letter to the Editor. Journal Orth. Psych. 11:201-203. 1982.

[86]Turkel, H.: Vitamin C and Immunization. Medical Tribune 24:39 (Feb) 1983.

[87]Vitamin C and Immune Protection. Science News 115:295 (May 5) 1979.

forms of schizophrenia."[88]

Aminophylline magnesium glycinate is one of the least nauseating forms of aminophylline, medication available by prescription only. For manufacturing reasons, theophylline sodium glycinate in a calcium carbonate base is sometimes used in the United States. The primary purpose of aminophylline or theophylline in the "U" Series is to dissolve stagnant, dried bronchial secretions. It relieves bronchial asthma and dyspnea; it is a myocardial stimulant and a mild diuretic. Concurrent use of caffeine is to be avoided.[89] Glycine (or calcium carbonate) is an antacid.

Nasal spray, in the "U" Series, is called UPNEOID C.

Naphazoline hydrochloride is a local vasoconstrictor. It widens aeration space in nasal passages and openings to sinuses. Chlorpheniramine maleate and pyrilamine maleate are antihistamines. (See Upneoid A). Methyl paraben and propyl paraben are antiseptics. The purpose of the nasal spray in the treatment of Down syndrome is to open nasal passages and promote development of frontal sinuses and lacrimal (tear) ducts.

For digestion: UPEPTOID A & B (#11 & 12)

Choline, which acts on fat metabolism by helping to remove or reduce fat deposits in the liver (i.e., it is a lipotropic substance), is necessary for the normal production of lipids containing phosphorus. These phospholipids,

[88]Rebec, G.V., Centore, J.M., White, L.K., Alloway, K.D.: Ascorbic Acid and the Behavioral Response to Haloperidol: Implications for the Action of Antipsychotic Drugs. Science 227:438-439 (Jan. 25) 1985.

[89]Combining coffee, theophylline may increase risk of CNS side effects among asthmatics (reported by Michael Simmons, M.D., UCLA).

with the addition of water, produce fatty acids. Choline and its dietary precursors, including methionine, which donates necessary methyl groups for choline, increase the rate of phospholipid formation in the patient with accumulations of fat within liver cells, as Benda found in Down syndrome patients. It is also an effective vasodilator.

I use methionine, choline, and betaine to combat the type of fatty liver associated with diabetes. Inositol is lipotropic in conjunction with a low-fat diet, is involved in central nervous system metabolism, is found in all organs, including the brain, and aids motility of the intestines. Betaine and methionine act synergistically with choline and inositol. Unsaturated fatty acids (sitosterol and linoleic and linolenic acids) help dissolve fats in liver. Dessicated liver substitutes for products of the underdeveloped liver in Down syndrome patients.

Lecithin is being investigated extensively for its cholinergic properties and as a precursor of prostaglandins. When I developed the "U" Series in the 1930's and 1940's, literature was not available on lecithin as a source of choline, inositol, linoleic and linolenic acid; therefore, it has only recently been supplemented to the "U" Series for some patients. (I do not recommend lecithin for my patients without concurrent use of # 11 & 12). It is contraindicated for pregnant women and infants.

Riboflavin (B_2) has functions similar to hemoglobin. It is essential for cellular oxidation, promotes growth, develops red and white blood cells, prevents myelin degeneration, and increases xanthine-oxydation activity of the liver. It helps convert tryptophan to nicotinic acid. It helps prevent nutritional amblyopia and cataract formation, fissuring and cracking of the lips and angles of the mouth. It is essential for healthy skin, mouth, and eyes.

Deficiencies cause insomnia, hair loss, mental sluggishness. It is a constituent of two coenzyme components of yellow enzymes.

Calcium pantothenate (pantothenic acid) is essential for carbohydrate metabolism. It is involved in adrenal function and is essential for steroid production. It reduces allergic manifestations; it is required for synthesis of antibodies and for folic acid utilization. It counteracts growth and bone-marrow retardation, helps eliminate abnormal fats in the liver, and is necessary for detoxification of organic substances. It acts synergistically with other vitamins of the B-complex, and as a coenzyme, it participates in numerous metabolic activities.

Para-aminobenzoic acid (PABA) is essential in cellular metabolism. It is a precursor of folic acid. It reinforces the action of cortisone in the formation of antibodies. Dosage levels are not to be increased because it reduces utilization of the supplemented thyroid products.

Pyridoxine (B_6) is needed for normal function of the nervous system. Deficiency induces a variety of problems including mental disorders, nausea, anemia, fibrosis of inner layers of blood vessels, hypoglycemia, insomnia, fluid retention, cracked lips and hands. It acts as a coenzyme in more than 40 enzymatic reactions, including protein and fat metabolism and conversion of trytophan to niacin. It may be involved in unsaturated fatty acid reaction and aids in assimilation of food. Megadoses (not those available in the "U" Series) of pyridoxine and niacin have been used to treat autism, schizophrenia, and to prevent seizure-like episodes.

Niacin or nicotinic acid is essential for normal digestion. A co-enzyme in numerous meta-

bolic reactions, it is also an effective vasodilator.[90] It is needed for numerous reactions in virtually all tissues; for example, for sugar metabolism. Megadoses have been used to treat mental illnesses and antisocial behavior. A deficiency between the 26th and 48th day of gestation may prevent development of limb buds and produce phocomelia. Later deficiencies cause depression, headaches, sensory dysperception, dermatitis.

For development: UTROPHOID (#4-5-13-25)

Folic acid is required with calcium pantothenate. It is essential for conversion of choline to betaine and to methionine. It is needed for red blood cell formation, required with ascorbic acid for tyrosine metabolism, and essential for normal metabolism of growing cells and tissues. Deficiencies cause anemia, poor memory, apathy, slowed mental processes, irritability, cheilosis, malabsorption. Deficiencies in the pregnant woman have been implicated as a cause of neural tube disorders in the fetus.

Cyanocobalamin (B_{12}) is needed for normal development of the red blood cells. With choline and folic acid it helps prevent edema. Deficiencies cause pernicious anemia, neurologic degeneration or psychosis, auditory hallucinations. Cobalt, a component of cyanocobalamin, is needed for normal growth and development.

Copper (copper sulfate) is required with iron for hemoglobin formation. It is associated with oxidation-reduction enzymes, as well as with ascorbic acid oxidase in cell respiration. Iron (reduced iron) is needed for formation of hemoglobin which carries oxygen and carbon dioxide, cytochrome, and other components of respiratory enzyme systems. Zinc is needed for

[90]Koch-Weser, J.: Cerebral Vasodilators - Niacin Derivatives. N. Eng.J. Med. 305:1562 (Dec. 24) 1981.

vitamin A metabolism, carbon dioxide metabolism, brain metabolism, carbohydrate and protein metabolism, growth metabolism, pancreatic function, and for the formation of insulin. It aids in the healing process of injured or infected tissues. Sublingual use has decreased the intensity and duration of the common cold. It is found in DNA, enzymes, hormones, and tissues throughout the body.

Calcium (calcium citrate or calcium orotate) prevents hyperesthesia, irritability of muscles and nerves, and tetany. It aids in the conversion of chemical intramuscular energy, and regulates blood clotting, heart rhythm, and neural function.

Magnesium is required for bone formation and normal body function, for calcium and vitamin C metabolism, and for functional integrity of neuromuscular systems. It maintains the normal structure of growing tissues and prevents involuntary movements and muscle tremors. By replacing calcium in tissue, it eliminates abnormal calcifications.

Manganese activates enzyme systems related to proper utilization of vitamin E and the B-complex vitamins. It helps prevent the deposition of lipids in the liver and helps synthesize hemoglobin. Molybdenum is needed with iron to form hemoglobin and is associated with carbohydrate metabolism.

Bone meal (#13) and dolomite (#25) supply minerals for bone development. Unless lead-free products can be obtained, a mineral combination with cholecalciferol (vitamin D_3) may be substituted. **Vitamin D_2 is contraindicated.** In a personal communication, Dr. John G. Haddad, Chief, Endocrine Section, University of Pennsylvania School of Medicine, sent abstracts of work done by Dr. Claus Cristiansen of Denmark on the differences between D_2 and D_3 in the healing

of anti-convulsant osteomalacia.[91] Dr. Cristiansen found that there is a significant difference in the action[92] and serum concentrations of D_2 and D_3 in anticonvulsant osteomalacia.[93] In my own decades of work with Down syndrome patients, I have discovered that these patients, with their severely deranged metabolic processes, also respond differently to vitamins D_2 and D_3 - the former leading to soft-tissue calcification, and the latter to bone development.

For excretion of fluids

A diuretic (#15) is to be taken in accordance with its labeling, twice weekly. Lasix, a potent diuretic, should be given for the first year. Hydrochlorothiazide should be given after the first year. Some patients may be given less potent products such as herbal diuretics.

Other supplements

Potassium, magnesium, iron, vitamin E, biotin, pantothenic acid, pyridoxine, chelated zinc, and vitamin C dosages may be increased as the physician determines.

For patients with cataracts: bromelain, papain, chromium chelate, rutin, extra digestive

[91]Personal Comm. 10 July 1984.

[92]Tjelleson, L., Gotfredsen, A, Hummer. L, and Christiansen, C.: Differential Effects of Vitamin D_2 and Vitamin D_3 in Patients Receiving Anticonvulsant Therapy. Dept of Clinical Chemistry, Glostrup Hospital, University of Copenhagen, Denmark.

[93]Tjellesen, L., Hummer, L., Christiansen, C.: Vitamin D_2 and Vitamin D_3 Are Metabolized Differently in Anticonvulsant Treated Epileptic Patients.

enzymes, and vitamin B_2.[94]

For patients with delayed bone development: dolomite, zinc, and bone meal.

For patients with premature ossification: vitamin A, thyroid, dolomite, and iodine.

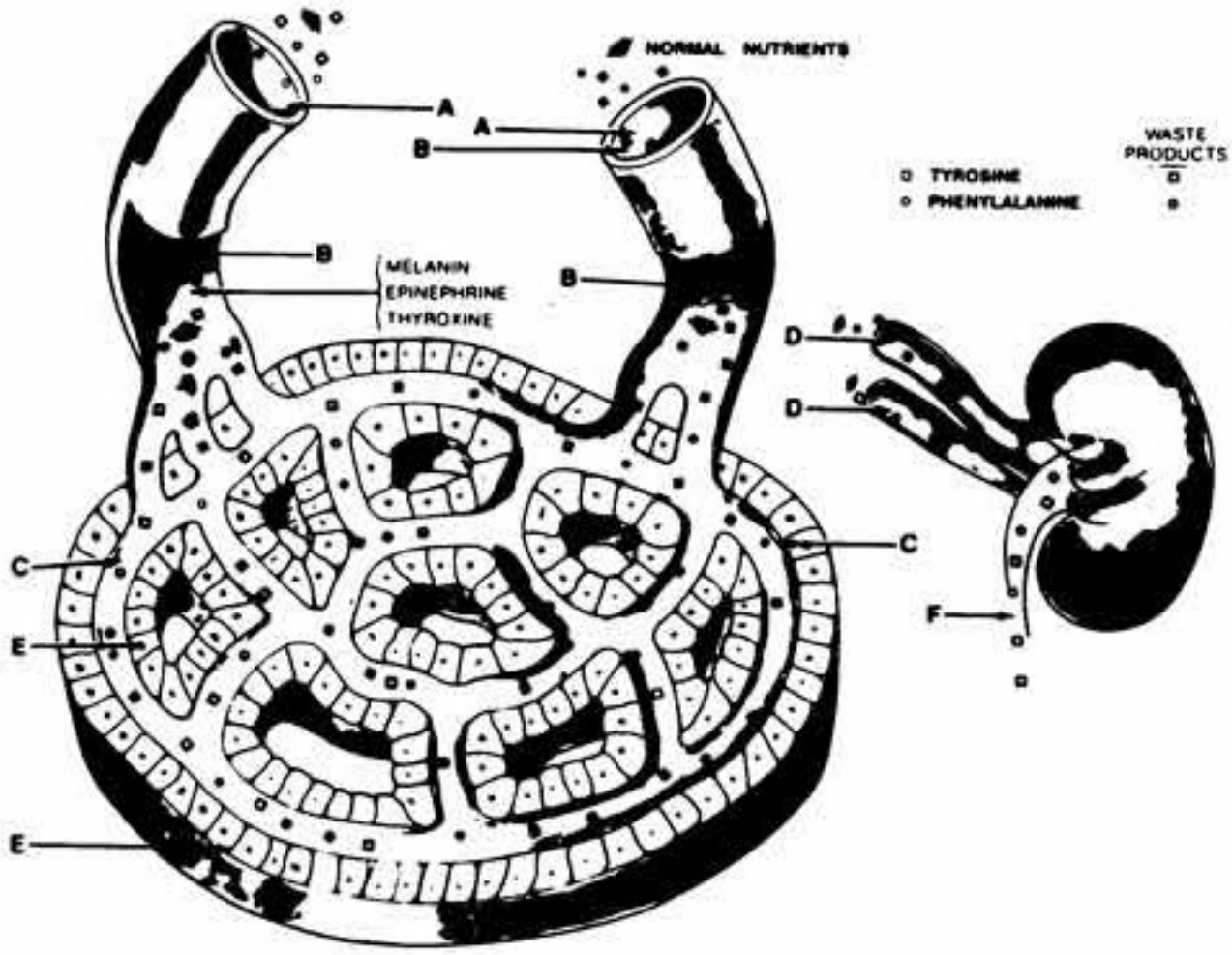
For hyperactive patients: tryptophan.

For patients who are developing or cutting teeth: a strong dental anesthetic to reduce nasal secretions and prevent or reduce the occurrence of frequent respiratory infections and otitis media commonly seen in infants and children.

Superoxide dismutase is not to be given to patients with Down syndrome. The gene for SOD-1 is located on chromosome 21.

[94]MacIvor-Meyn, V.: Bromelain. Anabolism 1:3 (Oct.) 1982.

NORMAL METABOLISM



NORMAL METABOLISM

A— POTENTIAL SPACE FOR CIRCULATING BLOOD, NUTRIENTS, HORMONES, WASTE PRODUCTS, ETC.

B— ARTERIES AND VEINS NOT BLOCKED BY HARMFUL METABOLITES.

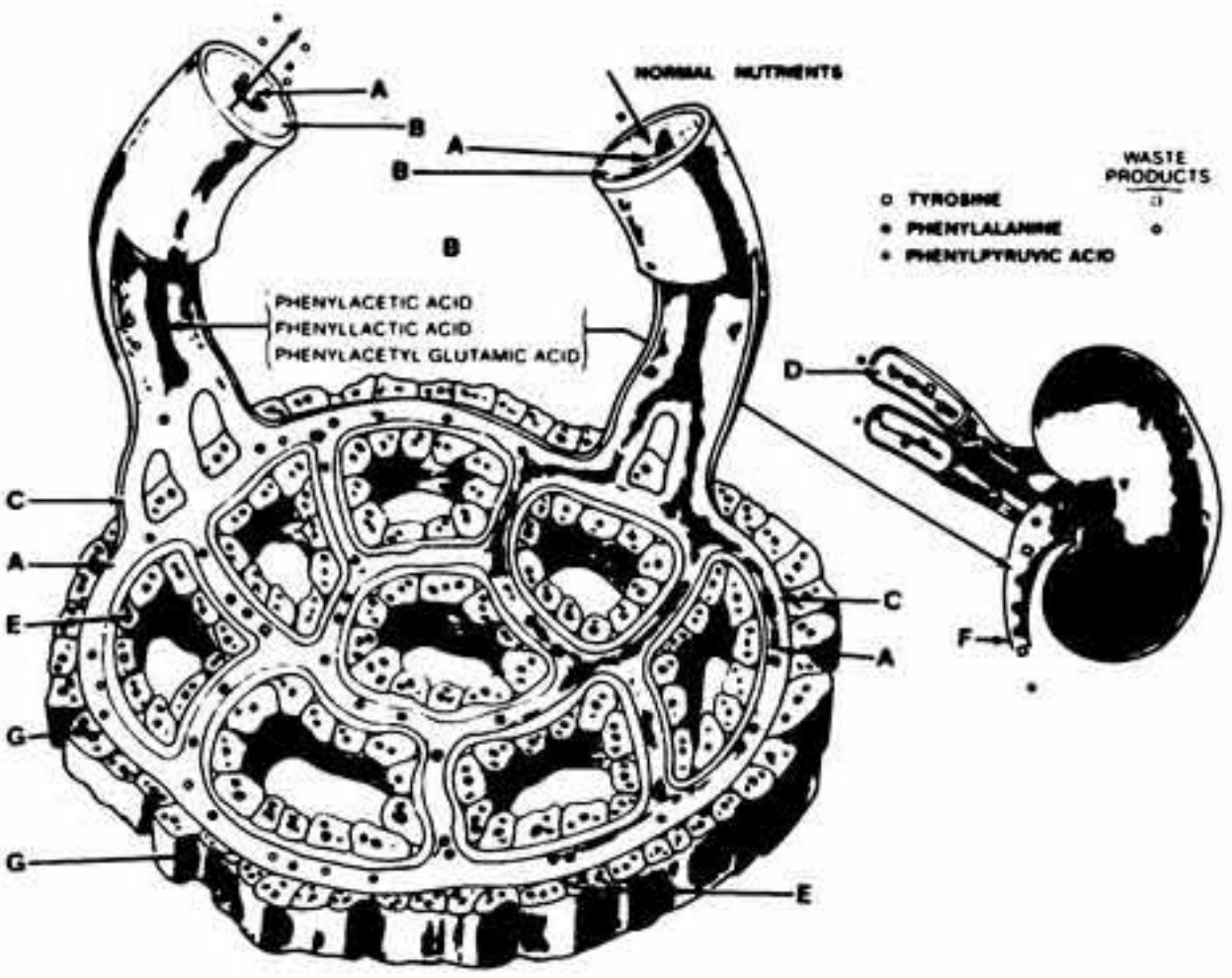
C— ARTERIES AND VEINS WITHIN ORGANS AND TISSUES NOT BLOCKED BY HARMFUL METABOLITES.

D— RENAL ARTERIES AND VEINS NOT BLOCKED BY HARMFUL METABOLITES.

E— ORGANS AND TISSUES GROW, MATURE AND FUNCTION AT NORMAL RATE IN A "TIMELY" MANNER.

F— URINE CONTAINS NORMAL WASTE PRODUCTS.

INBORN ERROR METABOLISM



INBORN ERROR METABOLISM

A— LESS SPACE AVAILABLE FOR CIRCULATING BLOOD, NUTRIENTS, HORMONES, WASTE PRODUCTS, ETC.

B— ARTERIES AND VEINS BLOCKED BY HARMFUL METABOLITES.

C— ARTERIES AND VEINS WITHIN ORGANS AND TISSUES BLOCKED BY HARMFUL METABOLITES.

D— RENAL ARTERIES AND VEINS ARE BLOCKED BY HARMFUL METABOLITES

E— ORGANS AND TISSUES GROW, MATURE AND FUNCTION AT LOWER RATE AS RESULT OF RECEIVING AN INSUFFICIENT AMOUNT OF NUTRIENTS, ETC

F— URINE CONTAINS FEWER NORMAL PRODUCTS PLUS UNMETABOLIZED NORMAL AND ALTERNATE METABOLITES AND THEIR ABNORMAL PRODUCTS

G— ORGANS AND TISSUES DEPRIVED OF NUTRIENTS, HORMONES, ETC., AS WELL AS AFFECTED BY HARMFUL METABOLITES GROW, MATURE AND FUNCTION AT A LOWER RATE AND UNTIMELY MANNER WITH RESULTANT INBORN STRUCTURAL ANOMALIES CHARACTERISTIC OF INBORN ERRORS OF METABOLISM, E.G., MONGOLISM, ARTERIOSCLEROSIS, PHENYLKETONURIA, ETC.

CHAPTER IX

Since ancient times, the resemblance between children and their parents or grandparents has been noted. Aristotle observed that a certain mark that appeared on the child's grandparent, but that did not appear in the parent, could reappear on the child. However, genetics did not emerge as a science until the nineteenth century. In 1810, Wollaston, who had published his discovery of five different types of urinary stones in 1797, identified a sixth type, and gave the underlying disorder a name: cystinuria. He observed that this disorder affected members of the same family.

Fifty-five years passed before Mendel, working with peas, formulated an explanation for some of these earlier observations.[91] It was a common belief at the time that characteristics of parents blend in offspring. Mendel demonstrated that such blending did not occur, but rather that a unit of inheritance, a gene, not expressed in the first generation can reappear unchanged in later generations. Each parent contributes one gene member of one pair. The two members of a single gene pair are not normally found in the same sperm or ovum (gamete). They separate and pass to different gametes. The genes that pass to the gamete recombine randomly.

In 1866, a year after Mendel's publication, the anomalies of Down syndrome were described by Dr. John Langdon Down. He considered the disease, which he called mongolism, a form of "ethnic regression."[92] The same year, Edward

[95]Mendel, G.: Versuche Uber Pflanzen - Hybriden. Ver. des Nat. Ver. in Brunn 4:1 (8 Feb. & Mar) 1865.

[96]Down, J.L.: Observations on Ethnic Classifications of Idiots. London Hosp. Rev, 111:25 1866.

Seguin, a pioneer in the education of the handicapped,[97] classified the constellation of mental characteristics as a distinct form of cretinism.[98]

In 1882, Paget analyzed the problem of inborn structural defects. Toward the beginning of this century, Garrod introduced the concept of inborn errors of metabolism. He discovered that certain genetic defects can be diagnosed by finding the abnormal metabolites in body fluids (blood, urine) or by visual examination.[99] Because examined fluids in Down syndrome patients appeared to be within the range of normal values, this disorder was not classified among diseases associated with metabolic disorders. In fact, nothing was known about the extra copy of chromosome 21, the cause of Down syndrome, until 1959. Until 1956, scientists believed that normal human beings had 48 chromosomes. However, the accumulations and retardations seen in newborn mongoloids suggested to a few investigators that excessive

[97]Scheerenberger, R.: A History of Mental Retardation. Brooke. Baltimore. 1983. 68-70.

[98]Seguin, E.: Idiocy and its Treatment by the Physiological Method. W. Wood & Co. New York. 1866.

[99]Garrod, A.E.: Inborn Errors of Metabolism. Lancet 2:73 1908

genetic material[100] [101] [102] might be the cause of the disorders. When I studied the X-rays of Peter, my first Down syndrome patient, in 1940, Waardenberg's hypothesis struck me as being most logical; moreover, I suggested that accumulations of unexcreted waste products contributed to the problem.

The Beadle and Tatum concept, one gene-one enzyme, was formulated in 1941. This hypothesis added credibility to the concept that Down syndrome was not a single-gene defect. Since 1953, when the structure of DNA was first determined by Watson and Crick, previous theories about the genes have been refined. A gene that encodes a single poplypeptide chain (not the entire enzyme) may have thousands of nucleotide pairs. The one gene-one enzyme concept upon which treatment of genetic diseases had been predicated can be reworded as "one gene-one poplypeptide chain."[103] Inheritance of nonchromosmal genes[104] further increases and complicates genetic variation.

[100]Waardenberg, P.J.: Das menschliche Auge und seine Erbanlagen. Haag. Marinus Nijhaff. 1932.

[101]Bleyer, A.: Indications that Mongoloid Imbecility is a Gametic Mutation of Degressive Type. Am. J. Dis. Child. 47:342. 1934.

[102]Fanconi, G.: Schweiz Med Wsch. 20:995, 1939.

[103]Thompson, J.S. and Thompson, M.W.,: Genetics in Medicine. Third Edition. W. B. Saunders. Philadelphia. 1980.

[104]Egger, J. and Wilson, J.: Mitochondrial Inheritance in a Mitochondrially Mediatated Disease. New Engl Jrl. Med 309:142-6. 1983.

Accumulations in Genetic Diseases.

Despite improved knowledge of genetics at the most basic levels, the understanding of metabolic pathways that manifest themselves as inborn errors of metabolism remains virtually intact: a metabolic block leads to the accumulation of the precursor before the block and a deficiency of the normal product. It is upon these principles that my treatment of genetic and chromosomal disorders is premised, and these principles have not been challenged.

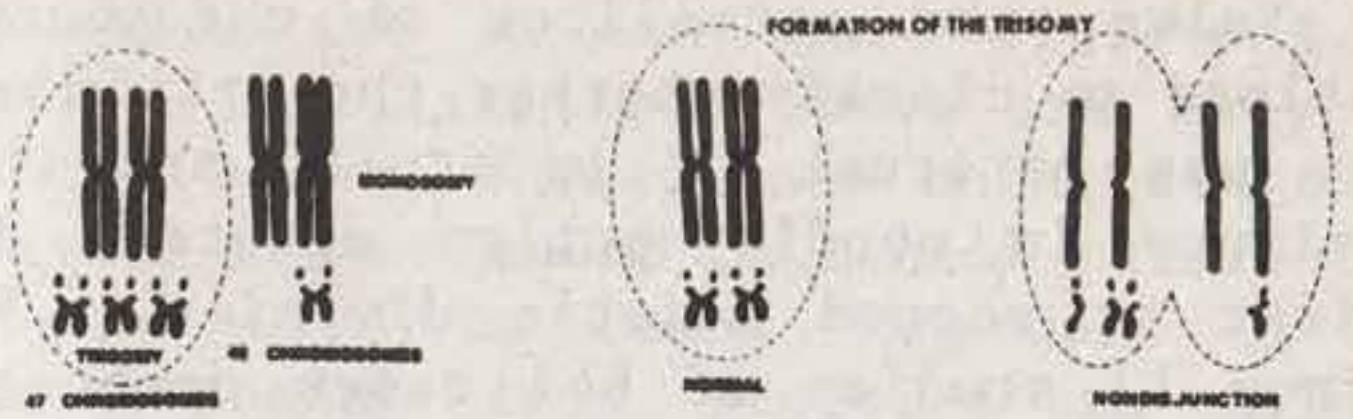
single-gene error
Substrate A (enzyme a->)B (b->)----C (c->)---normal metabolism, normal product (D).
A (enzyme a lacking or abnormal)----metabolic block: accumulation of substrate, deficiency of the normal product (D).
Alternate pathways may lead to abnormal products (D_1, D_y, D_z), which may cause harm or irritation.

I hypothesized that Down syndrome was a genetic disease similar to, but not the same as, inborn errors of metabolism. It was similar to the single-gene defects because of the presence of stored substances that interfered with development; it differed because the condition was identifiable at birth.

Certain genetic diseases, such as Type I (juvenile onset, or insulin-dependent) diabetes, phenylketonuria (PKU), or cretinism (congenital lack of thyroid) become clinically apparent only some time after the infant's birth. Before the child's birth, maternal enzymes, hormones, or the excretory system remove excesses; lacking end products are provided in sufficient quantity to prevent prenatal deficiencies. These babies generally appear normal at birth.

In 1956, the normal human chromosome count

was determined to be 46.[105]



The mechanism for dividing the number of chromosomes in the sperm and ovum (gametes) is called meiosis. During meiosis, half the chromosomes go to one "daughter" cell, the other half to the other. If a pair of chromosomes fails to separate (nondisjunction), two members of the same pair go to the same daughter cell. One of the cells has 24 chromosomes (including two chromosomes of one pair), the other has 22. If the gamete containing 24 chromosomes joins with a normal sperm or ovum, the chromosome count will be 47. The extra copy of the chromosome is called trisomy. The most common triplication is trisomy 21, Down syndrome. The chromosomal basis of Down syndrome was established in 1959, when an extra copy of chromosome 21 was discovered independently by Jerome Lejeune[106] and Patricia Jacobs.[107] It is now believed that only a portion of the chromosome is responsible for the disease.

Trisomy 21 is rarely hereditary. Statistically, it is related to advancing

[105]Tjio, J. and Levan, A.: The Chromosome Number of Man. Hered. 42:1. 1956.

[106]Lejeune, J., Gautier, M. and Turpin, R.: Les Chromosomes humain en culture de tissue. Comp. Rend Ac. Sci. 248:602. 1959.

[107]Jacobs, P.A., Baikie, A.G., Court-Brown, W.M. and Strong, J.A.: The Somatic Chromosomes in Mongolism. Lancet. 1959.

parental age. The error can occur in ovum or sperm.[108] Varients in the regions on the short arms, stalks, and satellites of chromosome 21 have helped to clarify whether the origin of the trisomy was maternal or paternal, and whether the failure in nondisjunction occurred during the first or second meiotic division. Pooled data from 13 studies of 641 cases demonstrated that first division maternal failures accounted for 21, first division paternal failures accounted for 45, first or second division maternal failures accounted for 90, first or second paternal failures accounted for 32, and 258 were uninformative.[109]

Mosacisim

A child who has some normal, some trisomic, and perhaps some monosomic cell lines is called mosaic. If nondisjunction occurs at the first division of the fertilized ovum (zygote), all cells are likely to be trisomic because the 45-chromosome (monosomic) cell at this stage of development usually fails to survive. However, accidental nondisjunction can occur during any stage of prenatal development. I disagree that

[108]Holmes, L.B.: Genetic Counseling for the Older Pregnant Woman: New Data and Questions. New Engl. Jrl. Med. 298:1419 (June 22) 1978.

[109]Mikkelsen, M.: Down's Syndrome Papers and Abstracts for Professionals 7:1-2 (July) 1984.

the vast majority of instances of trisomy 21 are due to a sperm or ovum with 24 chromosomes. Because there are so many more divisions that occur after fertilization, there are many more chances for error. Undiagnosed mosacisim may be a relatively common cause of mental retardation. There would also be fewer "degrees" of Down syndrome, ranging from profound to mild or borderline normal, if the error were present in all cells of most affected persons. The mosaic patient can resemble the trisomic patient, look completely normal, or display any variety or combination of characteristic features.[106] A parent may have undiagnosed mosaicism. If the sperm or ovum contains 24 chromosomes, it will produce a trisomic child.

If a trisomic patient has few of the physical features of Down syndrome and is mildly mentally retarded, the diagnosis of mosaic Down syndrome may be difficult or impossible to confirm.[107] [108] [109] In a few cases of mosaicism, the abnormal cell line has been known

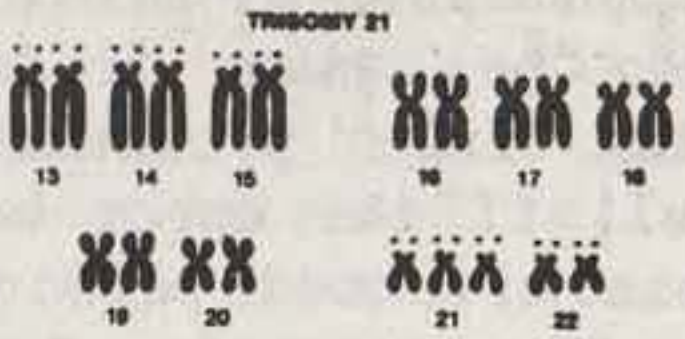
[110]Ladda, R.L. Maisels, MJ. Dosset, J.H., Dobell, Y.: Chromosomal Mosacisim in Down's syndrome: A Diagnostic Challenge. Dev. Med. & Child Neurol. 19: 688 (Oct.) 1977.

[111]Pfeiffer, R.A.: Inborn Autosomal Disorders: The Phenotype of Autosomal Aberrations. In Proceedings of the Third International Congress of Human Genetics. Ed.: Crow, J.F. and Neel, J.V. Johns Hopkins Press, Baltimore. 1967. pp. 103-122.

[112]Robson, N.H.: Human Chromosomal Abnormalities. Australian Ann. Med. 11:281. 1962

[113]Turkel, H. and Nusbaum, I.: Treatment of the 'Slow Learner' Op. Cit. 1978.

to disappear.[114] [115] [116] [117] Nondisjunction at a very early stage of prenatal development may produce mosaicism in either the placenta or the embryo, and not necessariy in both.[118]



In 1960, translocation was discovered. In this form of Down syndrome, the extra chromosome is attached (translocated) to another chromosome. The child who inherits 46 chromosomes that include a translocation has sufficient genetic material for the count of 47 chromosomes. The child develops just as if the extra chromosome were detached. Even in translocation Down syndrome, about 2/3 of all

[114]LaMarche, et al.: Disappearing Mosaicism - Suggested mechanism is Growth Advantage of Normal over Abnormal Cell Population. R.I. Med. Jrl. 184 (March) 1967.

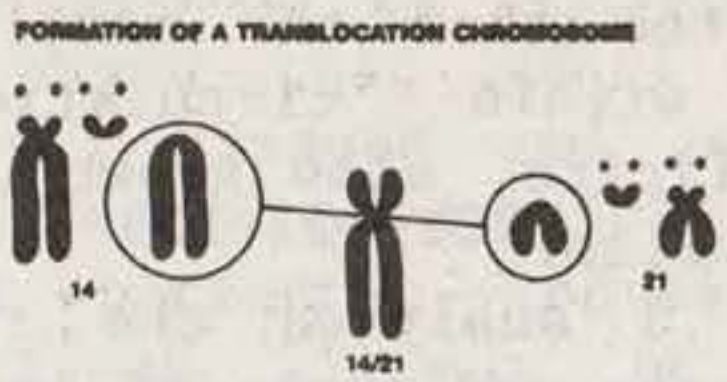
[115]Porter, et al.: Evidence of Selection in Mosaicism. Jrl. Med. Gen. 6:310 (Sept.) 1969.

[116]Neu, et al.: Disappearance of a 47 XX, C+ Leucocyte Cell Line in an Infant who had previously Exhibited 46, XX, 47, XX, C+ Mosaicism Pediatrics 43:624 (April) 1969.

[117]Hook and Yunis: Trisomy 18 Syndrome in a Patient with Normal Karyotype. JAMA 193:194 (Sept. 6) 1965.

[118]Kalousek, D.K. and Dill, F.J.: Chromosomal Mosaicism Confined to the Placenta in Human Conceptions. Science. 221:665-667 (August 12) 1983.

cases are the result of a new mutation.[119]



Down syndrome was thought to be unrelated to other metabolic disorders because the examined biochemicals seemed to be within the normal range.[120] Since excess wastes were pushed into tissue, investigators did not know what to look for or how to look for it, particularly since techniques and instruments were not as well developed twenty years ago. I pointed out that there must be a biochemical imbalance involving hundreds or thousands of excessive gene products because there was an extra chromosome:

chromosomal trisomy
A--------B------C----------normal metabolism----

A--------B------C----------normal metabolism----
Normal metabolism of the two normal chromosomes. All 46 chromosomes and their gene products.

Normal gene products of the third copy of the chromosome lack consecutive enzymes for

[119]Miller, W.A. and Erbe, R.W.: Prenatal Diagnosis of Genetic Disorders. Southern Medical Journal 71:20 (Feb.) 1978.

[120]Nelson, W., Ed.: Textbook of Pediatrics. Eighth Edition. W. B. Saunders. Philadelphia. 1964.

further conversion, and accumulate (primary accumulations).

I postulated that the massive mechanical interference within circulation led to nutritional deficits, slow growth, and abnormal cerebral metabolism.[121] [122] [123]

In 1960, I analyzed the records of 69 patients. The rate and areas of improvement were found to vary between patients. For example, the "U" Series significantly accelerated bone development in 11 of 13 patients with retarded bone ages. The bones of 10 patients were prematurely ossified; 70% benefited when abnormal calcifications were removed. Sixty-nine percent of edematous patients improved. Various statistical measurements revealed different levels of improvement, but those seen radiographically were the most impressive.

I believed then as now that amelioration of Down syndrome was a worthwhile goal. When I met Dr. Lejeune at an international convention in the Netherlands in 1963, I was stunned by Dr. Lejeune's question, "Can your patients do cube roots?" Now that inexpensive calculators can perform that function, this feat possibly seems less impressive: Dr. Lejeune treats Down syndrome patients with some of the same vitamins and other nutrients included in the "U" Series. For 20 years, however, improvement of ameliorative therapy was forestalled by the medical opinion that failure to cure a disease somehow diminished the importance of treatment.

[121] Kennedy. C.: The Cerebral Metabolic Rate in Mentally Retarded Children. Arch Neurol 16:55. 1967.

[122] Outlook: Nutritional Needs of Retarded Children. Med World News (Dec. 6) 1974.

[123] Science 221:781. (Aug. 19) 1983.

Beginning in 1974, some of the products of chromosome 21 were being identified.[124] By 1977, genetic mapping by McKusick and others proved beyond doubt that SOD 1 - CuZn SOD - which is in all tissues and is located on chromosome 21, appeared in 50% excess.[125] In Down syndrome patients, increased oxidative damage in trisomy 21 may be due to the biochemical imbalances associated with the 50% excess of this product. Some of the associated features are rapid aging of skin cultures, immunological disorders, changes in metabolism comparable to those seen in older people, decrease in I.Q. with age, and presenile dementia.[126] Excessive gene products of one chromosome also alter levels of enzymes located on other chromosomes. For example, Dr. P.M. Sinet has found increased glutathione peroxidase (GSHPx), an enzyme found on a different chromosome.[127] Conversely, three siblings with Down syndrome with a partial trisomy 21 who had normal SOD-1 levels. It is therefore not

[124]Tan, Y.H. et al.: Human Chromosome 21 Dosage Effect on the Expression of the Interferon Induced Antiviral State. Science 186:61 (Oct. 4) 1974.

[125]McBride, G.: The Newest Thing in Maps -- One that Localizes Human Genes. JAMA 237:7 (Jan. 3) 1977.

[126]Sinet, P.M.: Metabolism of Oxygen Derivatives in Down's Syndrome. In: Alzheimer's Disease, Down's Syndrome, and Aging, Eds. E. M. Sinex and C.R. Merril. Annals of N.Y. Ac. of Sci 396:83-94. 1982.

[127]Sinet, P.M. et al.: Increase in glutathione peroxidase activity in erythrocytes from trisomy 21 subjects. Biochem Biophy Res Commun 67:910-915. 1975.

necessary to have excessive SOD-1 in order to have Down syndrome.[128] After all, it is not just one biochemical that is out of balance in Down syndrome: it is the combined accumulations of all the excessive gene products.

The medical consensus that there were no metabolic imbalances in Down syndrome was so deeply entrenched that as recently as 1977, some medical students were still being taught that the extra genes encode structural defects before birth and then "turn off" (Expert's testimony in Superior Court, Los Angeles, California #C 88260). It is now recognized that a third copy of one whole or partial extra chromosome disrupts homeostasis and all functions.[129]

To test the hypothesis that a small percentage of the genes on the extra chromosome cause most of the damage, specific genes have been studied. Dr. H. Goodman and colleagues, of Bowman Gray School of Medicine, who, in 1966, found elevated serum uric acid in Down syndrome patients,[130] have studied taurine, which has two alternative genes, one for rapid taurine

[128]Habedank, M. and Rodewald, A.: Moderate Down's syndrome in Three Siblings having Partial Trisomy 21q22.2qter and therefore no SOD-1. A Hm Genet 60:74:77. 1982.

[129]Shapiro, B.L.: Down's syndrome - A Disruption of Homeostasis. Am Jrl Med. Gen 14:241-169. 1983.

[130]Goodman, H.O.: et al.: Serum Uric Acid Levels in Mongolism. Am J Ment Def 71:437-446 (Nov.) 1966.

reabsorption, and one for slower reabsorption.[131]

However, even if some specific damage is blueprinted by a relatively small percentage of genes, there is a biochemical imbalance because of the additional excessive gene products. The gene for SOD-1 is evidently not on the section of the chromosome responsible for the clinical features of Down syndrome, as has been learned by the study of children with a partial trisomy. Yet, whatever is administered to compensate for the "damaging" genes must be forced through the massive accumulations caused by the numerous excessive gene products and, in accordance with my theory, unexcreted wastes. In Down syndrome, organs of elimination and excretion, like all other structures, are underdeveloped because the excessive gene products take up space needed for delivery of nutrients. The underlying theory is comparable to nutritional treatment of Type II diabetes.

Various treatment modalities have been recommended for Down syndrome. For a number of years, Dr. Clemens Benda administered pituitary hormone and thyroid. February 13, 1973, he stated in personal correspondence that he had discontinued use of this treatment "because the product was not entirely successful." Rosner's discovery that serotonin levels were low in Down syndrome[132] led to the hope that supplementary serotonin would improve muscle tone and mentality. However, this treatment was destined

[131]Goodman, Harold O.: Theoretical and Empirical Science in DS. Down Syndrome Report. People with Special Needs (Youth ARC Newsletter) 4:3 Spring, 1982.

[132]Rosner, F. et al.: Studies of blood enzymes in Mongolism. JAMA 198:238 (Oct. 17) 1966.

to fail[133] because many normal chemicals are, to a greater, or lesser degree, reduced because of the primary and secondary accumulations.

The primary accumulations result directly from the excessive gene products; the secondary accumulations, which are fats, fluids plus water-soluble substances, and minerals, result from the inefficient function of organs of waste elimination. EDTA removes too many minerals to be useful in Down syndrome. DMSO has been used with some success.[134] Approximately 2/3 of patients treated with cell therapy benefit.[135] Unlike the "U" Series, cell therapy does not remove waste accumulations. Both treatments supplement nutrients. The "U" Series also provides antihistamines aminophylline, and diuretics to remove fluids, and vasodilators to improve circulation, especially to the brain. Both treatments provide substances to build up the liver, adrenaline, and thyroid. A basic difference is that the "U" Series is intended to clear out the tissues so that the development of the body can proceed on its own, with the help of supplemented nutrients. Cell therapy provides the building blocks, similarly to the

[133]Coleman, Mary: The Use of 5-Hydroxy-tryptophan in Patients with Down's Syndrome. In: Down's Syndrome (Mongolism) - Research, Prevention, and Management. Ed. Koch, R. and De la Cruz, F. Brunner/Mazel. New York. 1975.

[134]Nassar, C.: Clinical Experience with Merinex in Children with Mental Deficit and Difficulties in Basic Learning. Monograph: Use of DMSO. Chile. 1969.

[135]Goldstein, H.: Sicca-cell therapy in children. Arch Pediat 73:234-249. 1956.

GTC Formula and other megavitamin therapies.[136]

Human Growth Hormone has been extensively investigated by Dr. Goren Anneren in Sweden. Three girls and two boys, ages 3-6 to 6-6, were treated for 6 months. The range of growth velocity before treatment was 2.3-2.8 cm. After 6 months of treatment, the range was 3.3-5.8 cm. Skeletal maturation and I.Q. did not improve. For example, the 6 1/2 year old girl's height went up from 5 to 4 standard deviations below the mean during the 6 months of treatment, representing a very good degree of "catching-up" to healthy children in height. Her bone age developed 6 months during the 6 months of treatment. Her I.Q. did not change.[137] The possibility of Human Growth Hormone treatment to improve the one parameter of height should be further investigated.

Dr. Frank Menolascino has noted the difficulty of designing studies to test the intelligence-enhancing effects of drugs. He has pointed out that therapy "to enhance the intelligence of a college student would be expected to improve his learning, memory, and general performance. A moderate and gradually accumulating effect would be considered desirable and quite acceptable. However, with a retarded person a drug is often scorned if it produces anything less than a complete and perhaps even a rapid 'cure' -- unless it

[136]Harrell, R.R., Capp, R.H., Davis, D.R., Peerless, J. & Ravitz, L.R.: Op. Cit 1981.

[137]Anneren, G.: Down's Syndrome - A Metabolic and Endocrinological Study. Acta Univ. Upsal. Upsala, Sweden. 1984.

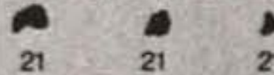
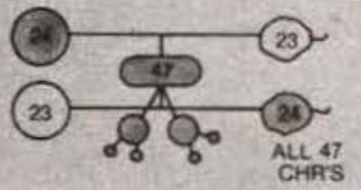
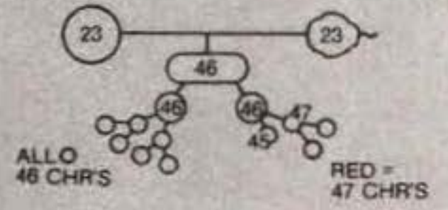
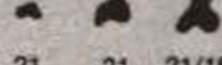
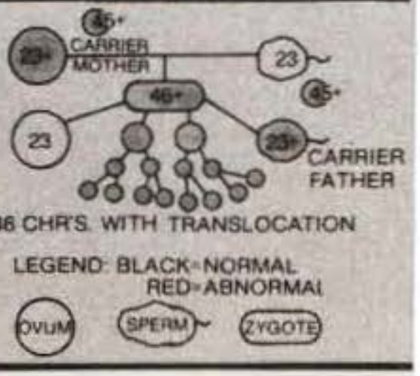
produces 'normality.'"[138] [139]. This point is applicable to the GTC Formula as well as the "U" Series.

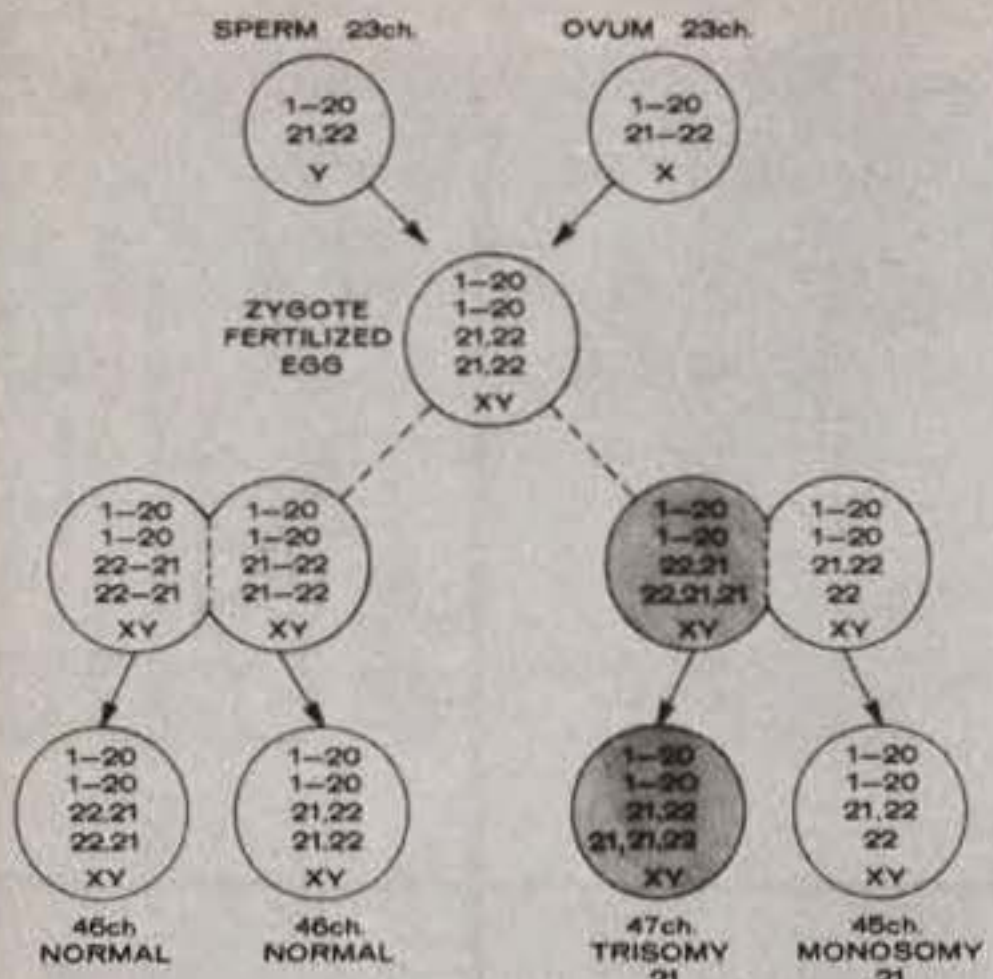
KARYOGRAM OF A PATIENT WITH TRANSLOCATION AND TRISOMY

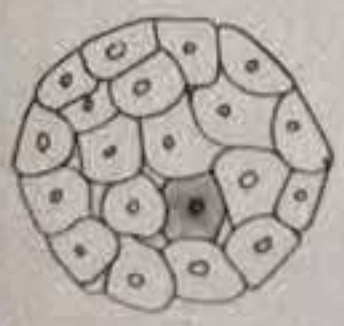
[138]Wolfensberger, W. and Menolascino, F.: Basic Considerations in Evaluating Ability of Drugs to Stimulate Cognitive Development in Retardates. Am. J. Mental Def. 73:414-423 (Nov.) 1968

[139]Menolascino, F.: Methodological Considerations in Evaluating Memory and Learning Enhancers. In: Curative Aspects of Mental Retardation - Biomedical and Behavioral Advances (Ed. Frank J. Menolascino, Ronald Neman, Jack A. Stark. Brookes Publishing Co. Baltimore. 1983. 137-145.

CLASSIFICATIONS OF DOWN'S SYNDROME ACCORDING TO CHROMOSOMAL PATTERN

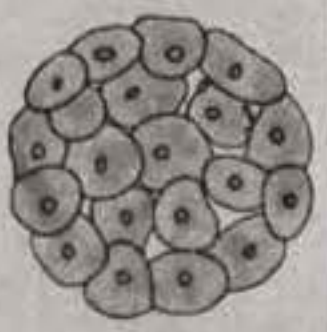
TYPE	GENESIS OF ABNORMAL CHROMOSOMAL PATTERN	CHROMOSOMAL PATTERN & NUMBER IN ZYGOTE	CHROMOSOMAL PATTERN & NUMBER IN EARLY EMBRYONIC CELLS	SEVERITY AND NUMBER OF INBORN STRUCTURAL FUNCTIONAL AND CHEMICAL ANOMALIES.	PATTERN OF DEVELOPMENT
STANDARD	ACCIDENTAL NONDISJUNCTION OF NO. 21 CHR. (MEIOSIS) USUALLY IN OLDER NORMAL PARENT	47 CHROMOSOMES AS NO. 21 TRISOMY  21 21 21	47 CH. TRISOMY 21	USUALLY SEVERE AND MANY ANOMALIES	
MOSAICISM	VARIABLE CAUSES MUTATION FOLLOWING CONFECTION (MITOSIS) 1. HEREDITARY PREDISPOSITION TO NONDISJUNCTION 2. ACCIDENTAL NON DISJUNCTION 3. INDUCED MUTATION: A. IONIZING RADIATION B. CHEMICALS, DRUGS C. POSSIBLY INFECTIONS D. POSSIBLY MATERNAL INFLUENCES (E.G. AGE)	46 CHROMOSOMES	UNAFFECTED CELLS 46 CHR'S. AFFECTED CELLS 3-21 CHR'S.	FEWER AFFECTED ORGANS & TISSUES 1. MENTAL RETARDATION PHYSICAL ANOMALIES 2. MENTAL RETARDATION NO PHYSICAL ANOMALIES=SLOW LEARNER 3. MENTALLY NORMAL; NO, FEW, OR MANY PHYSICAL ANOMALIES.	
TRANSLOCATION	TRANSLOCATION OF NO. 21 CHR. USUALLY IN YOUNGER CARRIER PARENT HAVING 45 CHR'S. NO. 21 MAY BE FUSED WITH OTHER CHROMOSOMES, E.G. 13, 14, 15, 22, AS 21/13, 21/14, 21/15, 21/22 ETC.	46 CHROMOSOMES AS 2-21 SINGLES 1-21 FUSED EG.  21 21 21/15	46 CHR'S. 2-21 AND 1-21/15	USUALLY SEVERE AND MANY ANOMALIES	

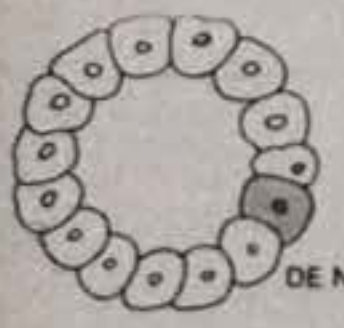




DEVELOPMENTAL STAGES
46 CHROMOSOMES 47

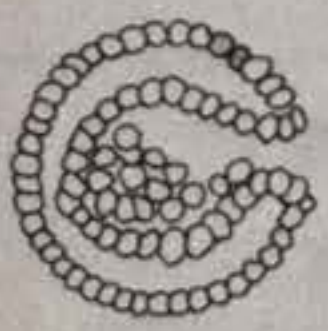
MORULA
SOLID SPHERE
OF CELLS





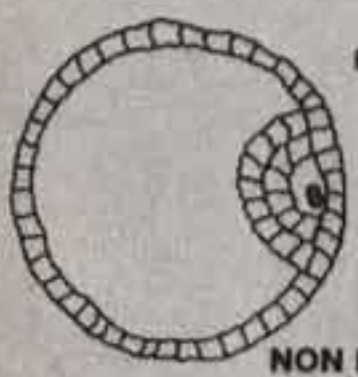
DE NOVO

BLASTULA
HOLLOW SPHERE
OF CELLS



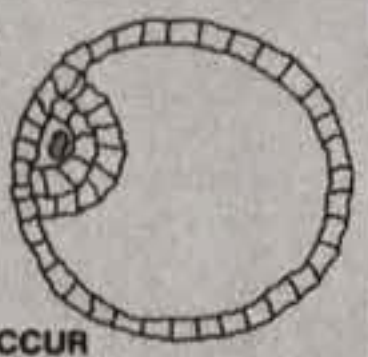
GASTRULA
PRIMARY CELL LAYERS
FROM WHICH ALL
STRUCTURES DEVELOP

MESODERM
ENDODERM
ECTODERM



AMNION
CONTAINS WASTE
ELIMINATION PRODUCTS
OF FETUS

INCLUDING
TRISOMIES
FEW MANY



NON DISJUNCTION CAN OCCUR
AT ANY STAGE OF DEVELOPMENT

THE EARLIER IT OCCURS—THE MORE CELLS INVOLVED

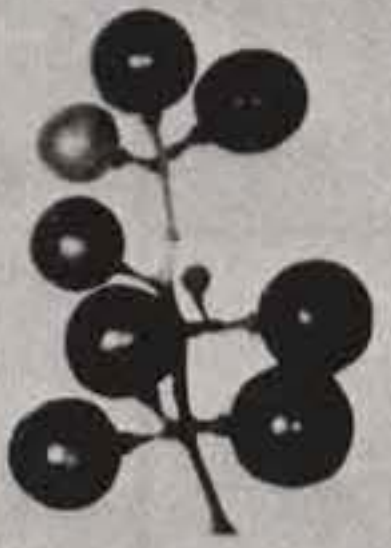
THE MORE SEVERE THE ANOMALIES – THE LONGER THE TREATMENT

GENETIC VARIATIONS

A MONGOL MONKEY

A FEMALE CHIMPANZEE BORN IN 1968
AT YERKES REGIONAL PRIMATE RESEARCH
CENTER IN ATLANTA, GEORGIA WITH DOWN'S
SYNDROME STIGMATA

EPICANTHAL FOLDS
SHORT NECK
HYPERFLEXIBLE JOINTS
SYNDACTYLY OF TOES
CARDIAC DEFECT
TRISOMY 22



RIPE AND UNRIPE GRAPES
ON THE SAME VINE

CHAPTER X

Since, in our society, mental retardation is one of the most serious impediments to normal living, education of the Down syndrome patient is important to him and his community. Unless each patient is given the opportunity to reach his full potential, society not only loses a participant in the economy but must support him. The cost of lifelong institutionalization of just one Down syndrome patient is about $1 million in a public facility. In private institutions, the cost is greater.

The mental retardation of the Down syndrome patient should be viewed as a result of structural and functional abnormalities. Since virtually every organ and tissue is involved, treatment of only the mental aspect is likely to fail.

Vision and hearing must be checked. Many patients are nearsighted and/or cross-eyed. Most have fine-lens opacities. Their ears and auditory canals are often plugged with waxy material, causing hearing loss. Teething can be a serious matter; dental anesthetic should be applied.

General socialization should be provided from birth. Infant stimulation classes are available in most communities. During the early years, the social age of the Down syndrome child is not far behind his chronological age. Contrary to common opinion, these children almost invariably learn to take care of their basic needs, such as dressing, eating, bathing, or going to the toilet without assistance, though there may be some delay in acquiring these skills.

As the body organs and tissues of the treated Down syndrome patient tend, over time,

to improve in structure and function, the patient undergoes a number of changes that are important to parents and educators. Generally speaking, the treated patient enlarges his range of interaction with the environment and becomes increasingly receptive to learning because of:

1. Improved appearance - The more normal appearance of the face and body is the result of a diminution of typical characteristics of Down syndrome, such as the bloated abdomen, puffy lids, epicanthal folds, enlarged tongue, abnormally short stature, and constant nasal or pulmonary congestion. As the child begins to look more normal, the tendency for the adults who work with him and the children who play with him to treat him more normally improves his chances for more normal social experiences.
2. Physical Improvement - The normalization of physical organs and tissues of the treated patient also results in improvement in motor coordination and muscle tone. He becomes more physically active over a longer time span and is capable of performances previously beyond his physical strength. If improvement in motor coordination is accompanied by reduction in pulmonary and cardiac abnormalities, more strenuous play becomes possible, furthering social improvement.
3. Improved health - Fewer sick days translate into more learning days.
4. Improved educability - In general, the child's attention span increases significantly, and there is an enlarged awareness of events, objects, persons, and ideas. Verbal ability improves in most patients. The teachers comment on the child's greater attentiveness and educability. The concept of mainstreaming the handicapped into regular classrooms is an opportunity for Down syndrome patients and a challenge to educators. These children can learn. Most children with Down syndrome are artistic, musical, and mechanical. They have

good memories and with patience can master simple abstractions. They can learn the alphabet and reading skills as well as basic arithmetic. With medical treatment, proper education to develop intellectual potential, training and socialization, Down syndrome patients may become partly or fully independent.

EDUCATIONAL METHODS OF TEACHING AND TESTING

(Visual Manipulative Technique)

An objective test by means of Brain-Eye-Hand coordination in words-formation by the use of

WORD RUMMY CARDS

4 COMPLETE SETS OF ALPHABETS
26 LETTERS IN EACH SUIT
ONLY 52 CARDS – AND 2 WILD CARDS

FUN FOR CHILDREN
CHALLENGING FOR ADULTS

- This is the original word card game.
- Improves Spelling and Vocabulary – Educational
- Stimulating – Fascinating – Thought Provoking
- Can be played in all Languages using the English Alphabet
- Contains Morse Code

Approved by
Boards of Education –
Teachers – Clergymen –
Recreation and Social Workers

THE PERFECT ANSWER TO ALL PARTY GAMES

ENTERTAINING! RECREATIONAL!

A GAME WHICH THE ENTIRE FAMILY CAN PLAY AND ENJOY

These WORD RUMMY CARDS are practical; they are small, strong, easy to handle and can be carried in purse or pocket. Properly utilized, they are a loose-leaf instruction and practice book, having clear and easily recognizable letters and numerals. The cards also bear numbers from 1 to 13 in each of the four colors. A color-blind individual, for instance, would be recognized by his inability to match the cards by the individual colors.

Tests can be administered equally well to normal or retarded individuals provided:

1. The subject understands what is required of him in performance
2. the subject is in a suitable condition to respond
3. the test must be taken from the range of understanding
4. the test is administered properly
5. the interpreter is not subjectively influenced
6. the results of the test lend themselves to objective and measurable interpretation by all observers alike.

Only such tests that meet the listed requirements can be considered a practical and valid interpretation of present knowledge of the tested individual in disclosing the stored learning as well as ability and capacity to utilize such learning properly. Tests may be used, also, to predict future performances provided nothing interferes with the subject obtaining and acquiring further education.

Performance tests by means of WORD RUMMY cards easily and rapidly manifest past experience because they are easy to explain, to understand, to administer, and to interpret since they are objective and not subjected easily to personal influence of the observer. Also, these tests are easy to rate and to standardize.

The individual can be taught quickly to perform the following exercises:

1. Recognizing, matching and copying individual colors;
2. Matching individual letters such as I, O, X, V, L, etc.;
3. Copying individual letters with crayons of the same color;
4. Learning more letters to copy and to pronounce; the order of the alphabet with capitals and with small letters; the numbers and their sequence;
5. Forming simple TWO letter words such as AT, IT, GO, NO, TO, etc.;
6. Forming simple THREE letter words such as RAT, BAT, CAT, DOG, HAT, etc., which can be shown in pictures, or as objects or subjects;
7. Re-arranging THREE, FOUR and FIVE letter words such as ART–RAT–TAR; GUNS–GNUS–SNUG–SUNG; CHEAP–PEACH, etc., and then to copy these words, to pronounce them and to tell their meaning.

The cards may be used, also, as an enjoyable social entertainment for children and adults of nearly all ages; parents may also play with their children. In addition, these cards may be used by aphasia patients or elderly people with loss of memory.

The Word Rummy Cards are approved by the Boards of Education and used in the cities of New York, N.Y., Chicago, Ill., Duluth, Minn., and others.

Barritt, Rex, S.W.; Play Materials in Child Therapy; PATHWAYS IN CHILD GUIDANCE, March 1968; Board of Education of the City of New York, N.Y.

Agranowitz, A., Director, Lakewood Speech Clinic, Long Beach, California and McKeown, M. R., Chief, Aphasia Clinic, Veterans Administration Hospital, Long Beach. Reading Recognition and Comprehension; APHASIA HANDBOOK FOR ADULTS AND CHILDREN, Edwards Brothers, Inc. Ann Arbor, Michigan, 1959.

Objective performance tests can be performed by setting up a group of 3, 4 and 5 letter cards in a way which does not spell a word, for example: NAT, PTA, MRSA, etc., and then timing the test as to how long it takes to make one or more words from these set-up letters.

Examples of re-arranging letters to form words –

ANT–TAN; APT–PAT–TAP; ARE–ERA; ART–RAT–TAR; ASP–SAP; BAN–NAB; BAT–TAB; BIN–NIB; NUB–BUN; EAT–TEA; EON–ONE; GAS–SAG; GUT–TUG; LOW–OWL; MAY–YAM; NAP–PAN; NET–TEN; NIP–PIN; NOT–TON; NOW–OWN–WON; ORE–ROE; PAT–TAP; PIT–TIP; POT–TOP; PUS–SUP; SAW–WAS

ACHE–EACH; ARNS–MARS–RAMS; ARTS–RATS–STAR–TARS; BANS–NABS; BARE–BEAR; BARN–BRAN; BORE–ROBE; BUNS–SNUB; CAST–CATS–SCAT; DARE–DEAR–READ; DIET–TIDE; DONE–NODE; EONS–NOSE; EVIL–LIVE; FILE–LIFE; FIRE–RIFE; GAPE–PAGE; GEAR–RAGE; GUNS–GNUS–SNUG; HARE–HEAR; HINT–THIN; KEEN–KNEE; KEEL–LEEK; KALE–LEAK; LIAR–LAIR–RAIL–LURA; LIST–SLIT; LEAP–PALE–PEAL; LIPS–LISP–SLIP; LITE–TILE; LONE–NOEL; MANE–MEAN–NAME–AMEN; MITE–TIME; MATE–MEAT; TAME–TEAM; NAGS-SNAG; NOTE–TONE; PATE–PEAT–TAPE; PART–RAPT– TRAP; PEST–PETS–STEP; POET–TOPE; PORE–ROPE; PROM–ROMP; POST–POTS–SPOT–STOP–TOPS; RARE–REAR; RISE–SIRE; RITE–TIER–TIRE; RUNT–TURN; SAVE–VASE; SKIN–SINK.

CHARE–REACH; CHAPE–CHEAP–PEACH; CHEAT–TACHE; LISPS–SLIPS; LITES–STILE–TILES; PORTS–SPORT; PRUDE–DRUPE; NEWER–RENEW; RUNTS–TURNS.

NOTE: THIS TEST CAN BE USED IN ALL LANGUAGES USING THE ROMAN ALPHABET.

NAME OR NUMBER | CLASS-SECTION | TEST NUMBER | DATE

TURKEL VISUAL–KINESTHETIC VOCABULARY APTITUDE TEST

This is an OBJECTIVE test to see how fast you can THINK and how well you can rearrange the WORD RUMMY CARDS (using only the CAPITAL letters on top of the cards) into a number of correctly spelled words, PRINTING in CAPITAL letters EACH of these words in the proper blank spaces adjacent to the letters which are identical to the particular cards given to you. You must use the WORD RUMMY CARDS to help you form the various words more easily by manipulating these cards into various sequences of letters to see if ONE or MORE VALID words can be formed.

You will note that there are FIVE blank spaces for each set of letters in which to PRINT your words. Fill as many spaces as possible with valid words. If only three words can be formed from the set of letters, leave two spaces blank. Your score will be lowered if you form words that do not exist; miss valid words; or do not spell them properly. Work as quickly as possible without sacrificing accuracy. YOU WILL BE TIMED. Your examiner will demonstrate the use of these cards.

DO NOT WRITE BELOW THIS LINE. THIS SPACE IS RESERVED FOR YOUR EXAMINER

SCORE:

Total number of words formed correctly ..... _____

Less number of words missed_____ improperly spelled _____ non-existent ____ _____

TIME USED .....minutes..... Final Score _____

REMARKS: _____ _____

_____ _____

_____ _____

_____ _____

_____ Examiner _____ _____

EDUCATIONAL CARDS CO., 19145 W. Nine Mile Rd. Southfield, MI. 48075

Set of Letters	Spaces for PRINTING Words.				
ATP	APT	PAT	TAP		
ARP					
ASG					
BNA					
BNI					
ETA					
MDA					
MYA					
NDA					
NTA					
OEN					
PLA					
PSA					
REA					
RTA					
TBA					
UGT					
UNG					
WLO					
DMEA					
AKLE					
ALEP					
SEAV					
RREA					

STUDENT'S NAME OR NUMBER	CLASS	SECTION	EXAMINER	DATE

TURKEL VISUAL–KINESTHETIC VOCABULARY APTITUDE TEST

This is an OBJECTIVE test to see how quickly you can THINK and how well you can rearrange the WORD RUMMY CARDS (using only the CAPITAL letters at the top of the cards) into a number of correctly spelled words, PRINTING each of these words in the proper spaces to the side of the letters which are identical to the particular cards given to you. You use the WORD RUMMY CARDS to help you form the various words more easily by manipulating these cards into various sequences of letters to see if ONE or MORE correct words can be formed.

You will note that there are FIVE spaces available for each set of letters in which to PRINT your words. Fill as many as possible with valid words. If only three words can be formed from the set of letters, leave two spaces blank. Your score will be lowered if you combine letters which do not form a valid word or if you use less letters from the set given to you to form these words. Your examiner will demonstrate the use of these cards. Work as quickly as possible without sacrificing accuracy. YOU WILL BE TIMED.

DO NOT WRITE IN THIS SPACE

SCORING:

Total number of words formed correctly _____

LESS Total number of words formed incorrectly _____

TIME USED: _____ FINAL SCORE _____

REMARKS: _____

_____

_____

This ability test is designed primarily to reflect accurately and objectively the ability to form words and to recognize words spelled accurately in the least possible time in the child from 4-7 years of age and any individual considerably older chronologically who may be a slow-learner, reader, mentally-subnormal or suffering from a brain disease or injury (encephalitis, meningitis, brain tumor, stroke, etc.). All of these are usually individuals who have difficulty in translating visual images to the cortex of understanding and back to be read, written or printed.

The manipulation of the cards into forming words, re-grouping and forming other words assists in impressing the word images more vividly into the mind of the child, assists in teaching the child that letters are the basic ingredients of language, and helps the child translate from visual concept to mental concept.

Progress in thinking, spelling and vocabulary can be followed by having the test repeated every 2-3 months.

EDUCATIONAL CARDS CO. 19145 W. Nine Mile Rd. Southfield, MI. 48075

Set of Letters	Spaces for PRINTING Words				
ATP	APT	PAT	TAP		

Set of Letters	Spaces for PRINTING Words				

UNITED STATES
GOVERNMENT PRINTING OFFICE
DIVISION OF PUBLIC DOCUMENTS
WASHINGTON, D.C. 20402

OE–37045

BOOKS RELATED TO COMPENSATORY EDUCATION

Compiled by: Lois B. Watt, Chief, and Myra H. Thomas, Curriculum Materials Officer,
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III PROFESSIONAL RESOURCES

HANDICAPS–MENTAL AND PHYSICAL P42

Turkel Visual-Kinesthetic Vocabulary Aptitude Test.
Detroit: Educational Cards, 1968. An objective test involving the manipulation of *Word Rummy Cards* to form correctly spelled words, as means of testing normal children ages 4 through 7, or any older person who may be mentally handicapped.

U. S. Department of Health, Education, and Welfare, Office of Education
Robert H. Finch, *Secretary*

James E. Allen, Jr., *Assistant Secretary and Commissioner of Education*

Bureau of Research
James J. Gallagher, *Acting Associate Commissioner for Research*

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Educational Materials Center, Bureau of Research, U.S. Office of Education, Washington, D.C. 20202.

CHAPTER XI

Introduction

Parents want to know why their children cannot receive the "U" Series from their own doctors. The next two chapters attempt to answer this question. The information has been obtained from original correspondence between Dr. Turkel and the staff of St. Rita's Home for Children near Buffalo, New York, telephone memoranda, letters from the AMA, publications, the NIH grant application, FDA correspondence, and transcripts of Dr. Bumbalo's testimony at an insurance trial, Marcom vs. Aetna Insurance, in 1977.

Clinical study

On the basis of improvements seen in a resident who had been treated and the reports of patients Judy and Evelyn, the staff of St. Rita's Home for Children proposed a study. Plans were laid June 11, 1961. Dr. Turkel was asked to contribute medication and placebos for a controlled clinical trial to last three years.

At the start, six children were to receive the "U" Series, and six were to receive placebos. The administrative staff and physicians knew the identity of the children in both groups. Dr. Turkel planned to supply medication during the first year, and St. Rita's Home promised to apply for an NIH grant for the second and third years. On December 1, 1961, the administrator of the Home, Sister Raphael Marie, reported that the clinical trial had commenced.

Sister Raphael Marie was enthusiastic: unanticipated improvements had become evident. For example, one of the children was in a hyperextension cast because of an undeveloped head of a femur. Her hip was routinely X-rayed. Dr. Berens, the radiologist, repeated the X-ray when he saw that the head of the femur had developed during the short period of "U" Series treatment.

During this initial part of the study, which was controlled but not double blind, the staff of St. Rita's Home, stated[140] that the treatment was promising. On the basis of these early improvements, permission was granted by the Bishop[141] for construction of a treatment center at St. Rita's for the "U" Series therapy. Actual fund-raising for construction was not carried out until after the code was broken, at which time a large celebration was held at the Home.

December 19, 1961, the medical staff submitted the age, height, and sex of each of the remaining 14 Down syndrome residents to Dr. Turkel, and asked that all 26 be included in a study. Moreover, Dr. Bumbalo, the chief investigator, proposed that the study become double blind. Dr. Turkel objected on the grounds that there were too many variables in Down syndrome and that the children were not suitably matched. However, since the AMA had previously interfered with several other planned studies, including one at the Levinson Foundation in Chicago, he eventually agreed that the study be double blind. He was afraid that otherwise the AMA would persuade St. Rita's to terminate the study.

Throughout the Bumbalo study, Dr. Turkel was listed as coinvestigator. His name was included on the NIH grant application for the second year. At the start of the study, Dr. Turkel wrote: "I would appreciate your re-taking those X-rays which were not clear. And it would be wise to have all the X-rays and photographs up-to-date and in perfect condition prior to the start of the medication."

[140]Young, W.: They Educate the Uneducables. Information (Nov.) 1962.

[141]At St. Rita's Love is the Key. Diocese of Buffalo. 1962.

January 3, 1962 the "before" photos of all 26 children were sent to his office, and Dr. Turkel was informed that X-rays had been taken. Twelve days later, the administrator of his office, a highly qualified woman with a Ph.D. degree, selected two groups as closely matched as possible. The six children in the original "U" Series group were placed into the treatment group, and the six placebo-group children remained controls. He thought that the original measurements of those 12 children would be kept, together with their new measurements, made when the new children entered the study. The children were selected by age and sex only; Dr. Turkel was not told until 1967 that some of the children were mosaic. The 6 original children were selected in accordance with their clinical condition. Of each pair, the child with the larger number of medical problems was placed into the "U" Series group.

In addition to the "U" Series or placebo, each patient was prescribed a dietary regimen that limited sugar, salt, vitamin D enriched foods and milk, peanut products. While conducting research with the Turkel instruments in 1952 at North Carolina State College, Dr. Turkel discovered that pigs, despite their excellent digestive systems, were unable to digest peanuts properly. He therefore determined that patients who have retarded organs of digestion should avoid peanuts. More recent research on the effect of peanuts has validated his reasoning.[142] .

[142]Lesions from Peanut Oil. Mod. Med. 38:15 (May 22) 1967.

CHART FROM DR. BUMBALO'S TYPESCRIPT

CONTROL			MEDICATION	
age		sex	sex	age
9 months		male	male	10 months
2yr.	4mo.	female	female	1yr. 9mo.
2	5	female	male	2 2
2	5	male	male	2 8
6	8	female	female	7 2
2	8	male	female	3 9
11	2	female	male	7 2
4	3	male	female	3 11
1	2	female	male	1 5
0	7	male	male	0 4
5	10	male	female	5 4
3	10*	female	female	3 8
2	3	male	male **	2 4

*(Control Group -- the 3 year 10 month old female left the Home.)

**(Medication Group -- The 2 year 4 month old male died March 14 before receiving medication, leaving behind the three-month supply, which was not later accounted for.)

One of the residents, a child with congenital heart disease, was the daughter of an attorney. He was actively involved with the program at St. Rita's Home and was a member of the Board of Directors. He and Dr. Turkel became friends, and eventually he became Dr. Turkel's attorney. His relationship with the Home's staff may have created a problem when the time came to raise questions about the results of the double-blind study. This problem could not have been foreseen. Between December, 1961 and April, 1962, his daughter, like all the other children receiving the "U" Series, improved. There was no reason to question the integrity of the other investigators, the staff, or the proposed protocol for an NIH grant.

In accordance with the protocol outlined in the grant application, the children were to be measured and photographed several times before the study ended. X-rays were sent to Dr. Turkel on February 6, 1962. On February 10, 1962, the grant application was filed with the National Institutes of Health. His role as coinvestigator was to ascertain that all medications and supplements were correctly supplied. No changes in placebo or medication, or in their admistration were to be made without his express approval.

Dr. Turkel was disturbed by the problem that in this study the patients were scheduled to receive dosage levels established by age alone, with none of the adjustments that are generally required in treatment of genetic diseases. It is important, for example, to continue to adjust dosages of insulin in diabetes. While he is on a low-phenylalanine diet, the PKU patient's blood levels are carefully monitored. L-dopa was considered ineffective in double-blind studies, and was not accepted for treatment of Parkinson's disease until Dr. Cotzias carefully adjusted dosages for

each individual.[143]

The Double-Blind Study

Despite his qualms, Dr. Turkel shipped the "U" Series for the additional 14 children at the end of February 1962. The five-month supply of medication for the first 12 children inexplicably lasted less than three months. The double-blind study began in March or April, and additional medication and placebo were shipped in June, September, and December 1962.

On March 9, 1963, Sister Raphael Marie asked Dr. Turkel to return the "before" photographs of all 26 children so that they could be compared with the "after" photographs, already taken. He never again saw the before-treatment photographs. He was not given access to the "after" photographs, although he requested them not only at the meeting at St. Rita's in April 1963, where the benefits of the treatment were being celebrated in conjunction with a fund-raising event, but also at the 1967 FDA Hearing.

ST. RITA'S HOME FOR CHILDREN
2110 MILLERSPORT HIGHWAY PLAZA 0640 BUFFALO 21, NEW YORK

December 1, 1901

Dear Dr. Turkel

Briefly we should like to inform you that we are in receipt of the capsules and have started administering the medications as of this morning. Thank you for the drugs.

Please, say a prayer that it shall be beneficial to the youngsters. God love you and yours,

Sincerely yours,

Sister Raphael Marie, R.N.
Administrator

SRM:

[143]The Unshakable Man Who Doped Out L-Dopa; Med. World News 11:24 (Nov. 14) 1969.

Finally, June 24, 1977, at the trial of Marcom vs. Aetna Insurance, Dr. Bumbalo (testifying for Aetna) vehemently denied, not once but several times, that photographs had been taken. He explained that it was unnecessary to take photographs, because "mongoloids look alike." He then contradicted himself, explaining that there was a great deal of variation between Down syndrome patients. He did not repeat the information that some of the children at St. Rita's were mosaic, as he had reported during the 1967 FDA Hearing. Dr. Bumbalo testified that it was impossible to assign I.Q. scores to the children.

He reaffirmed that he had added vitamin D_2 and had omitted nasal spray. Dr. Turkel would not have objected to supplementation of water-soluble vitamins to both groups. Vitamins of the B-complex are coenzymes along various metabolic pathways. Vitamin C helps protect against virus infections to which Down syndrome children are particularly susceptible. However, Dr. Turkel would have objected most strenuously had he known about Dr. Bumbalo's alteration of the formulation of the "U" Series when he omitted routine use of the nasal spray and added vitamin D_2 (ergocalciferol). Dr. Turkel restricts D_2 because of its association with

ST. RITA'S HOME FOR CHILDREN

2110 MILLERSPORT HIGHWAY PLAZA 0640 BUFFALO 21, NEW YORK

March 9, 1963

Dear Dr. Turkel:

1st Ltr Rec'd 3/13/63

We would appreciate your forwarding the pictures taken of our children at the start of the research program. The Doctors have another set taken recently and they would like to compare and determine what changes there might be. May we have them as soon as possible, please, Doctor. You shall hear from us in the near future.

Please, remember us to Mrs. Turkel.

Sincerely yours,

Sister Raphael Marie

Sister Raphael Marie, R.N.
Administrator

soft-tissue calcifications.[144] [145] [146] [147] [149] [150] [151] [152] Vitamin D_2 is a vegetable source of the vitamin; in animals, vitamin D_3 is formed by the action of sunshine on the oils of the skin. If there is not enough sunshine, fish oil is a natural source. To prevent rickets in this latitude, supplements in the form of bone meal and fish oil were included in the placebos as well as the "U" Series.

Although many authorities on vitamin D metabolism consider the two forms identical in human metabolism, Dr. Turkel's many years of work with Down syndrome patients have convinced him that they metabolize vitamin D

[144]Hypercalcemia Caused by Vitamin D. Mod. Med. 38:126. 1970.

[145]Goodnight, F.: Vitamin D Excess seen Adding to Atherosclerosis Risk. Mod. Med. 16 (June 25) 1975.

[146]Villee, Claude A.: Biology. Seventh E. W.B. Saunders. Phil. 1977 p.441.

[147]Jukes, T.H.: Carcinogens in Food and the Delaney Clause. JAMA 241:617 (Feb. 9) 1979.

[149]Excess Vitamin D Damages Arteries. MWN (June 12) 1978.

[150]"D" for Dangerous. Med. News Trib. (Dec. 12) 1969.

[151]Strebel, et al.: Mechanisms of Tissue Calcification in Aging. Arch. Path. 81:563 (June) 1966.

[152]Fleishman, A., et al.: Vitamin D and Hypercholesterolemia in Adult Humans. In: Atherosclerosis - Proceedings of the Second Int. Symp. Ed: Jones, R. Springer-Verlag.

abnormally, as they do so many other substances. A similar difference in the metabolism of the two forms of the vitamin has been observed by Dr. Claus Christiansen of Copenhagen, Denmark (cf. page 158).

Had there been **no** improvement in the treated children, the before/after photographs would have been the best evidence of negative results. Therefore, Dr. Turkel considered the disappearance of the photographs proof that there were physical improvements in the treated children, improvements not seen in the controls, despite the procedural errors of the study.

The hope expressed by Dr. Bumbalo that educational services and good care could prevent the known decrease in I.Q. of Down syndrome patients has not been realized to date.

Studies conducted before the advent of infant stimulation and educational opportunities for Down syndrome patients have confirmed a constantly increasing discrepancy between mental development of normal children and Down syndrome children, indicating that the I.Q. of Down syndrome children declines as they grow older. During the past 20 years, many gains have been made in the training, nutritional and medical support of these retarded patients in the expectation that the decline would not occur. To test this hypothesis, I examined the records of patients. The sample was taken from the current group of trisomy 21 patients between the ages of 0-1 to 20-11. No one on the programs of the Institutes for the Achievement of Human Potential, the National Associationm of Child Development or on medical regimens such as the GTC Formula or Cell therapy was included.

Index cards, available on all patients, provided information regarding the ages of the children at the time of the first examination. The cards were grouped by their ages as follows: below 1 to 2-11; 3 to 5-11; 6 to 8-11; 9 to 11-11; 12 to 14-11; 15 to 17-11; 18 to 20-11.

In order to obtain a sample from each age group, one card was drawn from each group, and ages were rounded down to the last birthday. The cards were then mixed and every 25th card was selected, for a total of 14 cards. The records of these 14 children were then examined.

I used the Peabody Picture Vocabulary Test or the Vineland Adaptive Behavior Scale. The revised editions of these tests yield standard scores with a mean of 100 and a standard deviation of 15. The instructions provided in the Manuals for recording chronological ages were followed to obtain the standard scores. The method used by educational and social services, namely rounding down to the age at the patient's last birthday, was used for the correlation study.

The ages ranged from one to 19, and the scores ranged from 30 to 100, with a mean score of 58 and a standard deviation of 5.8. The Composite Adaptive Behavior score (Vineland Scale) of the youngest patient was 100. This score indicates no retardation in this patient at the age of one, in her communication, feeding, socialization, play, or motor skills. Patient 2 was also tested with the Vineland Scale, and obtained a score of 72, within the range of low-normal intelligence. Classification of mild mental retardation begins with I.Q. 70. Patients 3 obtained a score over 70 on the Peabody Picture Vocabulary Test, which tests passive knowledge of words. On the same test, Patient 4 obtained an I.Q. of 97. All older patients scored in the range of mental retardation. There is a significant negative correlation between age and score: the I.Q.s decline as the ages of the patients increase.

Pt.	Age	I.Q.
1	1	100
2	3	72
3	3	76
4	4	97
5	4	63
6	6	43
7	7	30
8	8	62
9	9	53
10	12	55
11	14	50
12	15	30
13	18	30
14	19	52

A sample of 14 patients is small. The population of persons with Down syndrome is estimated at 250,000 in the United States. However, the 209 current Down syndrome patients treated by Dr. Turkel are not entirely typical of all Down syndrome persons. They have parents who make a special effort on behalf of the children. None had been institutionalized, and all were enrolled in training programs appropriate to their ages. The fact that these well-cared-for children suffered the same types of decrements in I.Q. reported by Benda in his study of institutionalized Down syndrome patients suggests that training is not enough: medical intervention is a necessary component of treatment for the Down syndrome person.

The staff of St. Rita's also apparently misunderstood the significance of the abnormal stature/weight ratio in Down syndrome. Weight loss was misinterpreted as a negative result even though Down syndrome patients are plagued by the problem of obesity.[153]

In April 1963, the study was unexpectedly terminated. Less than ten months later, the

[153]Peuschel, S.M.: Obesity in Down Syndrome. Down's Syndrome News 8:47 (May) 1984.

"negative" results were published without photographs or other documentative evidence, in the the prestigious Journal of the American Medical Association and other publications (US and Canadian National Association for Retarded Children Newsletters). The development of the first six children who were treated for about 4 months was not considered. The diuretic was not used. Flushing caused by the niacin identified the treated children to the physicians and staff, so that the study was not truly double blind. "A few patients had flushing of the skin for about 20 minutes immediately after taking the medication."[154].

The unexpected bone development recorded by the radiologist was deleted from the JAMA publication. Weight loss may have been misinterpreted as being a negative effect. Obesity is a serious problem in Down syndrome. Since weights for Down syndrome children are all "likely to fall below the 5th percentile for nonretarded children," the values for $(weight/height)^2$ should be used to evaluate overweight in these children.[155] In Dr. Turkel's own patients, there is a high negative correlation between gain in height and weight, as the case of Evelyn (Chapter I) demonstrates.

Photographs vanished. Health records were not submitted, although one of the first benefits of treatment with the "U" Series is

[154]Bumbalo, T.S., et al.: Typescript. This sentence was edited out of the JAMA article. Prior to the conclusion of the double-blind study, Oliver Field of the AMA stated that a study was going on and the treatment was no good.

[155]Cronk, C.E., Chumlea, W.C., Roche, A.F.: Assessment of Overweight in Children with Trisomy 21. Am J. Ment. Def. 89:435-436 (Jan.) 1985.

improved general health. The study was prematurely terminated, even though Dr. Turkel offered to contribute the second year's medication. The protocol established in the NIH grant application was not followed. In 1967 and in 1977, contrary to the evidence of the protocol, Dr. Bumbalo testified that Dr. Turkel was not a coinvestigator and therefore was not entitled to review the raw data.

Dr. Turkel's role as coinvestigator was ignored after he shipped the medicines. He was not informed, in accordance with prior agreement, whether any of the children failed to benefit, so that he could adjust the dosage level. Although Dr. Bumbalo's typescript is ambiguous, dosage may have been reduced to prevent the niacin flush. Dr. Turkel was not given access to the data underlying the allegedly negative results. Charts that only summarized changes in height, weight, chest and head circumference were submitted. When the data were requested for analysis by an independent statistician, there was no response.

According to Dr. Bumbalo, the other coinvestigators were consulted during preparation of the typescript. However, one other coinvestigator was not a coauthor. Although Dr. Turkel's attorney was told that the psychologist did not want her name on the report, he was unwilling to question the religious staff. Dr. Turkel was not consulted prior to publication, was not listed as coauthor or coinvestigator, and learned about the article only from the Food and Drug Administration.

Incorrect information was apparently provided to the AMA with the manuscript. Wayne County Medical Society ordered Dr. Turkel to appear before its Ethics Committee in 1979. In its files, the medical society had the information that a child receiving the "U" Series had died. When I pointed out that Peter M----,

the deceased child, had not in fact been treated with the "U" Series although assigned to the treatment group, the chairman of the Ethics Committee countered, "Oh yes he was, my dear, but I'm not suggesting that the "U" Series caused his death."

It was originally agreed that Dr. Turkel would adjust dosages if the children failed to benefit. In a clinical study of the "U" Series, the starting dosage level is based on the patient's age or size. It then is increased gradually until clinical observation indicates that the proper dosage level has been reached for that particular stage of treatment. Supplements are added as needed. This method was used by Dr. Turkel to determine efficacy. The integrity of the double-blind study could have been maintained: dosages could have been adjusted for the children in the control group if they showed no improvement. Dr. Turkel was told that the Sisters "knew" which children were receiving the "U" Series because some were improving not only socially - both groups improved socially - but in many other ways, especially health. Evidently, the Sisters were able to distinguish one group from the other not only by the niacin, but also by the greater improvements seen in the treated children.

The Double-blind Method: Pro and Con

The advantage of the double-blind protocol is that neither the investigator nor the patient is influenced by the placebo effect inherent in any treatment. Some people will improve regardless of the active agent in a treatment, simply because they feel that something is being done to help them. The double-blind study determines the difference between the positive changes that can be attributed to the placebo effect and the changes that are due to the active agent. If the difference is not statistically significant, the result is said to

be negative. This "negative result" does not necessarily mean that there was no improvement attributable to the treatment, but rather that the difference had not reached the 95% level of significance. Because it helps sort out some of the changes that would have occurred even without treatment, the double- blind method is considered an important way to prove the efficacy of a new therapy.

Testing Dr. Roger Williams' genetotrophic theory in accordance with the double-blind protocol, Dr. Ruth Harrell and colleagues[156] reported benefits of megavitamin therapy for the mentally retarded in 1981. Down syndrome children were administered thyroid. In Down syndrome, the thyroid is almost invariably sluggish,[157] and the children are very obviously malnourished. In attempted replications that report negative results, it is clear that thyroid was not properly supplemented. One investigator, Dr. George Smith, objected to the rationale he was testing because it postulated a beneficial effect of a specific grouping of vitamins and minerals, not restricted to specific vitamin-dependent diseases, but for an almost unlimited number of pathological conditions.[158]

Dr. Turkel has proposed that an almost unlimited number of pathological conditions with an underlying genetic basis result in the accumulations of an unmetabolized substrate and/or a deficiency of products derived from

[156]Harrell, R.F., Capp, R.H., David, D.R., Peerless, J., Ravitz, L.R.: Op. Cit. 1981.

[157]Sluggish Thyroid in Down's Syndrome. Science News 123:74 (July 30) 1983.

[158]Smith, G. et al.: Failure of Vitamin/Mineral Supplementation in Down's Syndrome. Lancet. July 2, 1983. p. 14.

that substrate. Dr. Smith's knowledge of a limited number of vitamin-dependent diseases had not led him to an understanding of medical/ nutritional therapy. When the accumulations of a genetic disorder prevent entry of certain vitamins and minerals, enzymatic processes are impaired. In addition, there is generalized malnutrition because these accumulations take up space in the circulation as well as in tissues. Many nutrients, as well as thyroid, remove a variety of these accumulations. Dr. Turkel and Dr. Rimland cited these facts to explain why both the GTC Formula and the "U" Series are effective.[159] [160] [161] A replication that yielded negative results (the treated group attained a mean increase in IQ of 1.2, while the untreated group, the increase was 0.7. The difference between the groups was not significant at the .95 confidence level. However, the GTC Formula did improve the I.Q. of the single patient who was also receiving thyroid in that study.[162]

For any particular individual, optimal (orthomolecular) concentrations of substances normally present in the human body may require

[159]Rimland, B.: Vitamin/Mineral Supplementation for Mental Retardation. Lancet. Sept. 24, 1983, p. 744.

[160]Turkel, H.: Vitamin/Mineral Supplementation for Mental Retardation. Lancet. Sept. 24, 1983, p. 745.

[161]Rimland, B.: Vitamin/Mineral Supplementation for Down Syndrome. Lancet. Nov. 26, 1983.

[162]Ellman, George, Silverstein, C.I., Zingarelli, G., Schafer, E.W.P and Silverstein L.: Vitamin-Mineral Supplement Fails to Improve IQ of Mentally Retarded Young Adults. Am. Jrl. Ment. Def. 88:688-691 (May) 1984

megadose supplementation or, conversely, restricted intake. There is a good deal of misunderstanding about orthomolecular treatment. High-dosage vitamin self-treatment and misuse have been classified within this category.[163] Orthomolecular therapy, including the "U" Series, does not consist of random administration of megavitamins.[164] It safely reduces accumulations associated with genetic disorders. It addresses the problem of malnutrition caused by these deposits as well as by the lacking end products that are not available because of the enzymatic block.

Accurate observations and measurements made by those who treat the patient provide the best means of testing results because no two people react in exactly the same way to the same drug in the same dosage. This variation of response is particularly evident in chronic genetic conditions. Dr. F.M. Forrests has pointed out that "many authors have drawn premature conclusions from their experience with drug therapy administered in insufficient quantity and for too short a time."[165] Articles published in the journals of the AMA and the Wayne County Medical Society have stated that

[163]Rudman, D. and Williams, P.J.: Editorial - Megadose vitamins, Use and Misuse. N. Engl. J. Med. 309:488-489 (Aug. 25) 1983.

[164]Rimland, B.: High-Dosage Levels of certain vitamins. In: Hawkins, D. Pauling, L., eds. Orthomolecular Psychiatry: Treatment of Schizophrenia. W. H. Freeman & Co. San Francisco. 1973:513-539.

[165]Forrests, F.M., Geiter, C.W., Snow, H.L. Steinbach, M.: Maintenance Problems of Rehabilitated Mental Patients: The Current Drug Dosage "Merry-Go- Round". Am. Jrl. Psych. 121:33 (July) 1969.

many trials do not last long enough.[166] According to Dr. Sellers, editor of the Detroit Medical News (1967), "Each patient becomes a case of a particular disease or malfunction. He is not one of a series but a single entity and anything less than unique consideration of the whole man will be something less than adequate."[167]

Dr. Roger Williams has reported a large range of nutritional requirements between normal individuals: "There are no two people exactly alike. . . . None of us is wholly normal physiologically. We each have a biochemical individuality that is as distinct as the individuality of our appearance. . . . In a well-known study of 19 healthy young men, it was found that one of them required 222 mg. of calcium to keep his body store intact whereas another in the same group required 1018 mg. per day."[168]

Dr. A. Hoffer, who with Dr. O. Humphrey conducted the first double-blind studies of vitamins, criticized the double-blind method: "I have concluded that the double-blind method has many imperfections. . . It leads to a large number of serious errors. . . its main function is to make it easier for government agencies to turn down new drugs. The design assumes that the comparison groups will be equivalent, will

[166]Review of Clinical Studies Suggests that Many Trials Don't Last Long Enough. JAMA 238:107 (July 11) 1977.

[167]Sellers, C.: Individualization. Detroit Med News 59:6 (Nov. 6) 1967.

[168]Williams, R.J.: We Abnormal Normals. Nutrition Today 19:23 (Dec.) 1967.

be homogeneous, and will be invarient. . .[169]

Dr. Altschule has emphasized: "Double-blind experiments are based on the assumption that the experimental subjects form a completely homogeneous group; that the experimenter before he starts knows exactly what is to be studied; and that he knows without a doubt that the method he intends to use is perfect for its purpose. . . All experienced clinicians recognize that it is impossible to gather a group of patients who are completely homogeneous in regard to clinical status."[169]

An outspoken critic of FDA policy, Dr. Arthur M. Sackler, international publisher of the Medical Tribune, has stated, "In the past, physicians have considered it valid therapeutics to correct markedly deviant physiologic parameters. Then came the 'double blind' demand. And hundreds of thousands of unnecessary strokes, kidney damage, heart crippling and deaths became the price paid for the FDA's 'need for more proof' and conformity."[171]

The problem with this "need for more proof" is that the studies which propose to "replicate" work that initially suggests efficacy for a certain treatment often fail to follow the same protocol as the original study. Therefore, they may erroneously conclude that the treatment under investigation is not proved to be effective, when in fact it was the study that was in error.

[169]Hoffer, A.: The Double-Blind Method Examined. J. Ortho. Psych. 2:97 (1973).

[170]Altschule, M.D.: Non-Chromosomal Genetic Factors. Med. Sci. 17:50 (Oct.) 1966.

[171]Sackler, A.M.: One Man and Medicine: the Voice of Protest. Med. Trib. (Jan. 30) 1985. p. 32.

For example, when Dr. George Smith "repeated" the study of Dr. Harrell in testing the GTC Formula, he noticed that Dr. Harrell gave thyroid to all the children who seemed to need it (on the basis of their early morning underarm temperature readings. According to another replication, only the one patient who received the thyroid and the GTC Formula showed statistically significant improvement). Dr. Smith decided that since some of the control children as well as some of the GTC-treated children received thyroid, that he would give NONE of the children thyroid, as this was not one of the differentiating factors in the study. However, to replicate the Harrell protocol, he should have given the thyroid to the appropriately selected children in both groups.

Similarly, in a trial that "repeated" the study of vitamin C's effect in colorectal cancer by Linus Pauling and Dr. Ewan Cameron, the Mayo Clinic claimed to have followed the protocol that has yielded such good results during the past dozen years. Dr. Cameron gave his patients 10 grams of vitamin C daily, and the patients have continued to take it as life long therapy.

The patients studied at the Mayo Clinic received vitamin C for an average of 2-1/2 months, a range of one day to 15 months. None died while taking the vitamin C, but the benefits did not last beyond the treatment period. As a result, high doses of vitamin C were deemed ineffective by the Mayo Clinic, and the results were published in the New England Journal of Medicine on January 17, 1985. The New England Journal of Medicine did not mention the difference in the time span of treatment. Even more importantly, the New England Journal of Medicine article did not mention what every "health nut" knows: anyone who takes megadoses of vitamin C, risks rebound scurvy by sudden withdrawal. There is a drop in the concentration of vitamin C in the blood to

dangerously low levels. At this time the patient is at greater risk, according to Dr. Pauling.§§§ The Mayo Clinic's protocol of very high doses of vitamin C for a very short time may have endangered some of the patients. The Medical Tribune reported Dr. Pauling's objection that the Mayo Clinic's "analogy with chemotherapy reflected a profound misconception about the use of vitamin C with cancer."[172]

A. Hoffer, M.D., Ph.D., commented: "If the research is not an exact replication of the original research, its conclusions have no scientific value."[173] He pointed out that the Mayo Clinic study did not replicate the work of Drs. Pauling and Cameron, and that many other studies that supposedly replicate research deviate greatly from the original protocol.

He commented also on the failure of later investigators to reproduce exactly the use of whole dessicated thyroid to lower cholesterol levels and help protect women against a recurrence of breast cancer. Researchers who proposed to replicate the study treated women with thyroid extract, triiodothyronine, or thyroxine. They reported no protective effect. However, they failed to use dessicated thyroid.

Replying to criticism that the original research was anecdotal, Dr. Hoffer pointed out that "double blinds are merely experiments in which a number of anecdotes are shuffled into separate piles using modern technology."

§§§Press Release of January 26, 1985 from the Linus Pauling Institute of Science and Medicine, Palo Alto, CA.

[172]Horwitz, N.: Pauling calls Mayo Clinic Study "Fraud." Med. Trib. (Mar. 6) 1985.

[173]Hoffer, A.: Editorial: A Basic Flaw in Modern Medical Research. J. Orth. Psych. 14:82-84; Thyroid and Cancer 14:85-87; Summer 1985.

CHAPTER XII

Parents ask, "Why hasn't the Food and Drug Administration approved the "U" Series?"

Dr. Turkel has attempted to comply with FDA regulations for the past quarter century.

Down syndrome belongs to a group of disorders called "orphan diseases." It affects relatively few patients (approximately 250,000). Medications produced for rare diseases do not tempt pharmaceutical companies. The drugs developed to treat them are called "orphan products." The FDA is presently attempting to find sponsors for some orphan drugs (not for the "U" Series). It is not economically feasible for a private individual to sponsor a drug, and no pharmaceutical company has been found to sponsor a New Drug Application for the "U" Series.

In 1959, Dr. Turkel went to the FDA to request new drug approval for the "U" Series. At that time, the implications of the extra gene products of the recently discovered trisomy had not been considered by FDA officials. They dismissed the argument that the extra genes explained the presence of accumulations that the "U" Series was designed to reduce. They mistakenly concluded that since the "U" Series could not remove the chromosome, it could not help the patients.

Between 1959 and 1962, the FDA had no authority to delay approval of a safe new drug if properly labeled. It had no authority to require proof of efficacy; however, it could legally prevent a sponsor from labeling the product for efficacy. At the same time, it often denied approval to market safe medications for unlabeled indications. Under the law in effect before 1962, if it disputed efficacy, the FDA had no authority to prevent the marketing of a safe drug. In actual fact, it did so without Congressional authority by means of its control over labeling.

Dr. Turkel admits that he was a novice in politics. He believed that if a physician developed an efficacious treatment for a devastating and previously untreatable disease, that the Federal agency charged with consumer protection and health would provide assistance. Former FDA Commissioner Edwards likewise stated that the agency existed to promote the approval of beneficial products. It was obvious to Dr. Turkel that the "U" Series was beneficial. The actions of the FDA bewildered him.

Between 1959 and 1962, the FDA failed to advise Dr. Turkel how to comply with the existing requirements. The FDA did inform him that a drug company had to be the sponsor of the IND and NDA. To comply, Ubiotica Corporation was formed to sponsor the "U" Series.

The Kefauver-Harris Amendments, authorizing the FDA to require "proof of efficacy" before issuing new drug approval, were passed in 1962. It was not until 1963 that Dr. Turkel was advised by his attorney, also a novice in FDA matters, to file an Investigational New Drug (IND) and New Drug Application (NDA).

November 26, 1963, FDA Commissioner Larrick sent Dr. Turkel a telegram and letter informing him that the IND had been withdrawn and, furthermore, that the "U" Series "should" be withdrawn from investigators, and that treatment of human beings "should" be discontinued. Dr. Turkel thought that the Commissioner's directive that a physician "should" discontinue treatment with a certain medication constituted an order. The Food, Drug, and Cosmetic Act does not limit the mannner in which a physician may use an approved drug;[174] however, in accordance with the instructions in the telegram and letter, Dr.

[174]Development of Orphan Products. FDA Drug Bulletin 13:2-4 (April) 1983.

Turkel complied with Commissioner Larrick's order to stop treating all patients with the "U" Series.

Six months later, in reply to Senator McGovern's inquiry, Deputy Commissioner J.M. Harvey stated: "We know of no reason why Denece (page 57) could not be used as a study patient."

Surely the FDA would not suggest, following termination of the IND, that a human being could be used as a study patient if there were the slightest risk of harm to that patient. In fact, there is an apparent contradiction. According to the FDA, the IND had been terminated: there should have been no further investigational studies and no more study patients. When her treatment was eventually resumed in 1969, Denece was not a "study patient" but a private patient. During the 1967 Hearing, Dr. Turkel was told that "should stop" was not equivalent to "must stop."

Shortly after the IND was withdrawn, Dr. Turkel attempted to comply with the 1962 regulations. He did not know that they were so "stringent" that it cost millions of dollars for new drug approval (the average cost in 1984 was $87 million over a period of seven to ten years). Dr. Turkel met with the FDA and the pharmacologist of a private, FDA-approved animal-testing laboratory to prepare a protocol for animal studies.

Dr. Turkel expressed concern. He asked his attorney whether, having set up the protocol and approved it, the FDA might then later consider it inadequate. The legal opinion was "in the event such [studies and] amendments are accepted as suggested by the FDA, we do not contemplate that at any later date the FDA will take a position that said tests are insufficient for the purposes designated . . . In view of the fact that Dr. Goldenthal is the Chief of the Evaluation Section of the FDA, we assume that his representations are <u>official</u> and therefore

binding as representations of the FDA." (October 7, 1965)

It was unfortunate that Dr. Turkel's attorney was personally involved with the "U" Series therapy and not an expert in the Food and Drug Administration. As it turned out, Dr. Turkel's forebodings were more accurate than the legal assurances.

At the initial meeting, Dr. Goldenthal stated that the prime and sole purpose of animal testing was to have the drug characterized toxicologically, and that there was no need for an individual toxicity level to be determined for any of the independent ingredients, all of them FDA approved, contained in the "U" Series.

The protocol was set up February 9, 1966 by Mr. Davitt and Drs. D'Auguanno and Goldenthal of the FDA. They strongly suggested that only the active components, not the vitamins, minerals, or enzymes, were to be tested, to prevent dilution of possible toxic effect. The specific studies, including the numbers of animal used, and the time limits, were approved by the FDA. The study began.

September 16, 1966 the toxicologist, Dr. Robert Turner, documented his conclusions. No deaths in the subacute studies were attributed to the tested substances. At the highest dosage levels, which are intended to be lethal for half the animals (LD-50), the dogs tended to vomit before the lethal dosage level could be reached.

Mr. Davitt and Drs. D'Auguanno and Goldenthal were not among those who evaluated the results. Reviewing this report at the 1967 Hearing, Dr. Frances Kelsey of the FDA complained that the protocol was poorly designed. She stated that the protocol, which had been developed by her colleagues, was unsatisfactory, rendering the results "incomplete."

Replying to her objections, Dr. Turner pointed out that officials of the FDA had

recommended omission of the nutrients. "The officials of the FDA agreed that only by leaving out certain ingredients, could the effect of the pharmacologically active ingredients be demonstrated at higher dose-levels."

He cited the hundreds of papers in the literature reporting the pharmacological effects of the components of the "U" Series:

"In studying drugs such as those mentioned above which are well known, and about whose pharmacological effects there are hundreds of papers in the literature, fewer studies and fewer animals are needed than in studying a new molecule, about which there is nothing recorded in the scientific literature.

"There is one other point to be made regarding the studies: taken as a whole the studies show that the drug is generally non-toxic at doses higher than those intended for human beings. . . . According to my recollection, the five studies outlined are the ones which the FDA suggested in order to satisfy their requirements.

"I disagree with Dr. Kelsey in respect to her reply on Page 1584. The specific statement is, 'The information was too scanty to permit me to draw any conclusions.' I believe the information is not too scanty for any conclusions at all. . .

"I disagree with the statement that the information provided is not sufficient for interpretation. I believe one can be confident that the LD-50 of the mixture, which contains the pharmacologically active drugs found in the study of acute oral toxicity, proves safety. On Page 1601, line 17, it is stated that the series of studies is too small. The studies performed were those suggested at the meeting with the FDA officials." (Correspondence, Oct. 26, 1967)

Regardless of the outcome of studies, the FDA seemed unwilling to approve the "U" Series:

We think it will be difficult for Dr. Turkel to prepare a rational plan for the further distribution of the drug for investigational use.

(Smart, 1/23/63)

There is no basis for considering that the random, empirical and scientifically irrational choice of drugs and dosages contained in this NDA is either safe or effective in the management of Mongolism. It is our opinion that it may be impossible to write suitable labeling for efficacy for this product: in view of the cytogenetic basis of mongolism, we recommend that you abandon work on this application.

(Lockhart, 8/2/63)

It is extremely unlikely that this product will ever meet the stringent requirements of the Food, Drug and Cosmetic Act, as amended.

(Hodges, 12/12/66)

Common sense dictates that medication for the treatment of a serious disease should not be withheld solely for the above-cited reasons. Dr. Turkel explained the rationale of the components of the "U" Series, as discussed in a preceding chapter, and described the benefits observed in clinical studies. His attorney prepared the clinical reports as instructed by the FDA, and Dr. Turkel showed serial photographs and X-rays to FDA officials at their various meetings. The areas of improvements seen in most patients include: general health, skeletal growth, reduction of fluid retention in the face and body,

development of the nasal bridge with consequent reduction of epicanthal eye folds, widening of the palate, and, to some extent, educability. He knows now that this information should have been incorporated into the NDA, but at the time Dr. Turkel and his attorney were following the verbal instructions of the FDA. Although no reason has been given for the FDA's failure to assist a physician who sponsored a new drug, a partial explanation may be that, at the time, the FDA was being criticized for its failure to apply its "stringent requirements" to large drug companies. Physician-sponsored drugs were ready targets.

Regarding Dr. Lockhart's objection: the cytogenetic basis of the disease leads to the physiological, metabolic, and mental defects. In tissue culture, there is a delay and decrease in cell doubling of Down syndrome fibroblasts, and these cells are hyperresponsive to certain biochemicals attributed to trisomy 21.[175] The biochemical defects have been indicted as a possible cause of the disturbances in brain metabolism.[176] Alterations in structure and function result in mechanical as well as biochemical abnormalities. The "U" Series operates at the mechanical level by reducing fluid and other accumulations, and at the biochemical level by providing B-complex vitamins to act as coenzymes and, together with other nutrients, to saturate malnourished structures.

With further reference to metabolism in Down syndrome, the FDA has been particularly

[175]McSwigan, J.D. et al.: Down syndrome fibroblasts are hyperresponsive to B-adrenergic stimulations. Proc. Natl. Acad. Sci. USA 78:7670. 1981.

[176]Down's syndrome in Adults: Brain Metabolism. Sci. 22:781 (Aug. 19) 1983.

concerned about Dr. Turkel's use of rather small dosages of thyroid: 1 grain of Proloid and 25 mcg. of Cytomel for adults, 1/10 that dosage for infants. Despite negative findings in a double-blind study of T_3 without nutritional supplements,[177] Down syndrome children clearly benefit from thyroglobulin and cytomel provided in the "U" Series. Moreover, a study of the GTC Formula† demonstrated that the only patient whose I.Q. rose significantly was receiving thyroid supplements.[178]

According to an FDA memorandum, Dr. Turkel "does not run lab tests on thyroid functions [because he] believes that hypothyroidism is characteristic of Down's syndrome." Presently, reports of thyroxine (T_4), triiodothyronine (T_3), and thyroid stumulating hormone (TSH) levels are included in records sent before each patient's first examination. If indicated, the thyroid component of the "U" Series can be increased, reduced, or eliminated for a specific patient. Dr. Turkel is also aware that there is a strong relationship between Down syndrome and abnormalities of thyroid.[179] He believes that virtually all Down syndrome patients benefit from administration of small amounts of thyroid.

[177]Koch, R., Share, J., Graliker, B.: The effects of cytomel on young children with Down's syndrome (mongolism): a double-blind longitudinal study. J. Ped. 66:776-778. 1965.

†Pers. Correspondence, R. Harrell, Ph.D., June 14, 1985. In a letter referring Down syndrome patients to Dr. Turkel, Dr. Harrell mentioned that the GTC benefits epileptic patients.

[178]Ellman, et al.: Ment. Ret. News. 1984.

[179]Abassi, V. and Coleman, M.: A Preventive Medicine Report on Down's syndrome and Hypothyroidism. Down's syndrome Papers and Abstracts for Professionals. 7:2-2 (April) 1984.

Dr. Turkel interprets the unusual appearance (densities) of the Down syndrome skull in X-rays as indication that the bones are thin and that the brain has accumulations of dispersed calcifications as well as fats and fluids. The same FDA memorandum claims that this interpretation of the "white" or dense areas of skull X-rays is incorrect:

"It was pointed out that what he was referring to as brain tissue in the skull x-rays was in fact bone, since the white areas in x-rays represent density, and density in this case meant bone."

Post-mortem examination shows that the skull bones of Down syndrome patients are thin and that the brain contains abnormal amounts of fluids, fats, and calcium. Work with Alzheimer's patients demonstrated that "The frequency of CTT-detected BGC [basal ganglia calcification] in 100 post-mortem DS brains was 11% whereas the histologically detected rate was 100%."[180] It is logical to assume, as Dr. Turkel does, that the X-ray shows what is really there: thin bones and brain calcification.[181]

The FDA denied New Drug Approval for the "U" Series in 1959 because the agency claimed that Dr. Turkel had not demonstrated efficacy, although the law then in effect did not require pre-marketing proof of efficacy. Dr. Turkel had submitted serial photographs and X-rays of patients, including Evelyn and Judy, to prove efficacy. Since 1962, the agency has criticized the animal studies, the use of thyroid, Dr. Turkel's interpretation of X-rays, and the medication's inability to alter the chromosome.

[180]Sinet, P.M.: Alzheimer's Disease, Down's Syndrome and Aging. Ed. E.M. Sinex, C.R. Merril. Ann. NY Ac. Sci 396. 1982.

[181]Benda, C.E.: Mongolism and Cretinism. Grune & Stratton. New York. 1949.

In many other countries, including England, Canada, South Africa, Switzerland, and particularly Japan, where the "U" Series has been used at 80 hospitals since 1964 and has been imported from Europe since 1981, and in Norway, where the treatment has been accepted as alternative therapy, also since 1981, the needs of patients have been given priority over bureaucratic requirements. Even in Russia, according to a Science Digest article of 1972, Down syndrome patients are treated with a combination similar to the "U" Series.

The FDA denies that the agency has created a drug lag. Dr. Halberstam introduced his critique of the FDA-induced drug lag as follows: "Verapamil, nifedipine, practolol, amiodarone, ajmaline, perhexilene, and etmozin -- how marvelous and mysterious they sound, somehow like frankincense and myrrh. . .

"The striking thing about the unavailable drugs on this list is the fact that, as presented by the experts, they are important drugs, crucial drugs, drugs for which we have few, if any counterparts."[182] They had saved thousands of lives abroad. Similar examples were presented by Dr. Nancy Mattison in her analysis of the current drug lag,[183] and in articles that appear constantly in medical journals.[184]

As early as the 1960's, the editor of the Detroit Medical News was reminding doctors about individual differences between all human

[182]Halberstam, M.J.: Editorial - Who's lagging now? Modern Medicine (Sept. 15-30) 1978.

[183]Mattison, N.: Drip, Drip, Drip... Private Practice (Sept.) 1984.

[184]FDA nixes plan to market synthetic growth hormone despite physicians pleas. Med. World News 25:6-9 (Oct. 8) 1984.

beings.[185] What is more safe or more efficacious for one patient may be useless or dangerous for another. The drug law, as interpreted by the FDA, fails to consider the total health picture. The drug lag is real.

While creating a drug lag, regulatory agencies were, at the same time, lax in the removal of unsafe products from the market. For example, during the years before the oral polio vaccine was approved for use in the United States, manufacturers marketed combination vaccines against polio, diphtheria, tetanus, and whooping cough (pertussis). Quadrigen was one such DPT-plus-polio vaccine.

The risks associated with the DPT vaccine are due to the pertussis component. The pertussis vaccine was important when it was developed. Before development of the vaccine and antibiotics, the annual death toll from whooping cough was about 7,000 patients. Presently it is 5-20 from the disease while approximately 20-25 children per year are permanently brain damaged by the vaccine. However, Dr. Robert Mendelsohn has pointed out that the character of whooping cough has changed. It is no longer a killer disease, and the vaccine may not be entitled to all the credit for the lower death toll.

To lessen the risks associated with immunizations, Dr. Turkel advises that his patients be given high dosages of vitamin C during the week before vaccination,[186] and, as with my own first child, to reduce the dosage level and to increase the time span for immunization. Children with certain disorders, including severe allergies, should not be vaccinated against whooping cough.

[185]Sellers, C.: Detroit Med. News. Op. Cit. 1967. cf. § 45.

[186]Turkel, H.: Vitamin C and Immunization. Medical Tribune (Feb. 9) 1983.

The risks of the 4-in-1 vaccine greatly exceeded possible benefits. According to records in the case of a child severely damaged by Quadrigen, inclusion of the Salk polio vaccine appeared to weaken the effectiveness of the whooping cough component, but it reactivated in some children and caused brain damage. Scottie was one of these children.

Scottie was born prematurely June 4, 1961. Although he weighed only 3 pounds 3 1/2 ounces, he did remarkably well. At 4 days, he was taking all bottle feedings without difficulty. He was out of the incubator at 3 weeks. July 1, 1961, he was released from the hospital. His development for 4 months was normal, including head control, focusing, and reaching.

When he was 4 months old, he was given his first Quadrigen shot. He had a mild seizure and high fever. A month later, he was given the second Quadrigen shot. He went into "infantile spasms." By the time he was 9 months old, the prognosis was poor. At 16 months, his motor development was at the 6-month level. According to his medical report, six months later, he was still functioning at the six-month level:

> The child gained well and went home after 27 days and apparently developed fairly normally until about four months of age. Following his series of DPT and polio shots, his condition apparently deteriorated, and he began to have seizures at six months of age...from the pertussis component of the DPT vaccine.

Parents of injured children in advocacy groups such as "Dissatisfied Parents Together" are questioning, among other things, whether the pertussis component of the 3-in-1 DPT shots is responsible for some portion of infants dying from Sudden Infant Death Syndrome (SIDS).

Critics of the DPT vaccine estimate that as many as 2,500 children are injured and as many as 100 children die each year as a result of the pertussis component.

Another drug that was mislabeled for many years was Chloromycetin. Its primary indication is treatment of rickettsial and other serious diseases that fail to respond to less potent antibiotics. For many years, it was prescribed for relatively minor ailments because the manufacturer failed to inform doctors that inappropriate use could lead to fatal aplastic anemia. The FDA lagged in its duty to require accurate labeling. People died needlessly.*

Thalidomide was the drug that led to passage of the efficacy requirements in 1962. A tranquilizer, it was recommended for use during early pregnancy to relieve nausea. The dangerous effects of thalidomide on the fetus were discovered in Europe. The hazards of a drug to a fetus should restrict its use to patients who are not liable to become pregnant (this precaution should limit the use of Accutane, an acne medication). The FDA should not deny valuable therapy to other patients who may need it.

It would be appropriate to permit patients for whom the benefits exceed the risks to have access to thalidomide to prevent skin-graft

*See also: Herxheimer, A., Immortality for Old Drugs? Lancet 1460-1461 (June 30) 1984. The article recommends that product approval be renewed, as in Norway. and that "regulatory authority must take direct responsibility for bringing its recommendations promptly and clearly to the attention of all prescribers, backing them up with the relevant information."

rejections in burn therapy;[187] [188] [189] and to lupus erythematosus, a crippling disease,[190] treat lepromatous leprosy,[191] [192] [193] chronic and "Behcet's syndrome, characterized by painful and persistent ulcers on the mouth and genitals." Nevertheless, thalidomide "never was marketed in the United States because the Food and Drug Administration refused to approve it."[194] Animal studies prior to 1959 could not have demonstrated the various benefits of the drug in the treatment of diseases like Bechet's syndrome,[195] but also could not have demonstrated its hazards when taken by humans during early pregnancy.

[187]Effects of Thalidomide offset by Vitamin B in Experiment. Med. Trib. (Oct. 18) 1973.

[188]Thalidomide a Life Saver, U.K. Researchers Suggest. Drug New Weekly (Jan. 31) 1966.

[189]Other Aspects of Thalidomide. Med. Trib. (Oct. 25) 1965.

[190]Another Aspect of Thalidomide. Med. Trib. (May 5) 1976.

[191]Yoder, Leo J.: Leprosy: AFP:25 (Feb.) 1983.

[192]Nielsen I. and Bennike, T: Thalidomide Enhances Defective Monocyte Function in Lepromatous Leprosy. Lancet 98 (July) 1984.

[193]Br. J. Dermatol. 108:461. 1983.

[194]Thalidomide being used to treat syndrome in England. Am. Med. News. Oct. 21, 1983. p. 15.

[195]Feagen, O.T.: Bechet's Disease: the Ochnsner Experience, 1979 to 1982. Southern Med. Jrl. 77:442-446 (April) 1984.

It was certainly not necessary for Congress to authorize the FDA to require "proof of efficacy" for all drugs because of the thalidomide tragedy. Either of two actions was possible: the FDA could have required the relabeling of thalidomide to prevent its use during pregnancy, as is commonly done with many other drugs. Alternatively, it could have denied New Drug Approval for thalidomide and other teratogenic drugs that were likely to be taken during pregnancy, and thereby deny other patients any possible benefits of those specific drugs without also denying all patients the use of drugs that manufacturers could not economically subject to the new requirements.

By rewarding the FDA for banning drugs, while criticizing the agency for approving them, and at the same time giving the agency the right to determine efficacy, Congress and the American people sent a powerful message: hold off on drug approval. If a drug is unsafe, certainly its efficacy should be determined before it goes on the market. This is what is meant by the "risk versus benefit" test. An unsafe drug for which the benefits cannot be established fails the test. A safe but ineffective drug that replaces an effective treatment may also fail the test, because it leads to greater risks for the patients. However, if there is no "orthodox" effective treatment for a disease, and the alternative is safe, then there is no risk: only possible benefit. It is under these conditions that the "U" Series was accepted as alternative therapy in Norway.

Bonine and other over-the-counter drugs may cause birth defects. They, too, may be incorrectly used during pregnancy. I was told by a pharmacist that Bonine was the "same thing" as Dramamine. Yet, Bonine, which requires no prescription and which can readily be taken by pregnant women who want relief from motion sickness, can also cause birth defects. In his

1972 New Hope book and elsewhere,[196] Dr, Turkel has enumerated many similar arbitrary, harmful FDA decisions.

No one wants to compromise safety standards or to introduce ineffective therapy. The FDA should review new drugs, new combinations, new generic formulations that differ from the originally approved drugs, and new indications. However, manufacturers do not sponsor drugs like the "U" Series that cannot be protected by patent rights unless there is a financial advantage to the company and its stockholders. The new orphan drug laws are somewhat less stringent, requiring one (rather than at least two) double-blind studies. If no commercial sponsor can be found, however, it would be appropriate for the FDA to try to find a sponsor.

It would also be appropriate for the National Institutes of Health, with their large staff and facilities, to run a study. In the case of the "U" Series, the NIH stated that they had been unable to find a single investigator to study the "U" Series between 1960 and 1975. They have not found one to date. The irony of this situation is that if Dr. Turkel had challenged the FDA's 1959 threat of prosecution for marketing a misbranded product, the "U" Series might have been commercially available prior to the 1962 regulations. At that point, clinical studies could have been prepared, as in Norway, prior to approval. The "U" Series is safe, and it would have been the government's responsibility to prove lack of efficacy, much more difficult than turning down NDAs. However, Dr. Turkel was too conscientious to market the product over the FDA's objections, and by 1962 it was too late.

[196]Turkel, H.: Controlled Clinical Trials Denounced. N. Engl. J. Med. 287:83 (Oct. 19) 1972.

The "U" Series is not indicated for women who may become pregnant. Therefore, the risk to the fetus is not a relevant issue. The targeted patient population has no other available therapy. The disease can be devastating to the individual, family, and society in terms of emotional and economic costs.§ The components of the "U" Series are each individually approved by the FDA. The combinations are well known. The "U" Series has been used for Down syndrome for 40 years without any serious adverse effects. Clinical results demonstrate the benefits.

§ Twenty-five years later, there is still a great deal of pessimism about the potential of the child with Down syndrome and the high costs associated with raising one. In Phillips v. United States (575 F.Supp. 1309, 1983), the U.S. District Court of South Carolina held that the plaintiffs, parents of a child with Down syndrome and the child himself, were entitled to damages for the child's "wrongful birth." This particular child attained an a mental age of 2-3 years at the chronological age of 4.4, for an I.Q. of 56 on the Stanford-Binet, placing him at the lower level of mild mental retardation. It was predicted that his mental age was never expected to exceed 7 years, and that he would not ever be able to take care of himself. It was anticipated that he would require around-the-clock care and attention for life, with a life expectancy of approximately 50 years. In addition to 24-hour lifelong care, he was expected to require "physical therapy, hearing and speech therapy, extensive medical services including ongoing pediatric, ENT, orthopedic, neurological, ophthalmological and dental care, as well as frequent medication and periodic hospitalization." The excess costs of raising the child were calculated at $1,283,765. An additional sum of $249,500 was awarded for mental anguish and emotional distress.

The FDA's prejudice was revealed in 1967 at an FDA Hearing requested by Dr. Turkel's attorney, who was convinced that the safety and efficacy of the "U" Series had been fully documented at conventions and in the literature. His attorney believed that any further documentation required could be given to the FDA at the Hearing. Only later did it become clear that the question at the Hearing was not whether the "U" Series was safe and effective but whether the New Drug Application was complete.

The clinical reports, if incomplete, were prepared by Dr. Turkel's attorney in accordance with the verbal instructions given by the FDA. According to Dr. Turkel's attorney, the FDA rejected the inclusion of specific patient information. The FDA did not inform Dr. Turkel what would constitute a complete Application.

After a lengthy Hearing in Washington, the Hearing Examiner, an FDA employee, ruled that the NDA was incomplete. This ruling was appealed to the Sixth Circuit Court of Appeals. Dr. Turkel was expecting a favorable decision.

Instead, the Court cited the double-blind study conducted by Dr. Bumbalo, the allegedly incomplete animal studies, and the evidence of Dr. John Nestor, identified as "a specialist in pediatrics, cardiology, and treatment of mongoloids." It was Dr. Nestor's opinion that Down syndrome patients cannot be treated for that condition. In specific evaluations of Dr. Nestor's comments, the Court made no reference to responses elicited during cross examination. The Commissioner of the FDA knew that Dr. Nestor denied approval of virtually all new drugs.

At the Hearing, Dr. Turkel outlined the basis of treatment with the "U" Series:

> While genetically-based inborn errors of metabolism are present within the embryonic cells, the appearance of the inborn structural, chemical, and

functional anomalies may take place any time during the life of the individual. . . In the event a partial or a whole chromosome is present in an excessive amount, as in mongolism, then the many thousands of additional enzymes will metabolize certain specific metabolites into the next [metabolic] stage, but since the consecutive stage enzymes are present in a normal amount, those excessive metabolites will remain unmetabolized. Though present in minute amounts, the total quantity rapidly blocks the various transport systems.

> Individually these metabolites do not reach above the range of normal values in the fluids, but totally they interfere with tissues, and cause developmental problems sooner in life than do single gene defects.

These developmental problems constituted the anomalies of Down syndrome. Dr. Nestor himself referred to the inborn anomalies of mongolism as including "congenital heart disease, strabismus, hernia, little finger of the hand, of the pelvis, of the hair, of the skin, of the muscles. . . yes, brain, too." (Hearing Transcript. p. 1331, August 15, 1967).

Yet, replying to a question of the Hearing Examiner, "So we are very clear here, Doctor, at the time you evaluated this NDA originally that the inborn anomalies of the body referred to the chromosomal abnormalities in the context of the paragraph," Dr. Nestor testified, while reading from the NDA:

> "Granting that there is no cure for mongolism or of the many other inborn

errors of metabolism, the goal of medical treatment is not to correct the abnormal chromosomal pattern, but to alter the various inborn anomalies of body organs and tissues so that they become as near normal in structure and function as is possible within the present limits of medicine."

Well, that is the way I - I think the only way I can interpret it. The word chromosomal pattern is in here and we talked about anomalies and inborn anomalies. What else can he be referring to but the basic defect in mongolism?

After mulling over Dr. Turkel's statement that at the present time is is impossible to alter the chromosomal pattern, he testified that the preceding sentence proved that the "U" Series was intended to alter the chromosomal pattern because Dr. Turkel used the phrase, chromosomal pattern.

Dr. Nestor's bias against the "U" Series was shared by others at the agency. April 4, 1968, he testified:

"The first I was really involved with [the "U" Series] was when I was asked to help prepare for this Hearing. And whether I knew about it - I probably vaguely heard about the "U" Series, some quack treatment for mongolism that people talk about."

This testimony from a physician who was considered dogmatic, a nit-picker, and one who made poor medical judgments, according to his own colleagues,[197] remained unchallenged by Judge Combs of the Sixth Circuit Court. He is

[197] Commissioner's Report. (Oct.) 1975.

the judge who had previously denied Dr. Turkel the right to an FDA Hearing: Dr. Turkel had to appeal to the Supreme Court. The Supreme Court approved a Hearing. When the result of the Hearing was appealed, the case was returned to Judge Combs. Shortly after deciding against the "U" Series, he resigned. Dr. Turkel feels strongly that Judge Combs should have disqualified himself and permitted another of the nine judges to hear his case. The Hearing Examiner even denied Dr. Turkel the right to see the records, memoranda, and work products of the FDA with respect to the "U" Series. Executive privilege was cited to deny his access to these records.

During this period, I became educational specialist at Dr. Turkel's clinic. I had been teaching at the high school and college levels for eight years before transferring to a private elementary school near my home. For the first time, developmentally disabled children were in my classes. It soon become apparent that some of the youngsters in the "slow track" had been misdiagnosed by the group intelligence tests administered by the faculty. Some of the children were immature, had short attention spans, or were unable, for one or another reason, to learn how to read. The children in this last group could comprehend spoken language but could not decode the printed word. Some of these were referred to a reading clinic using the Doman-Delacato program.

When I began to work with the "mongoloid" patients in 1967, it seemed that these children, almost uniformly stereotyped as severely retarded, were also misdiagnosed. Parents in those days were routinely advised to institutionalize their handicapped children. Dr. Turkel was improving their general health, physical structures, and function. It was important to determine whether and how much their intellectual abilities were improving.

At that time, little effort was made to educate them. Only a few pioneers, among them Doctors Glenn and Robert Doman and Carl Delacato, were actively attempting to improve the Down syndrome child's mental ability.[198] Their work was based on the insights of Dr. Temple Fay, professor of neurosurgery at Temple University School of Medicine. Glenn Doman was influenced by Dr. Fay during the early 1940's. Shortly after World War II, Glenn Doman, Carl Delacato, a specialist in education, and Glenn's brother, Robert J. Doman, M.D., collaborated in the development of successful programs for the brain injured. Their methods, originally developed during 1956 and 1957, had the goal of establishing "in brain-injured children the developmental stages observed in normal children."[199]

The Doman-Delacato treatment has benefited retarded children, including those with Down syndrome, as well as those with brain injuries and specific learning disabilities. Dr. Turkel familiarized himself with the program and visited the Institutes for the Achievement of Human Potential in Philadelphia. The application of this method to Down syndrome and many other conditions has since been perfected by Dr. Robert J. Doman and his son, Robert J. Doman, Jr., at the National Association of Child Development.

198 "Controversy: The Institutes and Patterning." Children Limited. NARC. April 1968. p.4.

199 Doman, R.J., Spitz, E.B., Zucman, E., Delacato, C.H., and Doman, G.: Children with Severe Brain Injuries: Neurological Organization in Terms of Mobility. JAMA 174:257-262 (Sept. 17) 1960.

In 1968, Dr. Turkel received a license to treat Down syndrome patients in Lugano, Switzerland. He had heard that the FDA Commissioner had proposed earlier approval for drugs used in another country. Therefore, he was determined to introduce the "U" Series to European physicians. Although he was away from his American office for half the year, spending six weeks at a time abroad, he was able to treat more patients than ever before because of the FDA's affirmative response to the question, "May Dr. Turkel treat Down syndrome patients in Michigan with the "U" Series?"

This clinic became an informal resource center, directing parents to appropriate agencies. Dr. Turkel received many honors during the decade, 1969-1979, most notably from the Japanese in 1974, and from the World Organization of Human Potential in 1975.

The burden shifted to the parents. There was a long waiting list. Instead of scheduling one patient a day, he examined two or three the same day. He gave the parents the background information. While he examined one child, I made a social or mental age determination of another, and the third went to the radiology clinic.

A system for answering monthly reports was established. Medical emergencies were handled by the child's own physician. Medical questions related to the "U" Series were referred to Dr. Turkel, and parents could receive a reply within two weeks. Questions related to behavior, socialization, and education were answered directly from the office.

February 1974, Dr. Turkel scheduled four patients: Alan, Gino, Brad, and Dale. Their parents became the catalyst for the new parents' advocacy group, US for DS. In October of 1974, Alan's mother organized a conference at Columbus (Georgia) College. Three months later, Dale's mother, Arline Burman, scheduled a conference in

Los Angeles. US for DS was incorporated in 1975. Later that year, the organization proposed to publish the first revision of Dr. Turkel's book.

The publication of UPDATE: New Hope for the Mentally Retarded was celebrated in Los Angeles on June 29, 1976, coinciding with Dr. Turkel's 73rd birthay. That edition found its way to Norway, where Mrs. Phyllis Nyquist organized a group of parents of Down syndrome patients. The mother of a Down syndrome son and a native of Michigan, she was determined that her son, and all Down syndrome children in Norway, would be treated by their own doctors. Case reports from the 1980 edition of New Hope were published in a Norwegian magazine, aiding parental efforts.[200] After Dr. Turkel lectured in Norway to practicing physicians, medical school professors, and Health Department officials, as well as to parents, her organization convinced the Norwegian Health Department to accept the "U" Series as an "alternative" treatment for Down syndrome.

At least 40 physicians are treating 60 or more patients in Scandinavian countries. Furthermore, the entire "U" Series is now used in Japan. Eventually, it may be possible to submit foreign data under regulations for rare (orphan) diseases.

While the FDA's right to require safety or approve labeling is not questioned, if saccharin can remain on the market with precautionary labeling, surely safe medical therapies can also be appropriately labeled and marketed. If subsequent clinical experience demonstrates that a safe drug is ineffective for its recommended use, doctors will not prescribe it, and drug companies will not market it.

[200]Series. "Nytt hap for mongoloide" Vi og Vart - Helse & Miljo. Oslo, Norway, Pori, Finland.

THE "DOMAN-DELACATO" METHOD AS MODIFIED FOR THE DOWN'S SYNDROME PATIENT

by Robert J. Doman, M.D.

Four children in every thousand births, forty in every ten thousand, four hundred in every hundred thousand, such are the numbers of children born with Down's Syndrome.

J. Langdon Down identified as "mongoloids" this group of individuals in 1866, and, tragically, up until recently that identification has significantly if not dramatically limited the opportunities of these labeled children, and thus has limited their potentials.

Today's child with Down's Syndrome CANNOT be understood in historic perspective. These children were identified as a group in 1866; the chromosomal abnormalities which produces their similarities was not known until the late 1950's. Most were denied access to the public educational system until the 1970's. They were given space in the nation's institutions. The cause is still not known.

As I write this article I am looking at a gift I received last Christmas: "Some of my Life Experiences" by Daniel and Mom. Daniel's little picture history portrays a child with a "normal" child's growth. Daniel's life is not like, does not relate to the old studies or textbooks. In none of Daniel's pictures is he wearing an institutional smock, is he pictured in the foreground of an abnormal environment, nor does he wear a scowl, nor is he obese, nor is his mouth hanging open, nor are his shoulders hunched.

He is cute, he is smiling, he is walking, he is standing straight, he is reading, he is home, he is loved, and he is being given an opportunity to develop. Daniel is no more like that Mongoloid child in 1866 than I am, but the world still thinks it can make a prognosis for his future based upon the poor institutionalized child, or the child who has been placed in limiting environments.

Most children being born today with Down's Syndrome are being condemned because they are being viewed in historical perspective. The prognosis for a child with Down's Syndrome today cannot be based on history for there is no relevant history.

In the past twenty years significant discoveries have been made and significant changes have occurred, but unfortunately most of the world is still ignorant of the possibilities which exist for today's child with Down's Syndrome. Most new parents are being told to expect limited development and are encouraged to place the infant in "special" environments, to plan on "special" classrooms, and to look toward Sheltered Workshops. To many parents this "special" world planned for their child looks good if one were to view Down's Syndrome in historic perspective. It is not if viewed from the perspective of the 80's with all the opportunities available to change the child. Do we concentrate on changing the world, expanding "special" abnormal environments, or do we change the child, help the child develop, help the child fit into the "normal" world, provide th child with an opportunity to make it?

In the early 70's I had the opportunity to work simultaneously as Clinical Director of a United Cerebral Palsy agency, which treated children with problems, including Down's Syndrome, from birth to adulthood, and to serve as the Clinical Director of a state-supported private special school, directing the educational and therapeutic programs and to serve as Director of the Doman Developmental Academys which consisted of three preschools which enrolled "gifted," "normal," and "special needs" children, including children with Down's Syndrome. The opportunity of working with the full range of Down's children from the model infant stimulation program at U.C.P. to

the preschool programs at the Academy, to the school age children within the school, and the young adults involved in U.C.P. permitted me to discover what they could do if given the chance.

I recall walking into one of the preschools and being greeted by a cute little 2-year-old child with Down's Syndrome in French, "Bonjour." Shelly then proceeded to demonstrate her reading ability with her first grade reader, and her special interest in math, where she was just learning how to borrow. I was discovering that most of these children that the state had labeled as "trainable" not only were educable, but if given the opportunity could surpass their "normal" peers.

What does it mean to provide a child with the opportunity to live, learn, and interact in a normal environment, the opportunity to receive individual treatment to aid in physical, perceptual, respiratory, and intellectual development? Opportunity means indivdually designed and administered academic programs. Opportunity means expectation for and feedback to produce appropriate social development. Opportunity means not being limited by limited expectations. The only appropriate short- or long-term goal for a child with Down's Syndrome should be to provide the child with as much as possible so that he may develop as well as possible.

The NACD Therapeutic Philosophy

The National Association for Child Development utilizes a therapeutic philosophy, as opposed to a therapeutic regimen. Accepting that each and every child is different, and thus has different needs, we apply a philosophy of treatment which results in a therapeutic program that varies significantly from child to child.

The philosophy, as well as some specific techniques as implemented by NACD, is based upon the "Doman-Delacato" program. This modification has been developed through the efforts of Robert J. Doman, Jr., Robert J. Doman, M.D., and the parents of many brain-injured children.

The treatment philosophy is based upon the acceptance of the concept of the plasticity and redundancy of the central nervous system, as well as the branching effect of the system which can be accelerated through specific stimulation, and motivation. It is further believed that function provides a means by which the level of organization of the central nervous system may be evaluated, and that the organization of the system follows an orderly sequence.

Through the utilization of a developmental profile, which measures a child's function in the receptive areas of visual, auditory, and tactile competence, and the expressive areas of mobility, language, and manual competence, it is possible to determine the child's level of function as it relates to his overall neurological organization. With this information it is then possible to design a treatment regime which provides specific stimulation to those levels of the brain which require further organization, in an effort to obtain full neurological organization.

Development of and movement through functional levels of the central nervous system is achieved through the application of appropriate stimuli which are delivered with sufficient frequency, intensity, and duration. The goal of such treatment is to accelerate the individual's rate of development, so as to assist him or her in achieving the highest functional potential.

Basic to the concepts of neurological organization are factors that include the premise that specific stimulation can accelerate the rate of development. Our understanding of

the plasticity of the central nervous system, and specifically the brain, implies a system that is capable of achieving normal function even with significant damage to the brain. The brain develops (becomes organized) as the result of an increase in the connections between the brain cells, and the increase in connections is a direct response of the brain stimulation. The brain, however, responds in different ways to particular stimuli. In this respect the brain is rather specific, in that at different levels of development the brain requires different forms of specific stimuli. Our growth in respect to the development of our program has been primarily in our learning more about the specific stimuli which have the greatest effect upon the brain at its various stages of development.

Affirmation of the Parent

NACD has in a few short years established itself as an organization that is doing the right thing at the right time. The NACD concept is an affirmation of the role of the parent and the family, and the potential that exists in our children, that can be realized only through the assumption by the parents of an active role in the development of their children. Since the very beginnings of the public education system, the parent has asked, "What can you do for my child; what can the system do so that I need assume a less active role in my child's development?" The advent of a host of government services even beyond the public education system has only increased the problem. The government and the institutions cannot meet the basic developmental needs of our children; they can only supplement the efforts of the parent and the family.

The schools and government services take on a whole new perspective if viewed as adjuncts or supplements to the family, and not as the entity with the primary responsibility.

Parents have finally come to realize that no one is going to do the job for them, and to quote the old axiom: "If you want something done right, do it yourself." The schools, the government, the institutions, the professionals, cannot assume the responsibility of the parent, and unfortunately, the more they try, the worse job they do. NACD as an organization has been built upon a base of parents who have assumed the responsibility for their children, and who are seeking knowledge so that they might better assist their children.

A Parents' Organization

The concepts of the National Association for Child Development are family and community oriented. All of our efforts and instructional methods are directed toward involvement and education of the family, so that they may take a more active role in the child's development and assume the responsibility that belongs to them.

NACD attempts to meet these needs through a unified effort of both family and staff. The NACD staff is employed by the parents involved in its programs; they exist to assist the parents in their efforts with their children. Historically there has been a strong delineation between the professional and the parent. The professionals have been encouraged to take the place of parents, and many parents have further encouraged this trend. NACD is based upon the premise that the parents know and understand their children better than anyone else, including the professionals. With assistance, the parents can gain the expertise and knowledge they need to assist their children in achieving their full potential. NACD is therefore first and foremost an organization of parents, as the Board of Directors is composed almost entirely of the parents of children on home programs. Each of the various branch directors is the parent of a child or children on one of our

programs, and the staff itself is comprised primarily of parents of children on these programs.

The future of our children is far too important for parents to continue to abrogate responsibility for their full development from birth to adulthood.

Philosophy Behind Commitment to the NACD Program

NACD is striving to assist in the development of all children through the example set by a few. Each family who enters into an NACD program bears a responsibility which transcends even the responsibility for their own children, for each child in the program is a model for thousands of other similar children. For every hundred children we treat, we affect thousands by example. The number of children we can directly work with is limited, but the effect of those we do work with is unlimited. In that, we require a strong commitment from each family involved, for without this commitment, no family can do its child or the program justice.

Commitment becomes a necessary part of the family's involvement with the child on his or her NACD program. The following commitments are critical to the success of the child on that program:

1. Assuming an active role in the child's neurological, educational, and social development. This commitment includes acceptance of responsibilities. Time and energy must be given by the family both in working directly with the child, and with the schools, clubs, and organizations with which the child is associated.

2. Supervising the child in his or her daily activity program. The child's daily program must be given priority by the family, and a commitment made to see that the program is carried out consistently.

3. Attendance at every scheduled revisit. Updating programs is vital. An outdated program is of little value and it may even be a negative influence toward the child's total development.

4. Regular communication with the child's Program Coordinator. Communication is essential for assuring the continuity of the program.

5. Ongoing parent education: the better the parent's understanding of the various aspects of child development and child management, the better the ability to successfully carry out their home program.

The "Special" Environment

Historically and traditionally, Down's children have been placed into Trainable Mentally Retarded (TMR) classes, and provided with the very minimum of what could be a truly developing educational atmosphere. Most research indicates that Down's children who stay in the home and who have been exposed to normal environmental stimuli function at a much higher level than those placed in a special educational environment. It only takes one visit to the TMR classroom for an individual to realize the extreme limitations placed upon the Down's children by a TMR environment. It is an unnatural atmosphere where the children are usually treated as if they are inferior human beings, whether the classroom be for 5-year-olds, 10-year-olds, or 20-year-olds. They are habitually viewed as incapable and subnormal, and they receive "instruction and therapy" on a level that corresponds to this unnecessary and incorrect train of thought.

One of the traditional characteristics attributed to Down's Syndrome is the inability of the child to learn to read, and poor retention of information. As with most other prophecies, this tends to become a self-fulfilling prophecy in that most Down's children are traditionally denied the opportunity to

learn how to read, write, and do simple mathematics. The TMR classroom instruction serves to perpetuate the restricted opportunities and environment found in these suppressed children. The Down's child often "progresses" from the TMR environment into one that is labeled as a "sheltered workshop," which in reality is usually a dead end for the mentally retarded.

It is an extremely sobering experience looking at these children and adults shuffling around, doing the most menial of tasks. One views them in the light of knowing that they have been categorized, labeled, severely limited in their opportunities, and as a result, they are quite possibly doomed to spend their lives in the atmosphere of one of these sheltered workshops, and/or a state institution.

What to do with the Down's Child

Without question, one of the most significant aspects of instruction for these children is to keep them in a normal environment. This often means excluding them from the so-called special education programs, and the social organizations for special children which actually only serve to further isolate and stigmatize them. We attempt to either place them in a normal school situation, or to keep them out of a formal school environment. We utilize schools only when we can also utilize normal environments. To assist in the child's social development, we lean more towards the structured and organized systems, such as the church groups, the normal learning environment, and the swimming, music, and gymnastic programs. It is also vital to have structured play activities within the home that will enable the child to interact with family members and friends.

Treatment of the Down's Child

In terms of specific treatment, we treat the Down's child much in the same way as the brain-injured child or the normal child on an accelerated learning program. It is preferable to begin working with the child as quickly as possible after birth. We at the NACD have been fortunate in that we have begun instruction with some children as young as one month of age. The basic program utilized for the children is that of evaluating function, determining neurological organization, and then providing them with an environmental program of stimulation and opportunity to assist the child on a step-by-step basis through the developmental stages.

Characteristics of the Down's Child

The range of function found in Down's children is extremely broad. One cannot really make any generalized statements that are applicable to these children, as they only serve to stifle and hinder their developmental growth.

Some of the more common characteristics found in the children are hypotonicity and problems associated with the mouth, and breathing. The children tend to breathe through the open mouth with the result that the tongue protrudes and thickens, and proper development of the entire mouth area is stifled (function determines structure), which in turn hinders proper articulation. This also affects the depth of their respiration, which therefore impedes the normal oxygen flow to the brain. Since they are not breathing through the nose, the sinus cavity does not properly develop, which appears eveident in their facial structure. Some of the specific areas of remediation are therefore the usage and control of the mouth and nose.

For the most part, we are talking about a developmental program of specific stimulation delivered with necessary frequency, intensity,

and duration. Again, each program is designed for the individual child, as various Down's children may have program needs that are very dissimilar.

Involvement in Academic Programs.

We also get the children in academic programs at as an early an age as possible. If we can anticipate a problem that is likely to occur in the future, if at all possible, we can provide the child with a learning or therapeutic environment that hopefully gets the child started on the right foot, thereby possibly eliminating the future problem. We begin with language-related activities, mathematics, and reading programs at a very early age. The training for these programs often begins a few months after birth.

Working with the Down's Child

In many ways the Down's child is a delight to instruct. They are always interesting, not only because of the children themselves, who often exhibit much higher learning capabilities than thought to be possible, but also because of their families. Sometimes, however, there are problems with the parents of Down's children.

Because Down's Syndrome was one of the first identified and categorized child-related problems with a definite loss of function, the classification and stigmatization of Down's is perhaps greater than any other category of child disability. The Down's child has become so stereotyped that even the families tend to fall back to the expectations of that stereotype. In that respect, they are difficult families to work with in many cases. Without question one of the basic requirements for a family is to contribute the time and energy necessary for a comprehensive rehabilitation program. The family must possess the necessary strength and hopes that their child can obtain higher degrees

of function, and they must be able to sift through society's constant barrage of negative opinions that the child will always lack normal functions and abilities. What could possibly be more damaging to a Down's child's developmental growth than a family unit who behaved as if there were no hope possible?

To recapitulate, the program we utilize is one that takes the child through the developmental steps providing an optimum environment in which the child can hope to realize his full potential. Many of the children we work with also utilize medical approaches to the problem, which in many cases prove to be a real adjunct to the program.

The Brain-Injured Down's Child

Because a child is Down's, this does not exclude him from having other problems in addition. As we know, the Down's child often has many medical complications, among them cardiac problems. Also, some Down's children are brain injured as well. Since they are brain injured in addition to having chromosomal abnormalities, this sometimes complicates the issue to a certain extent. We need to utilize a medical-neurological approach to these children in addition to the basic therapeutic approach. As with any brain-injured child, it is necessary that they receive a full neurological evaluation to determine if there is the need for any medical intervention, whether it be various drugs or surgical procedures. Ignoring the fact that a Down's child is brain injured would mean that chances for success would be very minimal, if not impossible.

Referring back to the treatment of the Down's child, oftentimes it was found that they experienced cardiovascular difficulties, indicating that the young child would often require heart surgery and usually recommendation for limited physical activity. We have discovered

on many occasions that after involving a child in the comprehensive program of rehabilitation and neurological organization, it was found that after a few years on the program that their cardiac problems had diminished to such an extent that surgery was no longer indicated.

How NACD Works

Parents of a Down's Syndrome child interested in possibly having their child on NACD's program should call the National Headquarters in Redlands, California, (714) 798-3028. At that number, Robert Doman, M.D. will answer any questions they might have. If the parents decide to have their child on the program, an appointment will be arranged, usually within a three-month period. The child will be scheduled to be seen at the nearest branch to his home where initial evaluations are done.

The parents will first be required to listen to a 6-hour set of cassette orientation tapes and to complete an accompanying outline book prior to the initial examination. If the family must travel any appreciable distance to the branch city for the evaluation, it is often best for them to plan to arrive the night before. This will allow the child and the parents to arrive fresh for the evaluation. They should expect the evaluation to take about three hours. They may want to bring a snack. They must bring the completed history form as well as any other available records or tests previously completed on the child.

The evaluation consists of several parts, including standardized testing in math, word recognition, and reading comprehension. Next, an important evaluation is made of the child's functional neurological level of performance to detect any neurological inefficiencies in areas of vision, hearing, touch, movement, speech, and hand functions. The results of such testing are

recorded on a Developmental Profile. The parents are asked about the child's behavior, eating and sleeping habits, etc. If the child is able to cooperate, tests are given to determine if he learns better visually or by hearing information. After evaluating the child, the Director holds a conference with the parents to review the history and to inform the parents of NACD's findings. The Director asks the parents how much time each day they feel at that point in their lives they can spend on their child's program, realizing their responsibilities to their other children, etc. The parents then decide for themselves how much time they will spend each day on NACD's program. If they say 4 hours a day, the Director will plan a 4-hour program; if they say they can only spend 1 hour, he will plan a 1-hour program. The average program for a Down's child is about 2 hours a day.

After the parents have made that decision. utilizing the results of the evaluation the Director will then write up a program individualized to the child's needs. Finally, the parents will be shown exactly how to do each part of the program. They will be given a duplicate copy of the evaluation and the program. They will then go home and gradually, as they are able, put the program into action. If problems or questions develop, they can obtain answers by calling their local branch or calling Dr. Doman at the Redlands office.

The child is reevaluated, using the same testing procedures, every 3 months as needed. On each reevaluation, the program will be changed as indicated by the new evaluation, and the parents will be shown the new program. If, for some reason, the family is unable to attend a scheduled reevaluation, they may arrange through the Redlands office for an alternative Phone Conference with that office, often done by Dr. Doman.

Aspects of Medical Treatment

Dr. Henry Turkel has devised treatments ("U" Series drugs) that can reduce in most children the anatomical, mental, and physical abnormalities characteristic of the Down's Syndrome child.

Previously, studies on medical treatment were few and far between; this was mainly due to the resistance of such treatment by the U.S. Food and Drug Administration officials. In spite of this, several medical treatments are now available, directed towards the maturation of retarded organs and tissues. Dr. Turkel's "U" Series drugs operate to remove or reduce unmetabolized metabolites and unexcreted waste products that interfere with normal development. The effectiveness of the treatment with the "U" Series drugs has been objectively demonstrated and followed by observation of the gradual dissolution of the metabolic accumulation in Down's Syndrome, and with this, the synergistic and accelerated development of retarded structures and functions toward normality.

Features of Success

It's extremely difficult, if not impossible, to determine which factors have contributed to the success and achievements of a patient. A number of children who are concurrently on our developmental programs and Dr. Turkel's "U" Series are progressing at a very acceptable rate. To what extent we can attribute that success to our program, Dr. Turkel, or the family atmosphere is undecipherable. Everyone is delighted with the child's progress, and it is immaterial to state that "this was the reason for his progress" so long as the progress exists. In many cases, however, Dr. Turkel's regime has been of definite value in assisting the child's physical growth and development. This provides the NACD with a child who can much more readily utilize the input that we provide with our developmental programs.

TREATMENT OF DOWN'S SYNDROME

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Preface:

The treatment of Down's syndrome is something like a challenge against hopelessness. A quarter of a century has elapsed since my first contact with handicapped children with Down's syndrome and their parents. My interest was aroused by a seemingly naive yet mysterious question raised by my beloved Professor, Dr. Takuma - why babies of similar aspect are born of different parents, without regard to boundaries of country or race - a question which would require profound study to answer. It is well known that Down's syndrome is caused by an abnormality of a chromosome, but to ponder the question of the real mechanism - why it has taken place - is still to grope in the dark. The medical community is still not only unable to discuss a treatment of the patient, but also to give any response to the parents, who are even to this day suffering deeply.

The subject of this paper, "Treatment of Down's Syndrome," is a taboo in pediatrics that I have been challenging with tenacity. Once more I wish to mention treatment and my thoughts on it.

Treatment and cure:

Generally, speaking, the treatment of a disease is aimed at its cure; but in fact, treatment is being given to a patient who is not expected to be cured by it at all, and it is rather regarded as the ethics of medicine. Is it why it is is said that there is almost no treatment for those patients with Down's syndrome? It is true at the present stage that no one can expect a cure for patients with Down's syndrome from the bio-medical point of view. Who can assert, however, that there is no benefit at all, when a man of common sense actually sees the status of those patients and the feelings of their parents?

When I think of the meaning of the treatment for a patient who is not expected to be cured at all, it has to do with the presence of a spirit or mind inherent in the practice of medicine. The doctor whose purposes are to treat a disease has a duty to devote himself to the cure of the patient. If a doctor takes an attitude toward the patient, from the beginning, that there is no treatment at all, or he will not provide any treatment at all, it is indeed too contrary to clinical medical practice. It is regretful that such an attitude, contrary to the ethics of the medical profession, prevails in the daily practice of clinical pediatrics.

Upon further consideration, however, I come to a question as to what is the cure for a patient with Down's syndrome. Strictly speaking, the cure would be to have the abnormal 21 trisomy returned back to the normal chromosomal pair. But no matter how far surgery for chromosomes may progress, it would be hopeless at present to expect it to materialize in the near future. The only treatment under present circumstances is the volition to make those abnormalities generated by the abnormal trisomy closer to normal conditions, even a bit, and this is the very treatment for patients with Down's syndrome, I believe.

All of those treatments which have been given so far in the USA and Europe fall under this category, and almost all of them are a symptomatic treatment. It is all right if all of medical knowlege is concentrated so as to have the body of a patient develop in a normal status, even a bit, or to have the retarded mental development improved even slightly, or to have the resistance to infection become higher than usual.

It means hopelessness if we become so pessimistic that we do nothing, without any treatment at all. While a treatment is continued even for a cancer patient who is going to die without any expectation for recovery, though it may be with resignation to destiny, it can be said without any hesitation how inhumane and how deviated from the medical principle it is that a doctor declares there is no treatment at all for a newborn patient with Down's syndrome - even though it is due to a genetic abnormal trisomy. I feel that treatment should be extended to those patients with Down's syndrome at this present stage, so that it may give a final hope to the parents whose dream it is that someday a medical therapy for Down's syndrome can be put in reality.

2. Treatments:

The treatments of Down's syndrome vary according to the age of the patients. For those baby or infant patients up to 4 - 5 years old, the treatment is mainly done by medications in the medical controls. For those patients who have entered primary school, a special education and training are required. With regard to the special education and training, I have already written another paper about it, so let me discuss here the former, namely the treatment by medications.

(1) Hormone therapy:

a. Thyroid hormone

b. Pituitary gland hormone

c. Thymus extracts
d. Adrenal gland extracts
e. Ovary or testicle extracts
f. Sicca-Cell medicine (Haubold, 1956)

(2) Vitamin therapy:
Vitamin A, D, E, B1 and B2, Nicotinamide, Pantothenic Acid, Calcium, Vitamin B6 and C.

(3) Massive treatment with glutamic acid.

(4) Other special therapies:
Low oxygen therapy, cranial surgery to remove cerebellar pressure by Rosner, and fresh cell therapy (Niehans).

Treatment with "MD" Series and its results:

There are many therapies with medications for Down's syndrome as mentioned above, but with regard to its effect, there has not been seen any firm therapy or treatment that has an established effect so far. It was in 1961 when Dr. H. Turkel announced at the 2nd International Congress on Mental Retardation held in Vienna about the effectiveness of the "U" Series (Table 1) as a result of his treatment of 100 D.S. patients for more than 10 years.

I have treated many D.S. patients with the "MD" Series, which are similarly formulated to the "U" Series in Japan, and the results obtained from these treatments have been announced previously.* Since then, the treatment with the "MD" Series has been continued with more patients than before, and it now gives a relief, though slightly, to those patients and their parents who have been accepted, as they are without any other treatments except for insufficient special education or training. In fact, as a result of the treatment, I have seen many of those mothers and patients or their families who once thought to die together at an early stage of the initial consultation and who made up her mind to devote her efforts for continuation of the treatment for patients. They came with bright eyes from the second

consultation, as if they were different mothers from the inital consultation. It is at that time when I used to feel indeed a great deal of relief, enough to sweep out my bitter experiences in my long devotion to Down's syndrome, with a feeling as if I were able to save at least two lives, of a mother and a patient. The very reason why I have been unable to contribute to anything in the medical circle up to this date would be because I have been intoxicated with happiness at seeing a mother's or patient's pleasure.

Back to the subject: It is very difficult for us to determine if the "MD" Series are really effective for those patients with D.S., or not. The most decisive factor to determine whether those abnormalities of D.S. are returned to those of normal conditions is, of course, to see the normalization of the chromosome. But that is absulutely impossible at present. Under the circumstances, I have taken the Iliac Index as a factor to determine the effectiveness rather than uncertain factors such as improvements in the patient's delicate or poor health or retarded mental development.

According to my investigation on the effectiveness by limiting the factor only to the Iliac Index, there were many patients who showed an improvement closer to normal value (80) as listed in Table 2. However, the relationship between the improvement and the period for treatment, or the fact whether the patient actually took the "MD" Series was not known. I cannot, really, it is impossible to say, of course, only with the improvement in one factor such as the Iliac Index, that those heavily handicapped patients were cured. There is as yet no method to exclude the changes in the natural development of patients by age, and thus and an unable to conclude prematurely that there was an improvement.

What I would like to say here is only that there have been more than 3,000 patients who have received the treatment with "MD" Series so far, and that these patient have been growing without passing away, ["the rate of death of the children's Down's syndrome up to the adolescence age used to be about 90% and it was regarded as an unavoidable destiny to these children because there was no proper method of treatment. Fortunately, however, only two patients among those belong to the Chigusa-Kai have passed away during these 8 years" - Dr. A. Tomoda, 1974], with the exception of a very few, and that I am meeting some of them every Friday at my hospital as an actual evidence.

I am also actually seeing those patients who are very much pleased with their own growth and healthy development, even though still retarded physically and mentally compared with normal children. It is an actual situation of the patients and their parents, and I think that is the effectiveness of the "MD" Series, rather than several hundreds of medical statistics and test results. I admit myself that there will be criticism for such an attitude, that it is not scientific. However, I would like to know what the scientific criteria are, to determine the cure of Down's syndrome. There would certainly be a weakness in the current treatment for Down's syndrome from the scientific point of view. However, it is humane to prevent a possible family suicide, which may occur when a patient is diagnosed firmly as Down's syndrome, by encouraging the family that there is a treatment even though it may not be scientific, and giving the family an intention to live with hope. It is my belief that the essence of medicine is to devote one's utmost effort for treatment of the hopeless Down's syndrome patient, and it would not be a right thing to dispute merely on the assessment of the treatment in disregarding the whole situation.

Of course, it is not my intention to deny the scientific mind. In short, I believe it would be essential for us to provide the treatment which is believed to be the best for the survival of heavily handicapped patients without questioning its effectivenss only, until a day comes in the future when all anomalous chromosomes can be cured as soon as a baby is born.

Dr. Turkel explained improvement of his patients by showing the changes in the face and body shape before and after the treatment with his "U" Series, through the photos of patients. However, I cannot agree with him immediately that there was an improvement with only such changes.

I have also taken photos of the faces of my patients at the time of my initial examination and after the first six months, and many of them have been filed at my office. Some examples are shown in Fig. 1 As you can see from these 11 examples, I can understand there were changes as patients grow. I cannot say with these changes alone that these patients are getting an improvement throught the treatment, but it can be said that I was unable to get such remarkable photos of D.S. patients as time elapses if they were are allowed to grow up without any treatment. Apart from an assertion whether it shows "no change" or to be in the direction toward improvements, I can say it is an actual evidence that these patients are changing gradually even though a little bit while they are living. It may be called a natural curing.

How "MD" Series are given to patients:

I have already mentioned several times previously about the "MD" Series, but there may be those doctors who are interested in the medication and yet do not know how it is obtainable for treatment. Therefore, let me explain here about the background history of its origin and how to obtain.

It was about 10 years ago when I showed the prescription of "U" Series to the Drug Department of my hospital (National Kohnodai Hospital) and at that time they told me that it was unable to formulate the medications. I was very much embarrassed, but fortunately Dai Ichi Yakuhin K.K. (President: Mr. A. Fukazawa) extended their cooperation for formulation, and the medicines were obtained on condition that they are used exclusively at my hospital. This was the medication now called the "MD" Series. Since then, my hospital has been issuing the prescription to the patients as an outside prescription (fig. 2), to be formulated by a specified pharmacy, Kaiun Pharmacy (Tokyo). Those patients who wish to be treated are able to obtain the medications from the pharmacy. At present, there is the only one pharmacy that can formulate "MD" Series in Japan.

If a doctor in a local community diagnoses a patient with Down's syndrome and wishes to treat with the "MD" Series, he can prepare a prescription for the Kaium Pharmacy to fill. If the patient lives in a remote community, it may be done by mail. The Kobato-Kai (Parents Association of Down's Syndrome Children in Japan) is taking care of receiving the medications, its mailing, etc., for those patients who are members of the Association, and live in a remote community, though they were diagnosed at my hospital.

From an ideal point of view, the medications of the "MD" Series would become available anywhere, when the patient with Down's syndrome wishes to be treated, as in the case of general drugs. While a groundless health drug is rather freely available on the market through an advertising campaign by a famous talent, the "MD" Series, which is to be said the only nutritive medications for Down's syndrome, are not available freely, under a stubborn regulation, resulting in the fact that there are many

patients who have not shared in the benefit of the medications. I dare say that it is truly a crazy situation. I have to say here that it is indeed sad to see the current situation.

Summary:

How should a clinical doctor handle the matter if a degenerative mutation of a human being called Down's syndrome, because of the trisomy 21, is considered "uncurable" even with the best of modern medicines? What are the reasons why there is no doctor at all who is willing to challenge Down's syndrome, whereas there are many doctors who are devoting themselves to study a cure or work on research for "incurable" cancers or senilities?

It would be because a great deal of effort is required and yet the reward is small, or because there are many other subjects which are attractive to those who are concerned. The reason why I am challenging Down's syndrome, which is one of the most difficult problems to solve, as a hopeless disease, is because I believe there is a treatment for children with Down's syndrome and their parents, in one way or another - even if there is nothing to do for the cure of the syndrome itself - whereby I can give a longer life to these handicapped children and their families in a healthier condition even a bit, who are visiting our hospital in succession for consultation. It is also my belief I may be able to take repose in peace if I could guide these children and parents to a condition or state where they can feel a pleasure to live even a bit and a recognition of the destiny.

Bibliography:

1. Benda, C.E.: The Child with Mongolism
2. Kurita, T.: Clinical Medicine for Down's syndrome and its Limitation. "Nichi-I Shinpo"
No. 2378, Nov. 22, 1969.

* preceding Japanese articles

COMPARISON WITH JAPANESE RESULTS

A constantly increasing discrepancy between mental development of normal children and Down syndrome children indicates that the I.Q. of Down syndrome children declines as they grow older. To determine whether this decline has occurred in children prior to "U" Series treatment, I examined the records of patients. The sample was taken from our current group of trisomy 21 patients between the ages of 0-1 to 20-11. No one on the programs of the Institutes for the Achievement of Human Potential, the National Association of Child Development happened to be in the sample, nor were those on medical treatments, such as the GTC Formula or cell therapy.

Index cards, available on all patients, provided information about the ages of the children at the time of the first examination. The cards were grouped by their ages as follows: below 1 to 2-11; 3 to 5-11; 6 to 8-11; 9 to 11-11; 12 to 14-11; 15 to 17-11; 18 to 20-11. One card was drawn from each group, and ages were rounded down to the last birthday. The cards were then mixed and every 25th card was selected, for a total of 14 cards. The records of these 14 children were then examined.

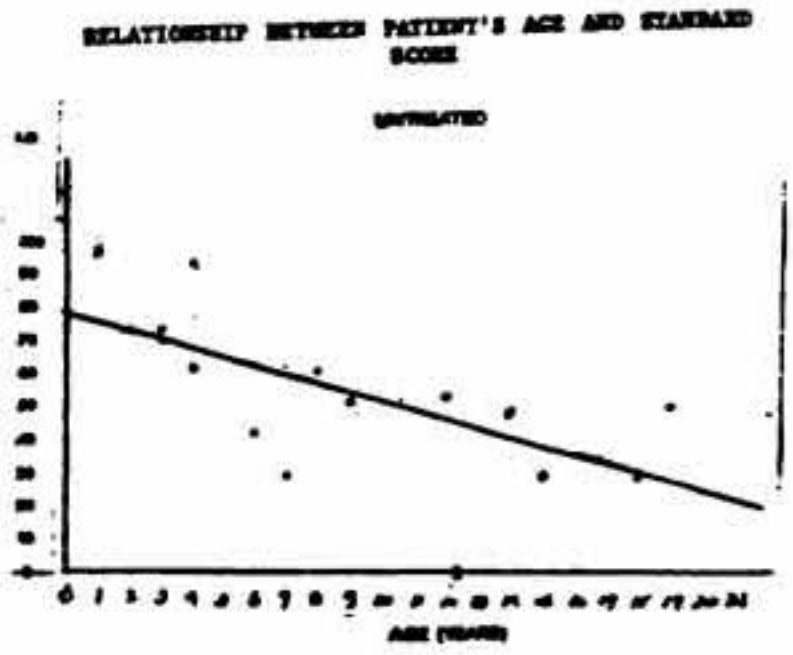
I use the Peabody Picture Vocabulary Test or the Vineland Social Maturity or Adaptive Behavior Scale. The instructions provided in the test manuals for recording chronological ages were followed to obtain the scores. The method used by educational and social services, namely rounding down to the age at the patient's last birthday, was used for the correlation study.

The ages ranged from one to 19, and the scores ranged from 30 to 100, with a mean score of 58. The Composite Adaptive Behavior score (Vineland Scale) of the youngest patient was 100. This score indicates no retardation in the

patient at the age of one, in her communication, feeding, socialization, play, or motor skills. Patient 2 was also tested with the Vineland Adaptive Behavior Scale, and obtained a score of 72, within the range of low-normal intelligence. Classification of mild mental retardation begins with I.Q. 70. Patients 3 and 4 obtained a score over 70 on the Peabody Picture Vocabulary Test, which tests passive knowledge of words. All older patients scored in the range of mental retardation. There is a significant negative correlation between age and score: the I.Q.s decline as the ages of the patients increase.

TABLE 1

Pt.	Age	I.Q.
1	1	100
2	3	72
3	3	76
4	4	97
5	4	63
6	6	43
7	7	30
8	8	62
9	9	53
10	12	55
11	14	50
12	15	30
13	18	30
14	19	52



A sample of 14 patients is small. The population of persons with Down syndrome is estimated at 250,000 in the United States. However, these patients are not entirely typical of all Down syndrome persons. They have parents who make a special effort on behalf of the children. None has been institutionalized, and all are enrolled in training programs appropriate to their ages. The fact that these well-cared-for children suffer the same types of decrements in I.Q. reported by Benda in his study of institutionalized Down syndrome patients 20-35 years ago suggests that training is not enough: medical intervention is a necessary component of treatment for the Down syndrome person.

Investigations with nutritional/medical therapy in Japan (modified "U" Series) have indicated that such treatment prevents the decline. I have examined the records of 31 patients treated in our office, in order to determine whether the "U" Series has prevented the decline in our patients. The results support the claim that this treatment can prevent the decline in most patients, particularly the older patients: the mean I.Q. remained stable during the year of treatment.

Japanese doctors have used Dr. Turkel's "U" Series in slightly modified form since 1964, at 60 - 80 hospitals, to treat thousands of Down syndrome children. They have reported, through the years, that virtually all children improve in general health, that approximately two-thirds improve in skeletal growth, structure (appearance) and physical function, and that approximately one-third improve in mental function while almost none decline. I wanted to find out whether: 1) the I.Q. scores of treated patients do not decline with advancing age; 2) the I.Q. scores of treated patients improve; and 3) our results are similar to the results in Japan.

In 1969, Dr. Makoto Iida of the Japanese National Institute of Mental Health and Dr. Ichiko Kurita of the Department of Pediatrics, National Hospital in Monodae, Japan, reported the effect of a modified "U" Series treatment on the mental function of 31 male and 21 female Down syndrome patients over a one-to-two year period, concluding that 45% of the males and 76% of the females did show improvement in mental function, with greater improvement evident in children over the age of 2. The mean scores rose from 53 before treatment to 55 after 2 years of treatment. These results were compared with the scores of seven children who refused to take the treatment. In the latter group, the scores decreased. The assessment scale was the Infant Mental Development Questionnaire (Tsmori and Inage), with a parent as respondent. A subsequent study by Dr. Atsushi Tomoda of the Takasago City Hospital Neurological Section reported the following results in 21 children treated over a two-year period: 8 scores improved significantly (more than 10 points); 11 did not change; 2 decreased.

In my study, the patient's names (total number: 209) were placed on index cards and mixed. Every seventh card was selected; the rest were replaced. If the selected patient had not been reexamined, the card was removed and the selection process continued. A sample of 31 patients was selected. The scores of the patients at the time of the first and second examinations were recorded.

The Peabody scores are listed without further identification. The Vineland Social Maturity Scores are identified as SQ scores. The composite score of the revised Vineland scale is identified as V-ABC. These three scales tend to result in higher scores, in our Down syndrome patients, than the scores of the Wechsler or Stanford-Binet scales. Possibly, they also result in higher scores than the Japanese interview scale.

TABLE 2

pt.	months	score 1	score 2	difference
1.	38	SQ 110	SQ 98	-12
2	5	100	89	-11
3.	9	100	84	-16
4.	190	39	51	12
5.	52	63	85	22
6.	19	SQ 94	SQ 91	- 3
7.	187	60	69	9
8.	91	50	80	30
9.	52	45	74	29
10.	63	65	60	- 5
11.	169	45	64	19
12.	59	81	78	-3
13.	39	70	75	5
14.	108	76	68	- 8
15.	38	70	69	- 1
16.	93	65	81	16
17.	152	38	48	10
18.	162	26	26	0
19.	70	26	28	2
20.	9	SQ 56	SQ 36	20
21.	189	19	16	- 3
22.	29	SQ 90	V-ABC 72	-18
23.	45	76	70	- 6
24.	50	97	108	11
25.	73	30	30	0
26.	105	62	63	1
27.	110	75	53	-22
28.	170	50	53	3
29.	227	30	30	0
30.	239	52	52	0
31.	146	55	61	+ 6
Mean age: 8 years. mean score		61.77	63.29	
median age: 6-1				

In the Japanese study, the increase in the 30 improved scores ranged from +2 to +24, while the the decrease of scores of the children who

failed to improved ranged from -1 to -18. The increase was considered significant if it exceeded ten points. In the Japanese study, a further adjustment was made in order to take into account the decline in IQ scores of untreated Down syndrome children. As a result of this adjustment, the conclusion was that the "U" Series improved the mental function of the Down syndrome child.

Our sample of 31 Down syndrome patients yielded similar results. Our patients' scores and the scores of the Japanese children were both in the range of mild mental retardation. The Japanese concluded that patients below the age of two did not improve sufficiently. Similarly, the youngest of Dr. Turkel's patients experienced a decline in their social quotients.

In view of this finding, parents may question the rationale of early treatment. The rationale is that the scores decline less than with untreated children, as demonstrated here and in Japan, while the health and appearance of the child improve dramatically. At the same time, enrollment in the program of the National Association for Child Development is highly recommended.

Fourteen patients obtained higher scores, four showed no change. The mean score of the retest was equal to, and in fact was slightly higher than, the original mean score. While the improvement was not statistically significant, the decline of the IQ score associated with the Down syndrome patient's advancing age is a well-known phenomenon. This overall decline, that occurs even in untreated Down syndrome children who are seen by Dr. Turkel, has not occurred in the present sample.

IN

MEDICAL AMELIORATION OF DISORDERS ASSOCIATED WITH METABOLIC ACCUMULATIONS

POPULATION I.Q.

4
PATIENT DIAGNOSED AS MONGOLOID AT BIRTH
I.Q. 70-90%

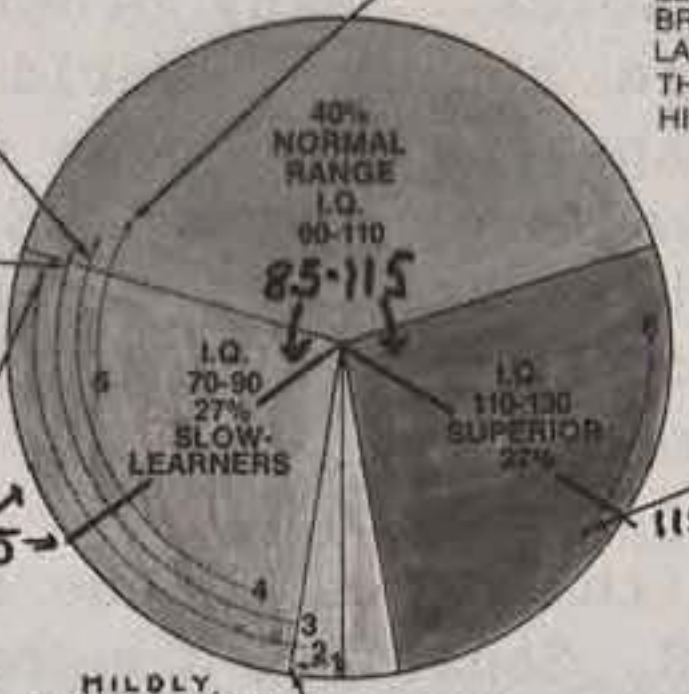
BORDERLINE RETARDED PATIENT, VISUALLY HANDICAPPED, CONSIDERED UNEDUCABLE BUT PERMITTED TO SIT IN CLASSROOM UNTIL AGE 16. PLACED IN INSTITUTE FOR THE BLIND FROM AGE 16-22. TREATED AT AGE 22.

5 I.Q. 70-90% ——NORMAL
SLOW NORMAL

TREATED UNSUCCESSFULLY WITH THYROID, VITAMINS, SPECIAL DIETS, THIS PATIENT REFERRED FOR TREATMENT AT AGE 16 WITH THE CLINICAL DIAGNOSIS OF DOWN'S SYNDROME. CHARACTERISTICS INCLUDED EDEMA, GENERALIZED ACCUMULATIONS, BRUSHFIELD SPOTS, EPICANTHAL FOLDS. LACKED ENERGY FOR SCHOOL OR WORK. THEN TREATED 2 YEARS. GRADUATED FROM HIGH SCHOOL, DRIVES AND WORKS.

3 I.Q. 50-70%
TRISOMIC PATIENT

THIS TRISOMIC PATIENT GRADUATED FROM HIGH SCHOOL WITH A 3.3 AVERAGE. WILL ATTEND COLLEGE.



6 I.Q. 110-120%
ABOVE AVERAGE

THIS COLLEGE FRESHMAN WAS STRUGGLING IN HER CLASSES. CHARACTERISTICS OF A DISORDER ASSOCIATED WITH METABOLIC ACCUMULATIONS: EPICANTHAL EYE FOLDS, WEIGHT GAIN EXCEEDING WHAT WOULD BE EXPECTED FROM CALORIC INTAKE, MARMORATED SKIN AND GENERALIZED EDEMA, HIGH ARCHED PALATE, UNDERDEVELOPED NASAL BRIDGE.

2
IDIOPATHIC MENTAL RETARDATION

MODERATELY RETARDED PATIENT
AGE: 6 YEARS, I.Q. 44± 15
ATTENTION SPAN: 15 SECONDS
INSTITUTIONALIZATION RECOMMENDED AT AGE 4. TREATED AT AGE 6.
AGE 8 I.Q. 85

1
PROFOUNDLY RETARDED PATIENT

FIRST TREATED AGE 6 YEARS 3 MONTHS
HT. 32" WT. 16 LBS.
DEVELOPMENTAL AGE UNDER ONE YEAR
BONE AGE 2 YEARS.

COST OF INSTITUTIONALIZATION PER PATIENT:
$46,000.[66] ANNUALLY (1975 FIGURES IN ALASKA)
$43,800.[66] ANNUALLY (1979 FIGURES IN MICHIGAN)

COST OF HOME CARE:
INCLUDED CONTINUOUS HOSPITALIZATION, LOST WAGES OF MOTHER AND SISTER TO PROVIDE AROUND-THE-CLOCK CARE.

THE SOCIAL COST OF MENTAL RETARDATION IS APPROXIMATELY $15 BILLION ANNUALLY:
1. FREQUENT ILLNESS—SURGICAL AND MEDICAL CARE OF THE RETARDED AT HOME, IN FOSTER CARE, IN INSTITUTIONS.
2. CUSTODIAL CARE
3. SPECIAL TRAINING AND EDUCATION
4. LOSS OF EARNING CAPABILITY.
5. EFFECT ON SIBLINGS—DEPRIVATION OF TIME, CARE, MONEY...
6. LOSS OF CIVIL LIBERTY—UNNECESSARY INSTITUTIONALIZATION.

THE SOCIAL COST OF BORDERLINE RETARDATION (I.Q. 70-90)
1. SPECIAL EDUCATION.
2. LOSS OF EARNING CAPACITY.
3. ACCIDENTS CAUSED BY ILLITERACY.
4. EXCESS CRIME.
5. COST OF PRISONS, POLICE.

FROM: MILD MENTAL RETARDATION: A GROWING CHALLENGE TO THE PHYSICIAN (GAP REPORT, VOLUME VI, REPORT 66, SEPT. 1967):

"THE MILDLY RETARDED ARE OFTEN CONSIDERED TO BE INDIVIDUALS WHO ARE EASILY LED INTO UNLAWFUL ACTS, OR WHO, AS A RESULT OF THEIR RETARDATION, COMMIT MORE CRIMES AGAINST PERSON AND PROPERTY THAN INDIVIDUALS WITH NORMAL INTELLIGENCE."

THE MILDLY RETARDED ARE OVERREPRESENTED IN PENAL INSTITUTIONS. COST OF DETENTION RISES CONTINUOUSLY.

TO PARENTS OF DS CHILDREN OF ALL AGES,

Twenty-five years have passed since the FDA prevented your doctor from prescribing the "U" Series, and how much more time may pass before the FDA finally permits prescription use no one knows. The FDA has been using the excuse that the "U" Series can't work because of the extra chromosome in DS. Yet, neither the FDA's own experts nor its consultants have ever used the "U" Series.

As a parent, I can attest to the fact that the "U" Series works. Many other parents have said the same in the Dear World section that follows. The Japanese have been using it since 1964, the Norwegians since 1981, and other countries have been using it - although the FDA has tried to stop them by abusing the powers of our State Department.

What can parents do? If thousands of letters land on the desks of the President, the Secretary of HHS, Senators, Congressmen, 20/20, 60 Minutes, attention will be paid. Parent power worked in Norway and it can work here. As in Norway, the "U" Series could be made available as a "alternative" treatment. There should be a criminal investigation of the FDA by the Department of Justice. It makes no sense that a combination of safe and proven drugs has been withheld these many years from the majority of our children. The harm and cost to parents and the government of this irrational blockage are inexcusable.

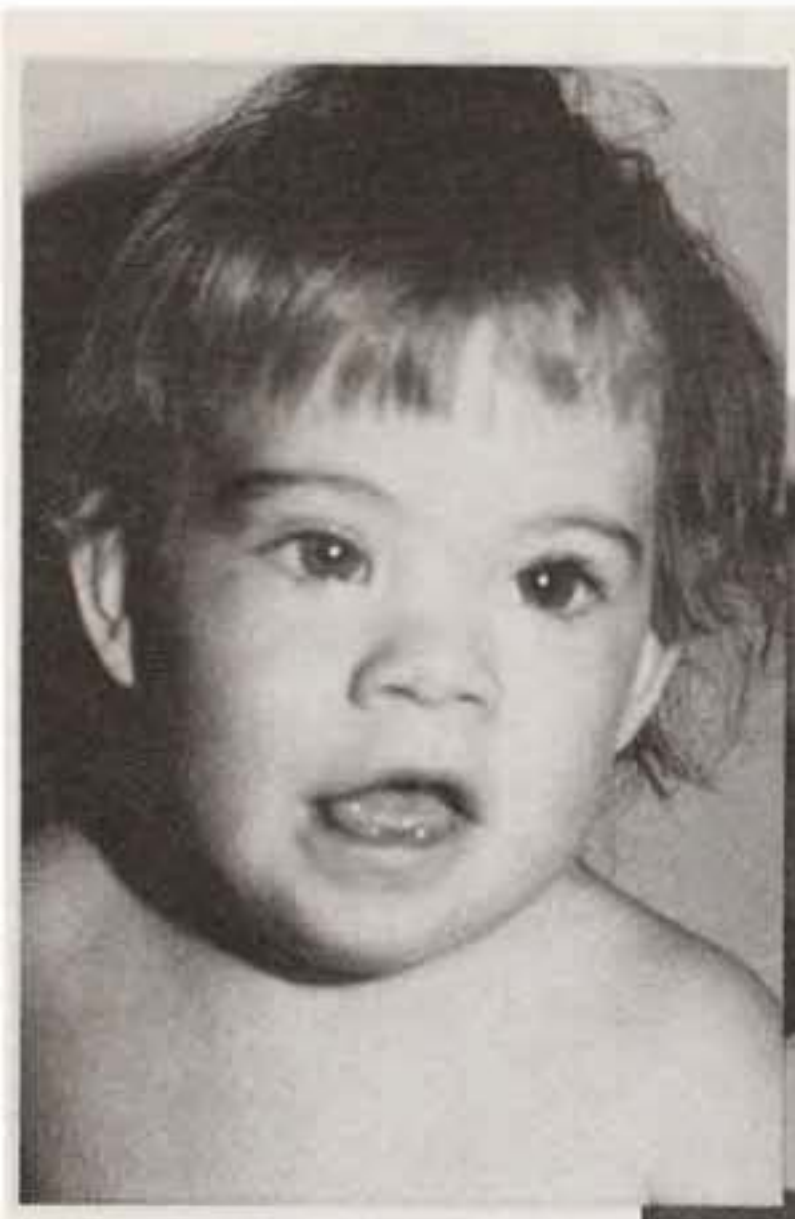
Arlene Bierman

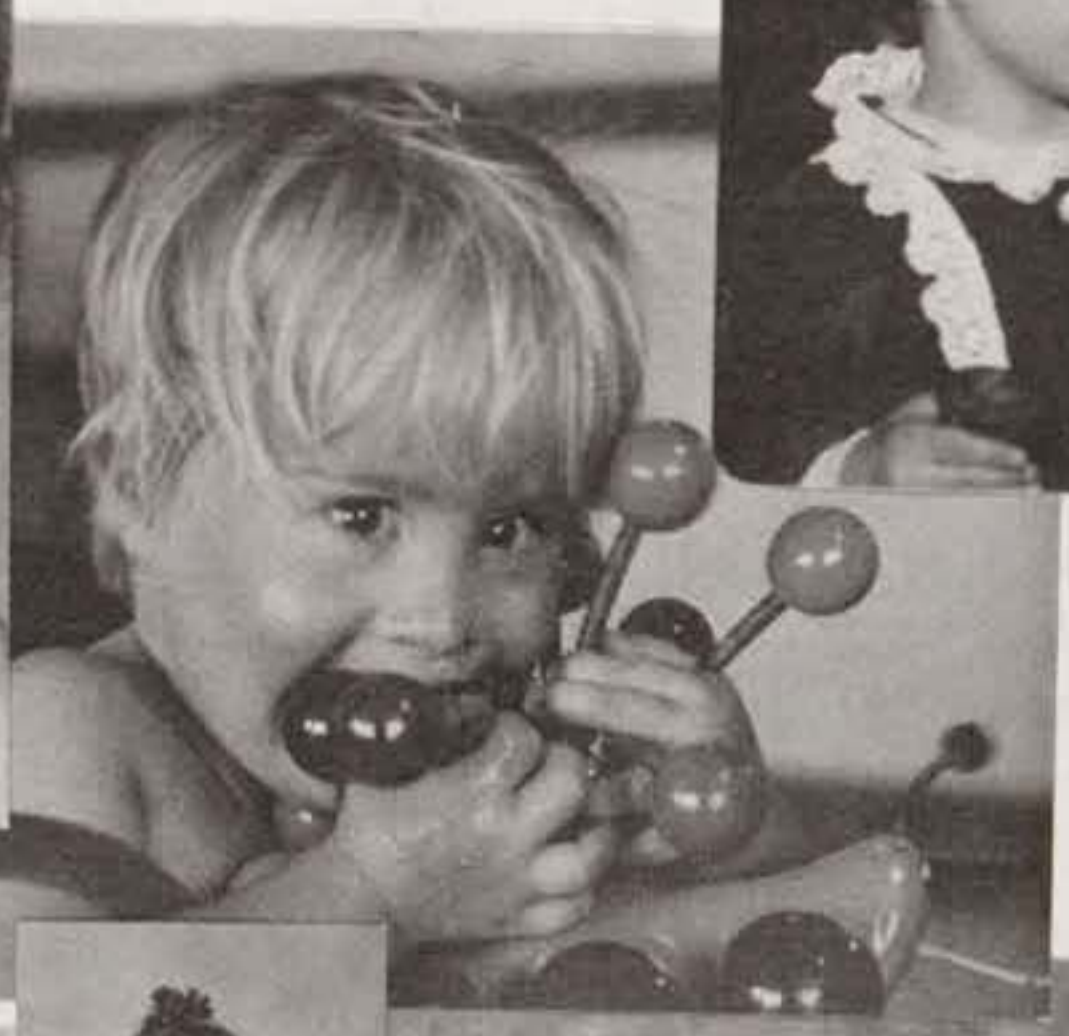
US FOR DS

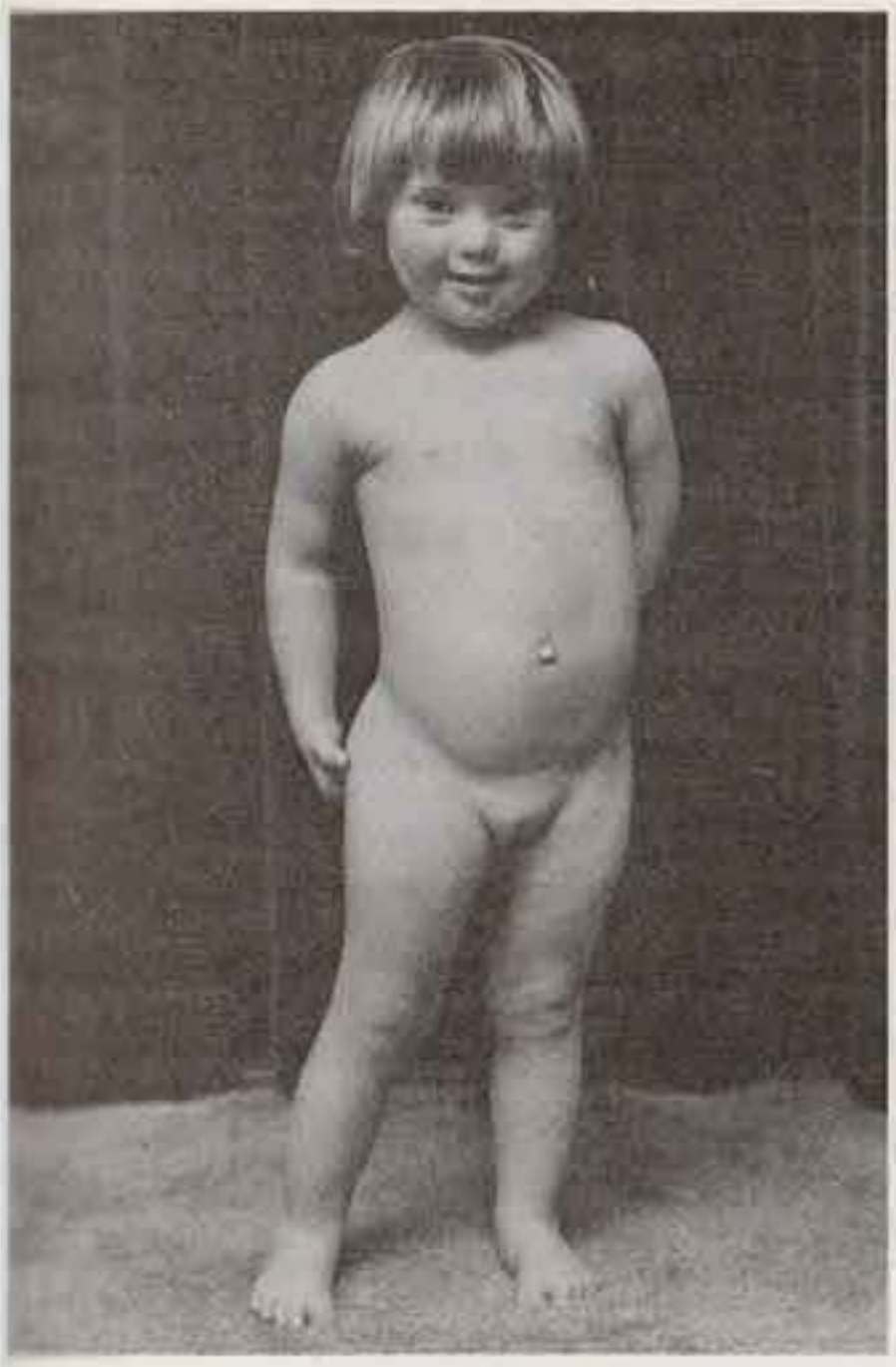
Post Office Box 64405
Los Angeles, California 90064

Dear World....

.....The following section includes letters from parents whose children, born with Down's sydrome, have experienced the benefits of the "U" series treatment, developed by Dr. Henry Turkel







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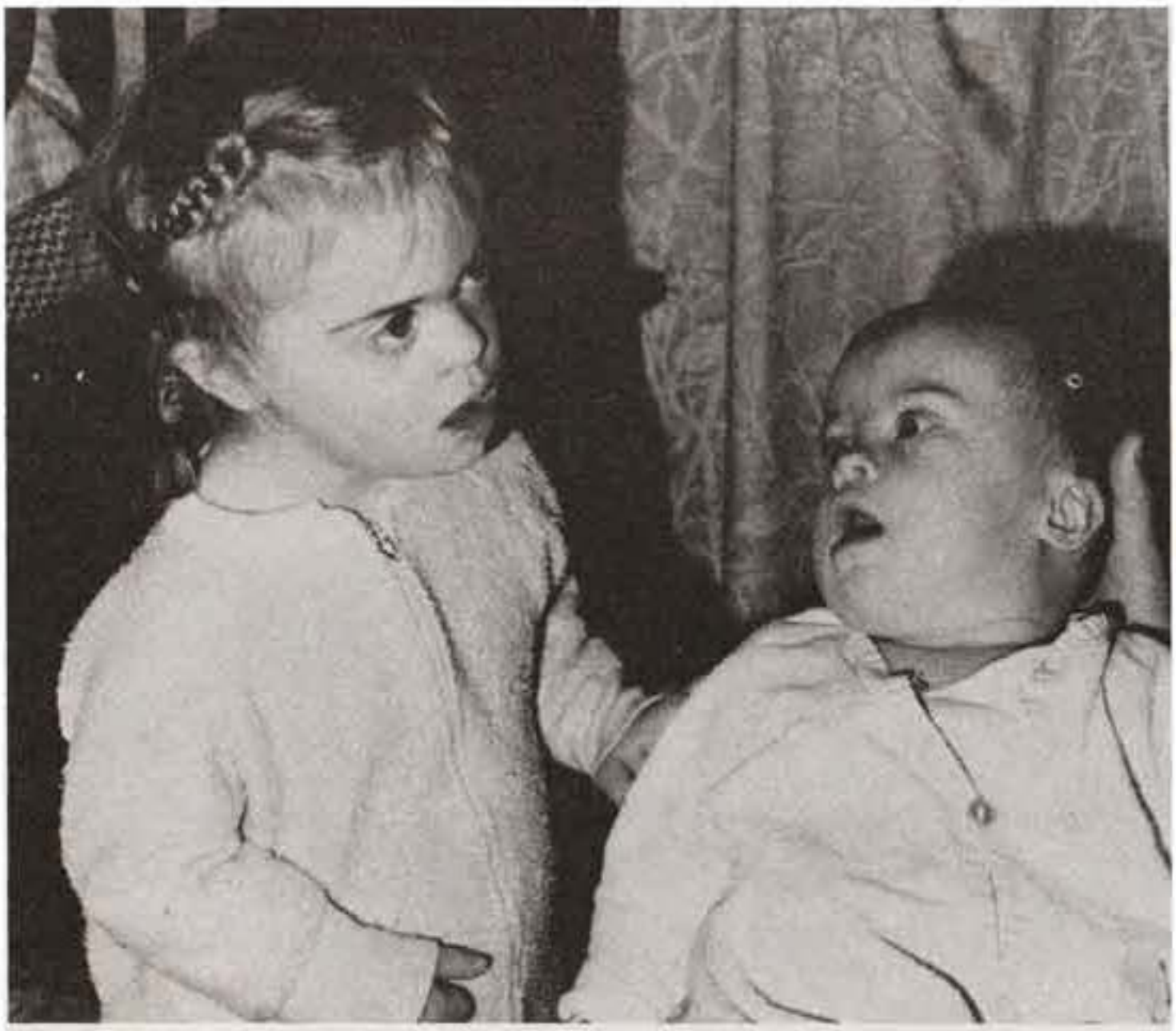

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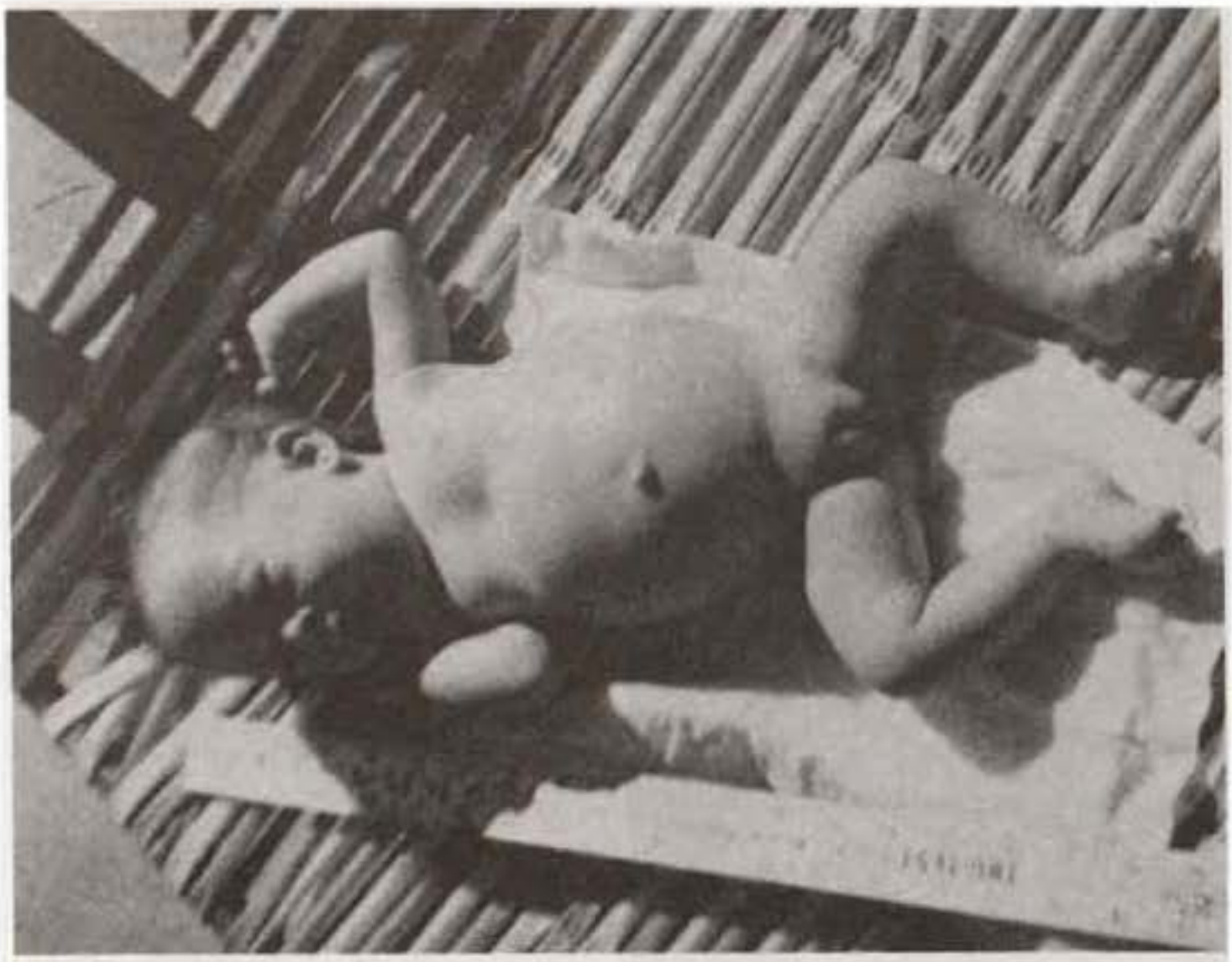

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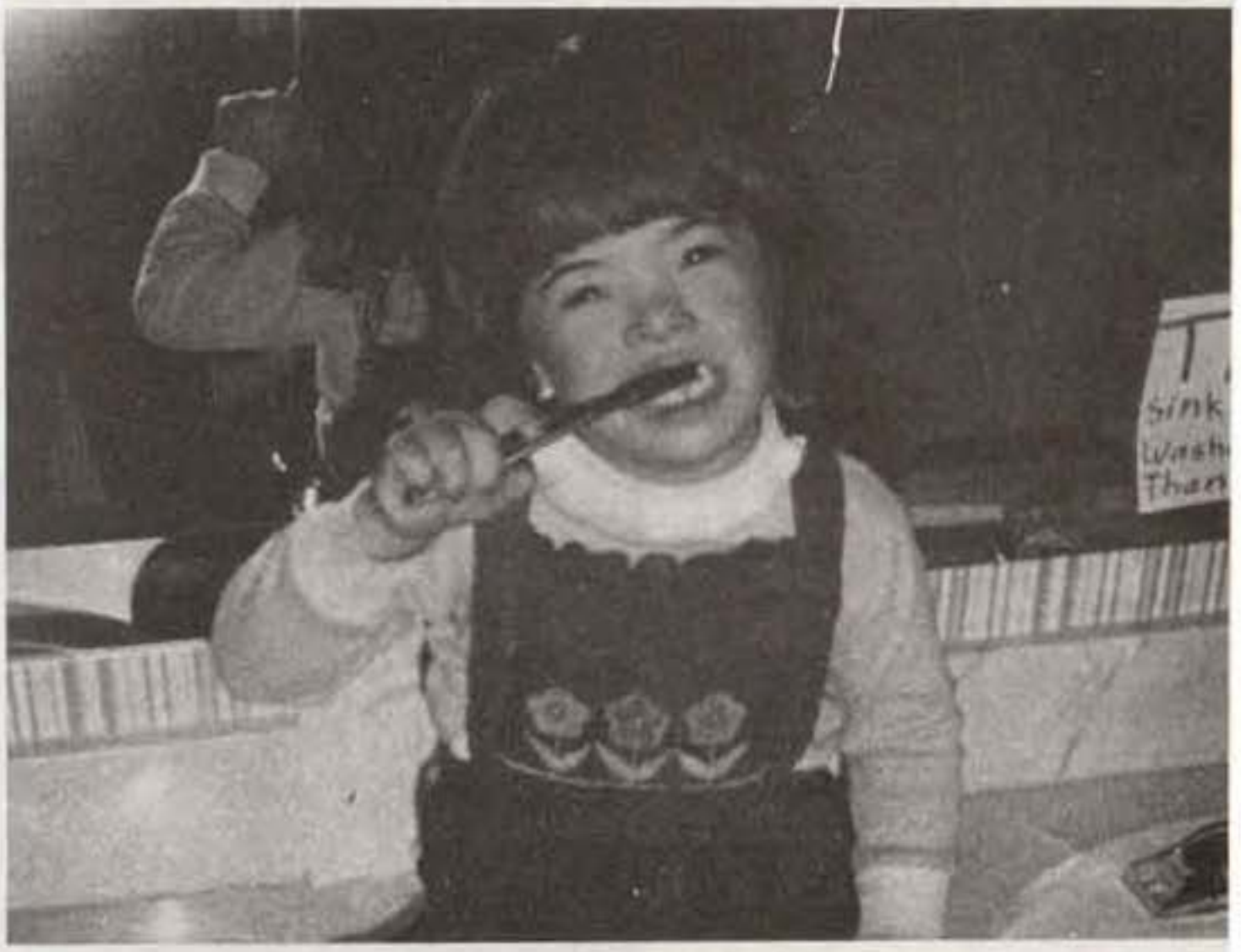

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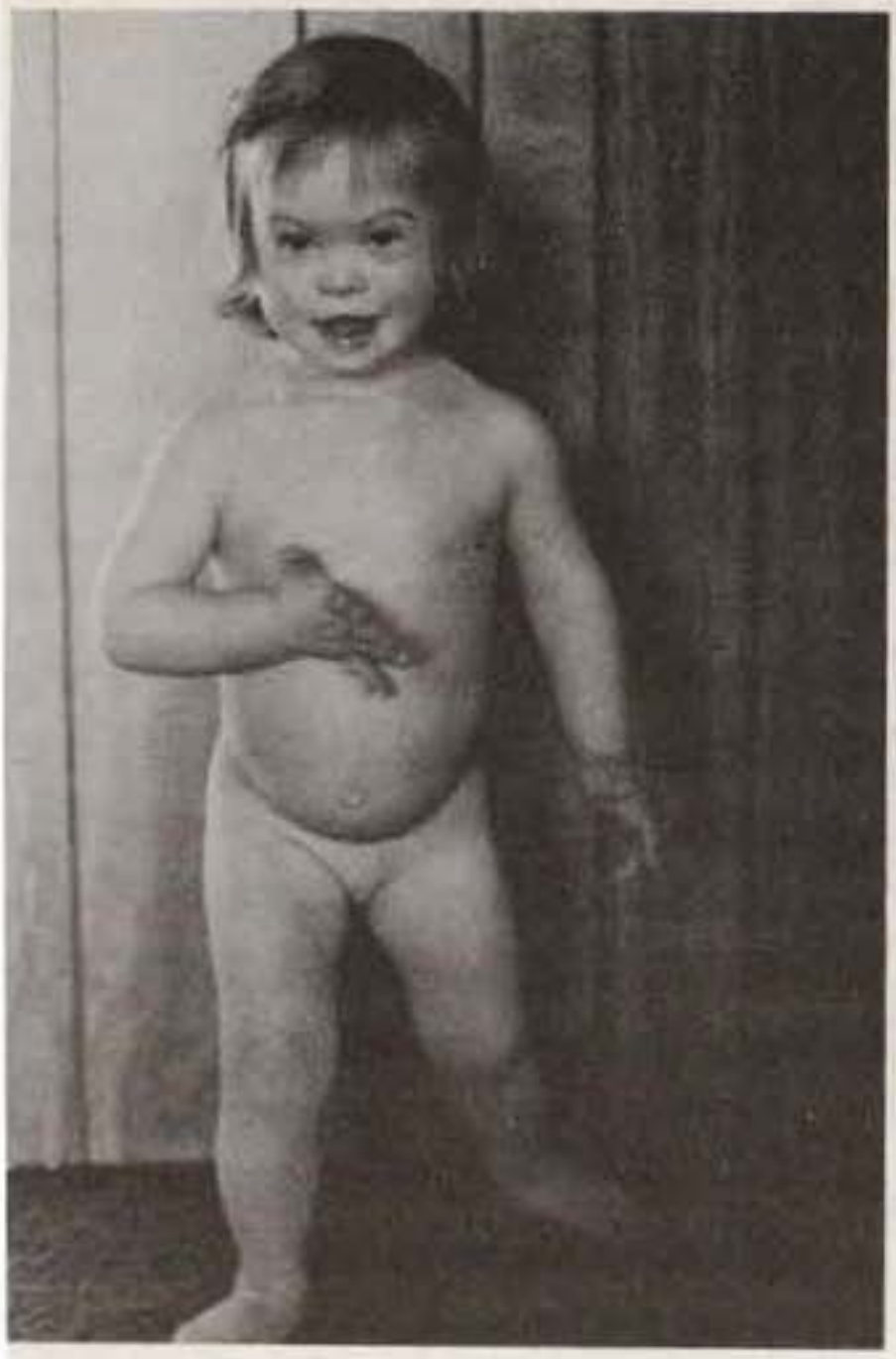


BEFORE

AFTER

MAY 29, 1984

DEAR WORLD;

MY NAME IS ARLINE BURMAN OF LOS ANGELES, CALIFORNIA. I AM THE NATIONAL PRESIDENT OF "US FOR DS", A ORGANIZATION WHICH SIGNIFIES THE "U" SERIES FOR DOWN SYNDROME. OUR ORGANIZATION IS COMPRISED OF PARENTS, FRIENDS AND PEOPLE WHO CARE ABOUT OUR DOWN'S CHILDREN; AND WANT THE "U" SERIES APPROVED SO THAT CHILDREN WITH DOWN SYNDROME EVERYWHERE WILL BE HELPED.

LIKE MANY PARENTS THROUGHOUT THE COUNTRY WITH DOWN'S CHILDREN, MY STORY IS ALMOST THE SAME. SEARCHING FOR A DOCTOR WHO CARES: OR A PROFESSIONAL WHO WILL SATISFY OUR CHILDREN'S NEEDS. SO FAR, ALL OF OUR SEARCHING AND EXPERIENCES HAVE BEEN IN VAIN. AFTER SEVEN YEARS OF THIS AGONIZING AND FRUSTRATION, I HEARD OF A DR.HENRY TURKEL THROUGH MICHAEL JACKSON'S RADIO TALK SHOW IN LOS ANGELES. THE SHOW'S HOST SAID DR. TURKEL WAS FROM DETROIT, MICHIGAN.

MY SON DALE WAS BORN JULY 20,1966 AND WAS IN AND OUT OF HOSPITALS CONSTANTLY. IT SEEMED I WAS ALWAYS CHANGING DOCTORS BECAUSE ALL THE ANSWERS TO MY QUESTIONS ABOUT MY SON WAS THAT NOTHING WOULD MAKE HIM FEEL BETTER. WHEN I TOOK DALE TO SEE DR. TURKEL IN MICHIGAN, HE WAS A EXTREMELY SICK LITTLE BOY. HIS NOSE CONTINUALLY FILLED UP WITH A THICK GREEN SUBSTANCE WHICH RESTRICTED HIS BREATHING, FORCING HIM TO SIT UP IN BED SO THAT HE COULD SLEEP. HE RETAINED A INDENTATION OF HIS STERNUM BONE FROM BIRTH, WHICH GAVE THE APPEARANCE OF SOMEONE HAVING SLUGGED HIM IN THE CHEST.

IT LOOKED AS IF HIS CHEST WERE FORMED FROM PUTTY OR CLAY AND A FIST HAD BEEN PUSHED AGAINST IT. DALE CONTINUALLY .. VOMITED MANY TIMES DURING THE COURSE OF EACH DAY. AT THE AGE OF SEVEN YEARS OLD, DALE WEIGHED TWENTY-SEVEN POUNDS; THE WEIGHT USUALLY TRUE OF A THREE YEAR OLD. HIS SKIN COLORING DID NOT LOOK HEALTHY. INSTEAD OF A NORMAL HEALTHY FLESH TONE, HIS COLORING HAD A GREYISH CAST.

WHEN I REQUESTED SOME MEDICATION TO GIVE MY SON ANY KIND OF RELIEF, OR COMFORT, DOCTORS WOULD ONLY GIVE ME ANTIHISTAMINES. THE ONLY CHANGES WHICH TOOK PLACE IN DALE'S CONDITION WHEN TAKING THE ANTIHISTAMINES WERE ADVERSE REACTIONS, AND DALE BECAME VERY SICK.

I WOULD LIKE TO SAY ON FEBRUARY 14, 1974 IS THE DAY THAT DALE REALLY WAS BORN. PRIOR TO THIS TIME EVERYTHING SEEMED TOUCH AND GO FOR DALE. WITHIN A WEEK HIS NOSE STOPPED RUNNING; THE VOMITING STOPPED; THE BRIDGE OF HIS NOSE FINALLY STARTED TAKING SHAPE; AND POSITIVE CHANGES WERE TAKING PLACE IN HIS HEART MUSCLE AND HIS OVERALL PHYSICAL APPEARANCE MADE GREAT IMPROVEMENTS. IT SEEMED EVERYTHING WAS CHANGING FOR THE BETTER. MY ENTIRE FAMILY DELIGHTED IN SEEING DALE'S PROGRESS.

THESE PHYSICAL IMPROVEMENTS ENABLED DALE TO EXCEL. MY GREATEST DESIRE WAS THAT MY LITTLE BOY WOULD FEEL BETTER AND BE ABLE TO FUNCTION MORE EFFICIENTY. THESE WISHES HAVE BECOME REALITIES BECAUSE OF DR. TURKEL AND HIS EFFORTS WITH THE "U" SERIES TREATMENT.

4221 West Cherrywood Lane
Brown Deer, WI. 53209
September 5, 1983

"DEAR WORLD":

Nicholas came to us on April 26, 1983. We already had a three year old daughter and having given birth to a son was more than we could even hope for. Our excitement lasted half an hour before the doctor came back to us to announce that he strongly believed that our son had Down's Syndrome. Our immediate reaction was devastation, soon joined by fear, anger, denial, and all of the feelings that every parent with a special child has known. He is now four months old, and together as a family we have grown, and learned, and have much hope for his future.

Fortunately, within Milwaukee there is a strong network of caring parents who are ready and willing to help new parents of Down's Syndrome children. We were lucky enough to meet another parent, June Maglio who herself had a child with Down's who had been on Dr. Turkel's "U" Series for a number of years, Through her we arrived at Dr. Turkel and have begun the vitamin series with Nicholas.

We strongly believe that we are giving our son the very best opportunity possible in his early months of life through the Series. While he has not manifested the severs symptoms that we know other parents have experienced with their Down's children, we none the less have noticed some pleasing results from just the single month that he has been taking the treatment. He no longer has to have his nose cleaned before being able to take a bottle, something that did seem to subside before the "Series" but that has improved since. He was always unable to have a bowel movement without being given large amounts of syrup in his formula; since being on the vitamins he eliminates quite normally daily. The thickness in the back of his neck has very noticably lessened, and he does not protrude his tongue nearly as much. He is bubbly, strong, holding his head and upper body unsupported well, and truly enjoys playing with his toys and the constant attention of his <u>attentive</u> sister!

People that pass and comment on how cute my baby is have no idea how they warm my heart! At this point, unless someone is told, they have no idea that Nicholas is our little Down's baby.

From the first day he was born people who cared told us to take a day at a time. This is still new to us, but already Nicholas has helped us to grow in a way that would not have been possible had he not been special. We feel so fortunate to be able to have him on the "U" Series at this initial part of his life so that he can become all the things that he was meant to become. We thank Dr. Turkel for being the vital force in the treatment of Down's Syndrome and hope that some day the New Hope that we have gotten through him can be available to every family with such a child.

Sincerely,
Barbara Balistreri
Mrs. Barbara Balistreri

Sept 6, 1983

Dear World

During the past four years our 7-year old Downs Syndrome boy, Steven, has received the U-Series treatment with the consequent benefit that his learning abilities have increased considerably. Some of the things that he accomplished during the treatment period are:

(1) Steven has learned to recognize. [from maps] 104 countries.

(2) He can name the capitals of any state of the U.S. or of any country in North, Central, or South America.

(3) He can recite the numbers from 1 to 100 in both English and in Spanish, but sometimes needs prompting.

(4) Steven has finished reading 51 children's books.

(5) He can play a few songs on the xylophone and organ.

Although Steven is still handicapped we are deeply grateful to Dr. Turkel for the benefits of his treatment which, in conjunction with teaching methods gleaned from Glenn Doman's books and others, enabled us to help our boy.

Sincerely

Jim Brenda

Linda Brenda

HUNTINGTON MEMORIAL HOSPITAL
THE GENETICS INSTITUTE
99 N. EL MOLINO – PASADENA, CA 91101
(213) 449-7603

CYTOGENETICS LABORATORY REPORT

Deely

DR. ____ . LABORATORY PROCEDURES
ADDRESS. 6330 Variel Ave.
Woodland Hills, CA 91364
Att: Ms. P. Posternack

PHONE NO. ____

PATIENT BAXTER, Daniel

PATIENT I.D. NO. 002723 / 99707001

LAB NO. 81-478

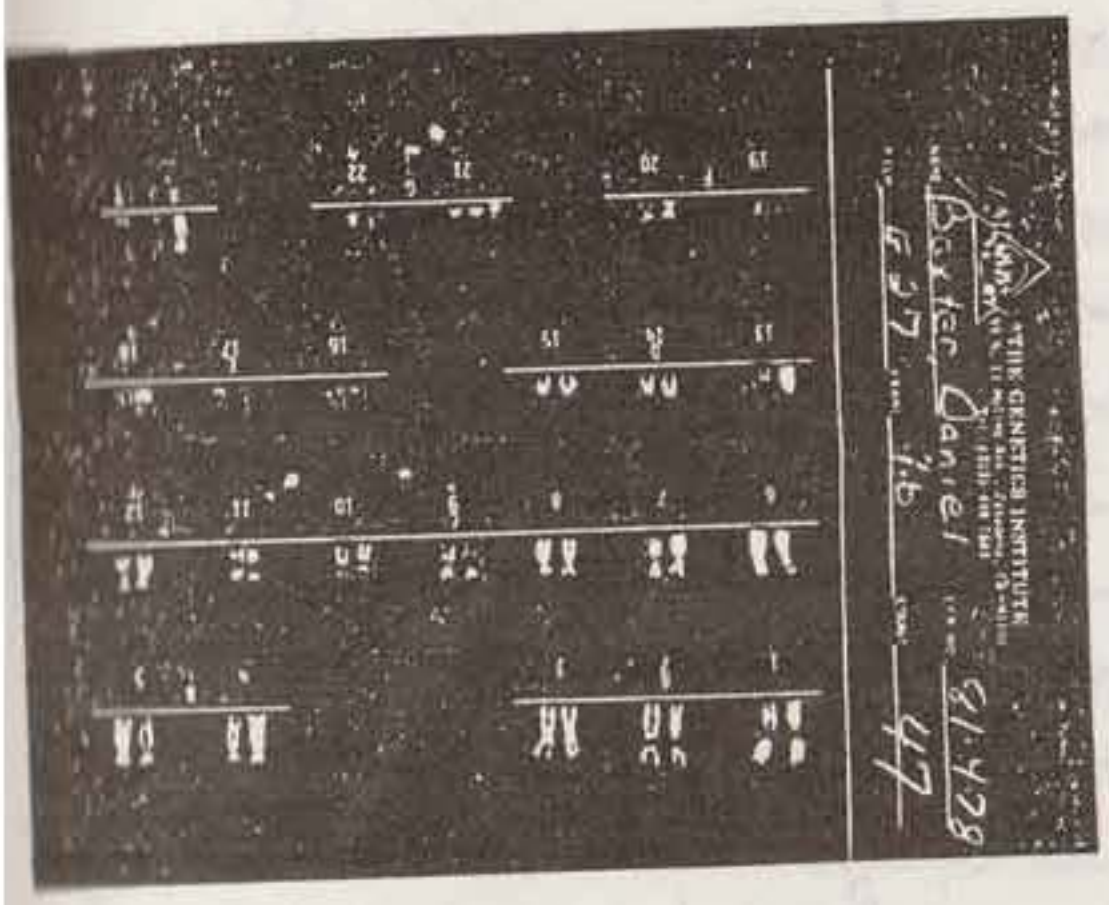
DATE SPECIMEN RECEIVED 04-15-81

DATE OF REPORT 04-27-81

NO. OF CELLS KARYOTYPED

KARYOTYPE: 47,XY,+21

INTERPRETATION: Consistent with Trisomy 21 Down Syndrome. No evidence of mosaicism.



TICIST O. Alfi M.D.

OMAR S. ALFI, M.D.

May 28, 1981

Dear Dr. Turkel and Mr. Hustamm,

Thank you for providing me with a miracle-in-progress. Danny began the III Series on February 12, 1981 and these pictures were taken on May 2, 1981, when Danny weighed 126½ lbs. (or 8¾ lb loss in eleven weeks) Today, after fifteen weeks of treatment, Danny weighs 125 lbs., stands 5'2½" ... and he hasn't needed an antibiotic since the day he commenced treatment!

How I wish you could see him in person each month! The enclosed copy of Danny's chromosome study verifies that he is a victim of Howe's disease. You will remember that his skin was as rough as cowhide; that is improved ... although not 'normal' yet. He is by far the slimmest, trimmest boy in his classroom. When he began treatment, he wore size 36 pants and needed suspenders because of his lack of contours; today he wears a size 33 pants - with a stylish belt. He no

longer wears an extra large shirt... he has trimmed to a size medium. I have donated his clothing to the Salvation Army, and am buying him new clothes. Fifteen weeks ago he wore a size 3 shoe; today he wears size 4.

Furthermore, he plays outside for hours, wearing shorts and a light, short-sleeved T-shirt... no sweater, jacket, hat. He has learned to climb on a trampoline and jump.

The most noticible difference is in his personality. He has become assertive, very strong-willed and much more observant. Before treatment, it was a battle to wake him in the morning; now, he frequently wakes before I do and dresses in clothes of his own choosing. He used to come home from school and flop across his bed; now he comes home and wants to jump on his bed.

He had a psychological test, and I am awaiting the results. I am certain that his I.Q. score is currently very

low... and that is inexcusable when the treatment for Hanna's disease has been known for forty years. To think that if we lived in Japan, a "less advanced" nation than the U.S., Nanny would be well or nearly well now!

I have also followed your dietary guidelines, and Nanny is living evidence to the success of the 'H' Series program. I am uncertain if his hearing has improved, or if he is now paying attention... so I am going to have another audiological test for him. In December, 1980 he evidenced impairment (see enclosed report).

I used to get weary writing letters to congressmen, other elected officials, and political appointees. You have my permission to use Nanny's full name, photographs, records, etc. in any way you wish, for we consider it a privilege and a blessing to further this wonderful program.

God bless all of you, and please tell Mrs. Turkel 'hello'. (I know she has suffered for this, too, and she

deserved recognition, too).

Thank you, thank you,

Susan Slater

BEFORE

AFTER

FAIRBANKS
Daily News-Miner
"America's Farthest North Daily Newspaper"
FAIRBANKS, ALASKA, MONDAY, JANUARY 23, 1984 35¢ Per Copy

Doctors debate U-series treatment

There's no cure for the abnormal chromosomes that cause Downs syndrome. On that point there's little debate.

But there's much debate on whether, and how, some of the specific ailments that make up the syndrome can be treated.

Dr. Henry Turkel of Southfield, Mich., believes that most of the ailments associated with Downs syndrome are caused by a buildup of chemicals in the bodies of Downs victims. In a healthy body, those chemicals are excreted, but the Downs victim, his excretory system incompletely developed because of the chromosome damage, is unable to expel them.

These chemicals, the 81-year-old Turkel theorizes, prevent the Downs sufferer from absorbing nutrients as a normal person does, and may block blood vessels. The situation may be aggravated, Turkel thinks, if the victim's digestive system is also underdeveloped, making it even more difficult for the body to nourish itself.

To alleviate these conditions, Turkel came up with his U-series treatment, consisting largely of vitamins and minerals that are readily available. Turkel says they remove the stored wastes that make Downs victims sick, allowing their retarded excretory and digestive organs to mature. Thus, in time, they can live reasonably healthy lives without any medication, Turkel claims.

Although he has been providing U-series treatment to Downs sufferers for some 40 years, Turkel has not managed to get it approved by the federal Food and Drug Administration as an effective therapy. While the FDA does not regard the U-series as dangerous in any way, it takes the position that its effectiveness has never been demonstrated, and so has never cleared it for general marketing.

It has been approved in some countries overseas, however, including Japan and Norway.

Since the each individual component of the U-series is FDA-approved, Turkel may legally prescribe them, singly or together, for his patients. But no one may package them together and offer them as a treatment for Downs syndrome without FDA approval, which is why Susan and Danny Baxter must travel to Turkel's Michigan office once a year for an examinaton and a 12-month supply of the U-series, which costs $2,400.

Other experts on Downs syndrome regard Turkel's theories, both on the storage of chemicals in the bodies of victims and the means by which they can be removed, as unproven and do not endorse his U-series.

The National Association of Retarded Citizens is co-sponsoring a University of Nebraska study on the effectiveness of megavitamin therapies such as Turkel's in treating Downs syndrome. The association for now at least, agrees with the FDA and the medical community in general that the U-series is unproven.

-Daily News-Miner, Fairbanks, Alaska, Monday, January 23, 1984

Danny's special child needing special care

By STAN JONES
Staff Writer

Each year, as the first of February approaches, Susan Baxter starts trying to figure out what she'll have to sell to raise the money.

Last year, and the year before, it was her car. The table and chairs from her dining room are gone, too, along with her sewing machine. This year, who knows? Maybe her piano, maybe her current car, maybe the beds, maybe the television set Danny bought with money from his paper route.

"You do what you have to do," she says.

Danny is her adopted son. He's 18. He likes bike riding, horses, and bowling. And he has Downs syndrome.

What Susan Baxter has to do is raise $4,500 by Feb. 3 so that she can take Danny to Michigan for treatment.

Downs syndrome, sometimes called mongolism, is a chromosomal defect that produces mental retardation and an array of physical ailments running from heart problems to recurring respiratory infections.

While Downs syndrome can't be cured, there is at least one doctor in the United States who claims to be able to treat and relieve some of the harmful effects produced by the abnormal chromosomes.

He is Dr. Henry Turkel of Southfield, Michigan. Because his experimental Downs syndrome therapy—which he calls the U-series—has not been approved for commercial distribution by the U. S. Food and Drug Administration, Susan Baxter and Danny have to fly to his Michigan clinic once a year. There, Turkel examines Danny and provides another year's supply of the U-series. The annual bill: about $4,500 for air transportation, lodgings in Michigan, the exam, and the medicine.

Because Susan has a job and because the U-series is an experimental therapy, Danny and Susan's annual trips to Michigan don't qualify for federal or state assistance, nor are they covered by health insurance.

As a result, Susan has to pay the bills herself, and that is what led in the past to the sale of her cars and other possessions.

"I have another one now," she says, "but if things don't work out, this one's got to go, too."

Susan adopted Danny in 1975, after she met him in a special education class she taught while getting her master's degree in Minnesota. He was 10 years old, a ward of the state, and, because of a heart defect, not expected to live long.

"He needed a home," Susan says of her decision to adopt him. "He didn't belong in an institution. He's just absolutely a joy, so loving."

Now they live in a small condominium off of Chena Pump Road. Susan works at the University of Alaska, while Danny attends Birch Special Education School. Last summer, he ran the paper route—with Susan's help—to raise money for the television set. In September, he and partner Darren Kadel rode a bike 20 miles to raise $2,750.50 for the battle against diabetes.

The years after the adoption were filled with medical bills that Susan says sometimes ran as high as $50,000 per year: bills for heart surgery, pneumonia, and the other ills that afflict the victims of Downs syndrome. Finally, things got so bad that Susan quit her teaching job in Anchorage in order to become eligible for medicaid to cover the bills.

Then, three years ago, she heard of Turkel's U-series, and started Danny on it: 163 pills every week; a small cupful at breakfast, lunch, and dinner.

While the effectiveness of the treatment is the subject of much debate and skepticism in the medical community, Susan has no doubt that it has helped Danny, and she's determined to stay with it, whatever the cost.

"The basic issue is, these kids are born," she says. "What are we going to do? We can let them die off, or we can treat them. It's just that simple."

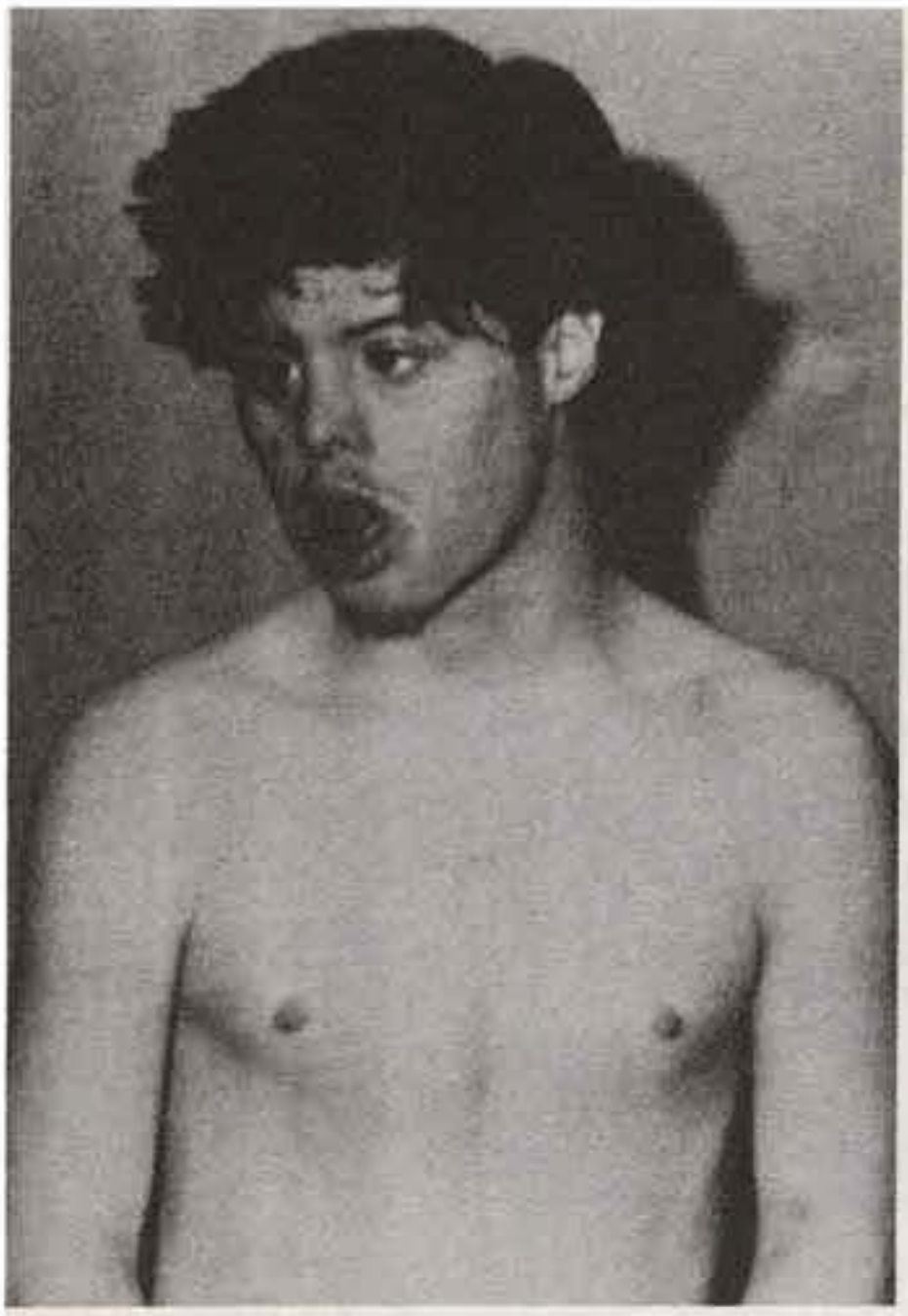
After starting the U-series, Susan says, Danny became more mentally alert, learned to talk, had fewer respiratory and ear infections, lost 20 pounds, and grew 3 inches. His doctors in Fairbanks agree that Danny's condition has improved since he started Turkel's therapy, but shy away from crediting it to the U-series, since Danny's the only patient they've seen who uses it.

This year, Susan has about $600 on hand, and efforts are being made to raise the rest of the money locally—from individuals, churches, and civic organizations. The University Community Presbyterian Church has agreed to provide up to $500 to fill the gap between Susan's resources, other contributions, and the approximately $4,500 needed. In addition, the church has agreed to serve as a clearing-house for donations, and the Eagles have agreed to put up $1,000.

"This is so hard for me to do," Susan says of the fundraising drive.

Contributions may be sent to: The Danny Baxter Fund, c/o University Community Presbyterian Church, P. O. Box 80570, Fairbanks, 99708.

MICHIGAN BOUND—Susan Baxter, left, needs to raise $4,500 by Feb. 4 so that she can take her adopted son, Danny, right, to Michigan for treatment of his Downs syndrome.



BEFORE

AFTER

Dear World:

My son, Larry Bettencourt, was prematurely born Sat., May 23, 1959, at 7:50 p.m. in St. Vincent's Hospital, Toledo, Ohio. By C section. It was a complicated delivery, and I was very ill for months after his birth. Larry was pronounced a mongaloid, and I was informed after many days that he would not live, as he had a septal defect in the lower left ventrical of his heart. He was very blue at birth, and it was a certainty that every breath he drew would be his last, as he was also full of the same infection that made me so ill. ''Peronitonitis''.

Four days passed and finally I saw my beautiful baby, but for only a few seconds. He was perfect to look at.

After two weeks we left the hospital. Larry's two sisters, Charlene 12, and Anne 10 and two brothers Marty 9, and Carl 7 were thrilled to finally see their baby brother.

Larry developed beautifully and could do things most babies do, but his coordination wasn't good.

At six months he turned blue again, and was back in the hospital with double bronchial pneumonia. Again we almost lost him.

I was told Larry would never walk as he wouldn't live that long. At 17 months of age he was back in the hospital again with pneumonia. A few days after he left the hospital, he learned to walk, despite the doctors' warnings. He was an absolute delight. Everything he did was a little late, but we expected that. At 3 yrs. of age he was talking in sentences.

Larry was toilet trained, and started school at age 4 yrs. He played his own electric record player. He rode in his fire engine and could pedal his trycicle. He excercised on his monkey bars and loved his swing. He would go out on Halloween night dressed up and carry his trick or treat bag. He was our sweet angel baby.

When Larry was 4 1/2 years old he underwent open heart surgery. You could hear the blood spurt through the holes when you put your ear close to Larry's chest. We were given 85-15 odds of his living. After surgery started the Doctors discovered 2 defects instead of one. The odds dropped. The second hole was directly behind the first. His stay at the hospital lasted 10 days, and he was back in school 5 weeks later. The surgery left Larry with a loud heart murmur. He did very well as time passed. He became active again and bounced back to his usual self. He could do much more now without tiring. I do not remember when he quit talking. It was gradual and finally one day it dawned on me that Larry was communicating, but he wasn't talking.

By the time Larry was seven years old, he had stopped playing with the children in the neighborhood and the nightmare was beginning. The next two years it seemed Larry lost interest in everything. He would go out in the yard and swing but seemed to be wary of running around as he once did. When he was ten years old his teacher called me from school and tole me to take Larry to an eye specialist as she thought he was losing his sight. I did so immediately, and was tole he was blind and glasses would do no good. It was such a shock to me, I just couldn't accept it. It couldn't happen to my baby. To be retarded and blind was more than I could bear. All I could do was cry for my darling.

He was put out of the school program and had nothing to do all day now. Around this time I was told there was an Institute in Columbus, Ohio where he could be rehabilitated. I took Larry down there, and he stayed for 10 months. I discovered it was a horrible institution. I brought him home and cared for him with no help from the Board of Retardation, because he was blind, and the Society for the blind wouldn't help, because he was retarded. For the next five years I cared for Larry at

home. He was obese and his tongue was so thick it stuck out of his mouth. He had a hard time eating as there wasn't room for tongue and food in his mouth. His nose ran thick mucus constantly. Again the time came when I could no longer care for my baby as I had been physically going down hill over the years, and there was no where for him to go, but back to the ''Warehouse'' in Columbus. It was at this time I read an article in our ''Goal'' newsletter. Goal is an organization for parents of the homebound and profoundly retarded children. Ann Grady, the president of Goal had heard of a Doctor giving an exhibit lecture called, ''Medical Help for the Mongaloid.'' He was to speak in Detroit, Michigan. I could hardly wait until the day came and we attended this exhibit.

I cannot describe the mixture of shock, amazement, and utter disbelief that I lived 60 miles from this doctor and had never heard of him. My baby had deteriorated for years when he could have had help a few miles away.

I asked Ilse Nesbaum, Dr Turkel&s associate if it would be possible for Larry to get this medication called the ''U'' Series. She said ''Yes, but we will have to put your name on the waiting list.'' I was hysterical inside and I wanted to scream, for I thought ''Here, we go again,'' nothing good for my son ever.

We went home and I prayed every day to hear from this doctor that could help my baby. About 3 months passed and one day I opened my mailbox and there it was! If I was still interested would I get in touch with the doctors office. I didn't wait to write. I called, and Ilse told me to get a chromosome study of Larry done, and she set up an appointment for him. I was so happy I was beside myself. When the time came, I brought Larry home from Columbus State Institution and we went to see this wonderful Doctor. It was April 28, 1975. We paid a visit to a radiologist a short distance from the Doctor's office and they took a series of body x-rays of Larry. Then Dr. Henry Turkel

told me my baby couldn't have the ''U Series'' for three months because for 8 yrs. he was taking a patent tranquilizer called ''Mellaril.'' He had to be withdrawn first. I was bitterly disappointed but help was on the way. I took Larry back to Columbus and the doctor there withdrew him from ''Mellaril.''

Finally the big day came, when Larry went to Detroit and received his first ''U'' Series on July 7, 1975. I was so happy. Next came the legal technology. I had to sign a waiver so they could give the medicine to Larry at the institution.

With all of this behind me Larry started the ''U'' series but they modified it and he didn't get one of the most important capsules as it would make him alert, and they had nothing to offer him in rehabilitation. In spite of this, Larry changed so dramatically they became alarmed. His tongue flattened and went back in his mouth and he went down to 106 lbs. which was great. His body started to look like a boy his age should look, and his nose quit discharging.

After a time they started to play games with me and Larry didn't get the ''U'' series the way he was supposed to. I was so weary of the whole bureaucracy. I could have screamed.

After six months, Nov. 10, 1975 I took Larry back to Dr. Turkel and it seemed his eyes seemed different so the Doctor added another supplement to his ''U'' series and my son's heart murmur was gone for the first time in his life.

In Columbus, Ohio they changed medical director and superintendent and the hassle was worse than before and they refused to give Larry the ''U'' series anymore. In May of 1977 I brought Larry home to stay. He received the full prescription of ''U'' series (for the first time) and was doing great. He was accepted back in Jay Shuer School and July of 1977 received his first paid of glasses that actually helped him to see. He was a much

happier boy.

In early December of 1977, Larry was admitted to the Northwestern Ohio Developmental Center (NODC) respite and became a resident Dec. 31, 1977. I had major surgery Jan. 4, 1978 and was unable to care for him. The center is a beautiful home and made up of 9 cottages, Educational Bldg. & Administration Bldg. Again Larry was refused his "U" series. In April, 1978 Dr. Henry Turkel, M.D. came to Toledo to make a home visit to Larry at the NODC and explained his concept of treatment to the Superintendent.

Shortly after Dr. Turkel's visit to Toledo, the Lucas County Board of Retardation signed Larry on to get the "U" series at school. With this he only received less than 1/2 of the prescribed amount. He had regressed badly again.

With less than 1/2 Larry started to pick up again.

In October of 1978 I took my son back to Dr. Larchia, his opthomologist. He said "If I had Larry's eyes in my head with glasses I could drive my car." Seven years before this the same specialist said, "Larry is completely blind in the right eye and has approximately a 13 inch snow flaked, flat vision in the left eye." The right eye is ready for surgery to remove the cataract but Dr. Larchia doesn't want to do it at this time.

The NODC has consented to give Larry all of his "U" series at the center now, and as of Feb. 12, 1979 he started to take all of his "U" series.

Larry has learned to swim and he was always afraid of the water. He can get on and jump on a trampoline by himself. He can dress himself and brush his own teeth. Larry has had a difficult time, but I pray he will continue to get his "U" series and to progress without anymore setbacks. Thank God for Henry Turkel, M.D. of Southfield, Michigan.

You have my permission to use any or all of this letter for publication.

3/14/79

Mrs. Trudy Repass, Mother/Guard., of Larry Bettencourt

247 Jervis St.
Toledo, Ohio 43609

JEFFREY A. FOSTER
Notary Public, Lucas County, Ohio
My Commission Expires July 30, 1979

December 1, 1978

Dear **World,**

Yes! We welcome the opportunity to share with others our rewarding experience with Dr. Henry Turkel and the U-Series.

Twenty three years ago, when our son David was born, with the pediatricians hopeless diagnosis of Down's Syndrome and equally hopeless forecast ringing in our ears, we resolved to never stop making the effort to improve our child's condition. Opportunities to institutionalize him or submit him to various drug experiments were quickly discarded. Rather we turned to his immediate needs: love; nutrition; exercise; careful stimulation; and frequent attention and we were satisfied in doing what we could to make his life full and his experience varied. Our family increased and as the younger ones grew we all learned a lot about and from David. We noted with sadness the summer after he completed the Special Education program (at 21) that signs of deterioration were visable. He had steadily gained weight since the age of 16 and the increasing burden to his system had already begun to seriously limit his capabilities and complicate plans for his future.

Then, early in 1977, we attended a birthday party. It was a sensation! because the young man, (honoree) whom we had not seen for at least a year, was noticably improved in his speech and body movements since our last meeting. His mother and grand-mother happily reported he had been on the U-Series for one year. Shortly after that time Dr. Turkel lectured at a city school and we were among the many persons attending. The theory behind the U-Series was simple and clear, the results in many case histories impressive. We decided to pursue the idea of obtaining the U-Series for David. We attended another birthday party. This one for Dr. Turkel himself given by the US for DS organization. We met several parents reporting considerable improvement in their children physically and mentally. We also sat in for a few days on the Marcom/Aetna trial. The battle had begun, however, the "Good Guys" medical bills were not required to be paid by their insurance company. We noted, for future, that professional documentation from and by developmental disabilities specialists could have been an important factor in this case. After this end we requested and received from our Regional Center complete physical and psychological evaluation on our son as of July 20, 1977 (Enc. #1) and discussed our intention of placing David on the U-Series with them.

Early in August, with the help of other parents, we traveled to Detroit to obtain Dr. Turkels consultation and medication. David's rapport with the good doctor was immediate and he cooperated with him completely and continues to do so with his diet and medication.

3/17/79 Dr. [illegible] has my permission to reprint this letter if they so credit. [illegible]

In October 1977 David was placed in a sheltered work-shop by Regional Center. We met at that time with the work-shop director and two representatives of Regional Center. David's abilities were discussed and a planned program for his progress was decided and the placement confirmed. Shortly after this their dietician visited us and we discussed in detail the U-Series program and David's diet. Recommended he limit his intake and substitute water for milk and juice. (We did not realize the changes to come -- without restricting intake.)

In late March of 1978 the senior Regional Center representative met with us again at the work-shop and again in our home. (By this time David had lost several pounds and had gained confidence by performing his work well and by using the public bus on one leg of the long trip to and from the shop.) We knew all these wonderful things already but were still unprepared for the quiet enthusiasm over Davids improved appearance and responses expressed by a renewed interest in the U-Series. We were greatly encouraged that the small daily evolutions became dramatic changes from the viewpoint of a six month interval.

By June David was making the entire trip to work and back (three busses each way) every working day by himself. His concentration improved, his taste in TV improved. He began to laugh occasionally at little jokes and come to conclusions regarding the impending action on the screen.

In October 1978, after one year on the U-Series and one year at the work-shop David's abilities have improved so that the Regional Center now recommends he be reassigned to a Vocational Rehabilitation program to train for a higher level job function. He has mastered a complete level of competency.

And now, lastly but not leastly, the results of this years psychological and physical evaluations (Enc. #2) are in and they reveal significant IQ point differences (advances) that must be taken note of. Additional testing is scheduled to bear out a more complete comparison with former scores. The skeptics among the professionals are shaken, and must eventually accept the simple beautiful truth that the U-Series and the amelioration of Down's Syndrome is a reality.

For our family and friends it is the continuing demonstration that faith in truth and the goodness of humankind will never be a disappointment. We are grateful to Dr. Turkel for continuing his work against all odds. We are grateful for the other parents who share with us God's indiscriminate blessing and who have formed the US for DS organization with it's high purpose to make the U-Series known and available throughout the world.

Most sincerely,

The Brunk Family

by Marilyn Brunk

CAROL KELLY, Ed.D.
Licensed Psychologist
1865 Greenfield
Los Angeles, CA 90025
(213) 479-0656

granted to D. Brunk 3/1/79

Permission to reprint part or whole

PSYCHOLOGICAL EVALUATION

NAME: DAVID BRUNK

DATE OF BIRTH: 09/18/55

DATE OF EVALUATION: 10/16/78

REASON FOR REFERRAL:

A psychological evaluation was requested in order to help determine David's current level of social and intellectual functioning.

PREVIOUS TESTING:

Records not available.

TESTS ADMINISTERED:

10/16/78

Wechsler Adult Intelligence Scale

Verbal IQ	47
Performance IQ	63
Full Scale IQ	51

Verbal Sub-tests	Scaled Score
Information	3
Comprehension	0
Arithmetic	1
Similarities	0
Digit Span	2
Vocabulary	0

Performance Sub-tests	
Digit Symbol	3
Picture Completion	5
Block Design	6
Picture Arrangement	2
Object Assembly	6

Peabody Picture Vocabulary Test

CA	23.0
MA	10.8
IQ	71

TESTS ADMINISTERED: (continued)

10/16/78	Wide Range Achievement Test	Grade Placement
	Reading	1.1
	Spelling	2.2
	Arithmetic	Kg.8
	Draw a Person	
	Bender Gestalt	
	Mental Age 9.6	
	Vineland Social Maturity Scale	
	SA 9.3	
	SQ 44	

BACKGROUND INFORMATION:

David Brunk attended TMR class placement throughout his school years. He was graduated at the age of 21 from Lanterman High School, and he currently attends a workshop at Self Aid in Glendale. He has attended the workshop for almost a year at this time. David has been participating in a program with Henry Turkel, M.D., which utilizes orthomolecular therapy which depends primarily on vitamins to attempt to ameliorate Down's Syndrome. Dr. Turkel's program is headquartered in Detroit, Michigan, and Mrs. Brunk reports that she has been traveling with David to the Center. She relates that she has seen great improvement in David's capabilities since he has been involved in this program.

David lives at home with his parents, a brother and a sister. He has another brother and a sister who are away at college.

SUMMARY IMPRESSIONS:

David Brunk is a 23 year old Down's Syndrome man who is personable and appears outgoing. He was cooperative throughout the testing session and seemed to enjoy himself very much. He talked freely about himself and was especially proud of losing 35 pounds after being placed on a diet a year ago. He is still slightly overweight; however, he is continuing to watch his diet.

On the Wechsler Adult Intelligence Scale, David achieved a Verbal IQ within the Moderate range of retardation. His performance score was significantly (16 points) higher and was within the Mild range of retardation. An analysis of individual sub-tests suggests that David's strengths are in the area of non-verbal organization and perception of part-whole relations and tasks involving assembly skills.

SUMMARY IMPRESSIONS: (continued)

David's performance on the Picture Completion sub-test, which measures visual alertness and memory, was also a strength as compared with his own test performance. Deficits were noted for David in the verbal areas measuring comprehension, abstract thinking ability, and word knowledge. On the Peabody Picture Vocabulary Test, a non-verbal measure of ability, David performed higher and achieved an IQ within the Borderline range of abilities. This would suggest that his receptive verbal abilities are better than his expressive abilities.

On the Wide Range Achievement Test, David could spell the word, "cat", which gave him a spelling grade placement of 2.2. On the Arithmetic section, he could count to fifteen (15), identify five (5) numbers, tell which of two numbers was larger, and he achieved an arithmetic grade placement of K.8. He was unable to compute any simple oral or written problems. His reading recognition placement is 1.1. He could identify all of the letters of the alphabet and read the word "in."

David's Bender Gestalt protocol was well executed. Two errors were noted including some slight perseveration on one figure and one angle incorrectly reproduced on one of the figures. Overall, his visual motor skills appear well developed. David did spend an undo amount of time (9 minutes) reproducing the designs.

Mrs. Brunk provided the information on the Vineland Social Maturity Scale. She noted that David has all of his self-help skills. He is encouraged to be independent in all areas. Mrs. Brunk related that David rides the RTD and transfers twice on his way to his workshop. He helps about the house with routine tasks such as taking the trash out, helping cook meals, changing his bedding, putting the dishes away, and carrying groceries. He buys his own clothing accessories and generally selects the clothing that he will wear. David achieved a Social Age equivalency of 9 years 3 months on this instrument.

DIAGNOSTIC IMPRESSIONS:

Down's Syndrome with Mild to Moderate level of retardation. Social and adaptive abilities within the Moderate range.

RECOMMENDATIONS:

(1) Explore the possibility of placement in the future in a small group residential setting.

(2) Continue placement in a workshop program.

Carol Kelly

Carol Kelly, Ed.D.
Licensed Psychologist

DEAR WORLD:

I would like to tell you about a wonderful little boy Joseph Wayne Bryant, Age 5, and his great success on the U Series.

Joey was born Friday the 13th of July, 1973. Joey was born premature, I was in the hospital three days before he was born, the doctor said for us not to get our hopes up, the baby was coming too early and his chances for living would be very slim, but to everyone's surprise, Joey weighed 4 lbs. He was in the hospital for several weeks, during that time he had yellow Jaundice, but at last he came home to his three sisters to them, he was perfect.

When he was three months old we took him to Children's Hospital and had Chromosome tests revealed Joseph definitely had Down's Syndrome. Joseph did real well, until he was 8 months old, He was hospitalized with pneumonia and a high fever, we didn't find out tell months later he had had encephelitis.

Joey slept day and night after being dismissed from the hospital, we would wake him up and force him to eat, during the time he was awake his head jerk and he would stare. Several Doctors told us it was just a weak muscle in his neck, that Joey was severly retarded, nothing would be done for him.

August 1974, we took him to Columbus to Children's Hospital, right away we were referred to a top Neurologist there. Joey was having damaging Seisures, we were told he was dying. They asked us Why we had waited so long to bring him. Our sweet sleepy baby had not cried or smiled since his sickness. Joey was started on a massive dose of Predisone, also given Mebaral and Dilantin. He gradually became more alert, one day he finally cried, we were so happy we all cried. He grew stronger, the seisures stopped, he could set up, he smiled all the time, but he was very nervous, his little fingers moved constantly, grinded his teeth, he would move his head back and forth. We were also told at Children's Joey may never walk.

Our five year old daughter took the Chicken Pox, I called the Doctor and was told with Joey on Predisone if he took the Chicken Pox it would be fatal. He contacted the Contagious Disease Association in Atlanta, Georgia that very morning , they flew the medicine "the Zig Shot" within 2 hours by plane, we drove Joey to Columbus, The Doctor met us there, as he opened the package that contained the medicine, he said , Do you realize what we have here, a great break through in Science, You could not begin to afford this shot, soon all children will be able to receive it and the Chicken Pox will be eliminated.

Joey was never satisfied when fed, always cried, After being on Predisone 1 year, Joey became weak, could not stand on his feet, Cried a lot, He was very nervous now, vomited his milk and food. A young Doctor at the Clinic told us to gradually take Joey off the predisone, but very slowly, he began to show improvement, I decided I would take him off all drugs, his nervous pattern stopped. When he had been off all drugs for 6 months with no side effects, and no sign of seisures, I read about Dr. Turkel in several magazines, I knew I had to get an appointment with him for Joseph. Finally we got the Appointment August 1976.

When Joey finished his school year in 1978, we went to Michigan in June, this time Joey was doing so well, we purchased a year's supply. He weighed 35 lb. and was 41½ inches high. He could feed himself, Use his potty, and could climb the stairs standing up.

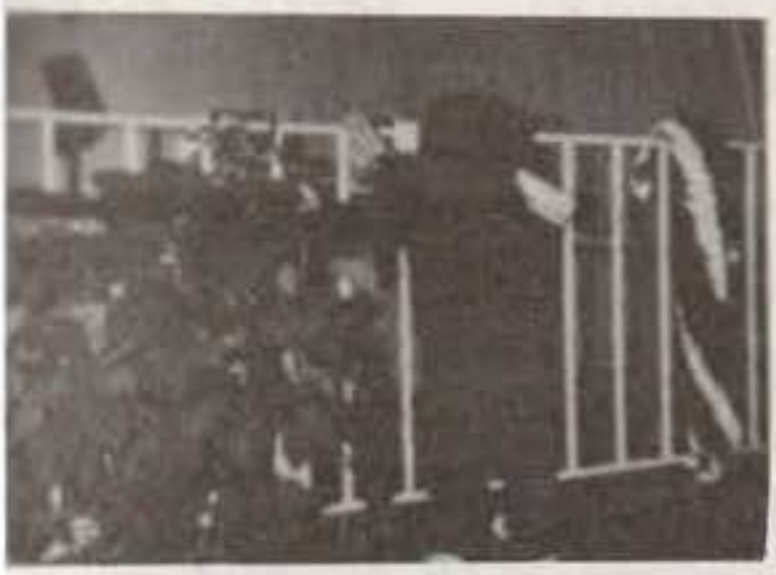
Joey enjoyed his summer. his sisters played with him all the time, read books to him, he liked going swimming, loved the water, he enjoyed visiting with his grandmother that was ill, she died in June, he would still want to stop when we passed her house. He enjoyed the sun, loved to pick his other grandmother's flowers next door when he got a chance, She never minded.

On July 13, 1978, Joey was 5 years old, he loved his birthday cakes. Just 13 days later July 26th, Joey was restless and it was a pretty day and my car was in the shop, we decided we would take Joey a ride in his big red wagon, we live in the country, he enjoyed his ride and sang and laughed all the way up the road, we visited a neighbor as we returned home down the road, we were walking facing traffic, we were approaching a curve ahead, when I heard a truck coming, My 11 year old daughter and I pulled the wagon off the berm of the road into a grassy area, when the truck came into view, the wheels were off the highway coming straight towards us, we ran into the field pulling the wagon, but we couldn't get out of the way fast enough, the truck hit the back end of the wagon, where Joey was setting, my daughter and I were thrown to the ground, When I got up and the air cleared, there on the ground face down in the dirt laid our precious little boy dead. He had been killed instantly. I was taken to the hospital in shock.

Joey touched so many lives in his 5 short years. The minister that preached his funeral, called him the minister of the Bryant Family, It has just been 4 months ago today as I write this, we miss him so, The little boy we thought would always be with us had been taken away so quickly. Thanks to Dr. Turkel the last 2 years of his life that Joey was on U Series was terrific, everyone who knew him was delighted with his improvements. He was so healthly and so happy and brought joy to everyone he met.

Gary at Birth

Gary age 2
before treatment



4 months on Treatment
first time in Christmas Look

age 4 years
1 year on treatment

Gary 4½
Happy Boy

Notice
the bridge
in his rear →

Gary's last
picture taken
on his 5th Birthday
July 13th 1918
Just 13 days
before he was killed

February 20, 1979

Dear World,

The gift of our child was in 1972. The fear and anxiety of parents is the future of their children more so if their child has a handicap.

In the 1973 March issue of "Prevention," we read of Doctor Henry Turkel and his U-Series treatment. We read it with joy and sorrow, knowing that chances were great it would never be for our child.

With concerned family, friends and our family physician, Doctor Arthur Kaslow who has treated our child for the last two years with loving care, diet, vitamins and nutrients much as Dr. Turkels treatment without the U-Series. Our child remained in good physical health but was developmentally delayed. Functioning at 3 years 5 months and communicating that of a 2 year 10 month youngster.

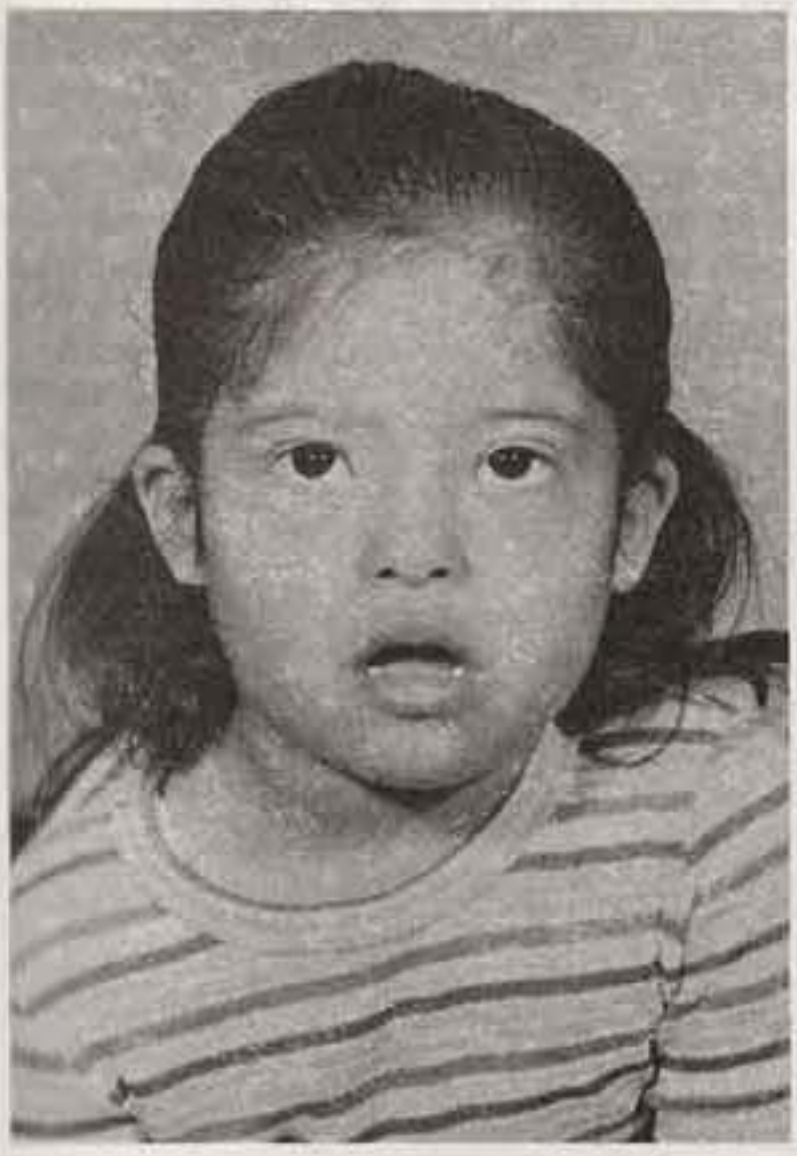
On November 1978 the impossible dream come true. We were able to fly our child to Dr. Turkel for treatment. The joy and excitement of it all!

In the short three months of treatment the improvements are fantastic. Her speech is improving daily. Four, five and six word phrases, which before treatment usually was one or two words or acted out her wants and needs.

she understands everything. Eye-hand coordination three months ago was next to none. Now she's learning to write her name. Behavior was hard to control. I never knew how she'd react or what she'd do. Now it's so different, she'll always behave when asked and doesn't wonder away, follows instructions most of the time. Having four other children I consider that normal.

World only you can help everyone who wants and needs the O-Seriel treatment have it. Please help.

Sincerely,
Genevieve Daugherty



BEFORE

AFTER

P. O. Box 6660
Clearlake Highlands, Calif.
95422

February 23, 1979

Dear World,

Today our daughter Jeanne celebrates her 21st birthday, a little more than three months before her high school graduation, after a total of only 11 1/2 years in public school from Kindergarten through twelfth, but a tremendous amount of home study/tutoring. Much of this is due to Dr. Henry Turkel's "U" series treatment which she has been on most of the time since June, 1972 -- longer than most DS children, but she also has the problem of needing a galactosemia diet.

Though born in Highland Park (within the city of Detroit), Mich., less than 2 miles from Dr. Turkel's office, it was to be, ironically, 14 years, many inquiries about the "U" series to different doctors, and many heartbreaks and health crises later, that -- from California-- we learned his address. Many of the health, development, and education difficulties would have been eliminated, we are thoroughly convinced, had she been able to be on the "U" series as an infant.

Meanwhile, she had spent 11 days in the hospital with respiratory and feeding problems, followed by 12 in a nursing home before joining her 8-year-old brother, Jack, her United Methodist minister father, and former teacher-secretary mother, now turned nurse-mother, at home. Ill health continued, with weekly (or thrice weekly!) doctor visits for years. Improvement came with the Doman-Delacato program and diet; but <u>elimination</u> of these problems, not until the "U" series.

Therapy improved congenitally dislocated hips so that at 17 months she could walk, and so be accepted in the play world of neighbor children. At age 3 she entered and enjoyed a co-op preschool nursery, where she spent 3 years part time.

Then further discouragements: public schools were uncooperative, and speech therapy though legally required was unfunded. A school psychologist told us "I'll admit you have her well trained, but this child is untrainable with no measurable I.Q." Certain that she was educable -- a belief reinforced by testing in New York where a psychiatrist had said she had the highest I.Q. of any DS child he had tested (in the high 70's) -- we shopped for schools. Denied kindergarten by the schools, except for free play period, and with pre-first limited to 1 semester, we learned of the Doman-Delacato developmental therapy program.

She was accepted at age 8 1/2, though very few DS children had been before. Three years, full-time, in two parishes with over 150 church members and friends helping with the "patterning" exercises, saw tremendous improvement. Simultaneously, with the start of this we learned of the galactosemia diet just developed, and started her on it. Now Kay doubled as full-time mother and director. Another two years, part-time, followed with Jeanne in school at first only half days.

Then the big breakthrough. At 14 Jeanne met Dr. Turkel in Detroit, and began taking some 25 pills a day, becoming more alert and responsive, and with better health than we could have hoped. Learning strides were significant. Vision improved; hearing improved; speech improved; school progress improved, and with teacher and speech therapist help, she entered high school in 1974, with 1st year on a half-time basis.

Today she takes part in numerous physical activities, with favorites being bicycling, swimming, and gymnastics (when available). She has sung in a church choir, high school chorus, and a community college chorus. She has also played volleyball 1 semester at an evening community college co-ed class; is an excellent basketball shot, if not team member; has learned the rudiments of baton twirling; plays a cello and guitar a little; is an avid reader; a good speller, types accurately, if (as yet) slowly, has excellent handwriting, and is a serious and methodical student.

From "unacceptable" in a trainable class, with hearing, vision, and muscle use improved -- chiefly through the "U" series, creep-crawl exercises, and galactosemia diet -- she has attended educable classes, and is now spending 3 periods a day in regular high school classes, and 3 in a special help CORE classroom.

Her learning skills are growing constantly; she is gaining in self-confidence, and has learned to work at her own speed. She has just passed her high school Driver Education course with A's on weekly chapter tests, and is looking forward to attending vocational school or further academic training, in one of the new community college special programs in California.

Thank you, Dr. Turkel, for all your help and encouragement. Until PREVENTION is possible, the "U" series helps us believe that "all things are possible."

E. Julius Davis

(Rev.) E. Julius Davis

Catharine M. Davis

Catharine M. Davis

BEFORE

AFTER

Sept. 1978

Laverne, OK 73848
March 9, 1979

Dear World:

Our little girl, Suzanne, age 5 years, has been on Dr. Turkel's U Series for six months. She has made so much progress in these past months——from a non-verbal child to one with a vocabulary of approximately 50 words. Most of these she speaks spontaneously.

Suzanne's motor skills are improving daily. Her attention span has increased to where she now works on her pre-school activities for 45 minutes or more without frustration. Self-help skills, such as dressing, bathroom training, have improved to where she needs very little if any assistance. In fact, she would prefer to do it herself.

Since our child is handicapped, it is her right to have adequate medical care to grow and develop to her fullest capacity. As the U Series is the only known treatment for DS children, it should be readily available in every state.

Mr. & Mrs. Ron Duncan

Mr. and Mrs. Ron Duncan
Box 676
Laverne, OK 73848

Signed this 9th day of March 197
My commission expires August 4,

Notary Public

March 1979

March 5, 1979

Dear World,

I am the nother of a six year old boy with Down's Syndrome. Byron is my only child, born when I was 39 years old. It was a very difficult time, to say the least, when after two months my doctor's nurse told me he might possibly have a disease that would affect him mentally. That's all she said because they weren't sure and the doctor was never there for me to ask him. A month or so later I finally asked my pediatrician what Down's Syndrome was (I had seen it as a possible diagnosis on an insurance form I turned in.) He explained it was what we used to call Mongolism. There wasn't anything that could be done, that many parents institutionalize these children, and that there would be medical problems. This was about the extent of his explaination -- all I could do was treat him as normally as possible. At eighteen months a new doctor thought I should have the Chromosome test done at the university and there the Trisomy 21 was confirmed. I was told then of a parent group that was meeting and about an Early Intervention Program which I joined. This was the beginning of some really good things. He was already 26 months old. Up until that time life was pretty frustrating and lonely, with lots of tears and fears.

Byron was three when a friend told me to listen to a TV show in which a doctor was talking about Downs Syndrome. It was so encourageing to hear that something was being done medically and after hearing the lecture in L.A. I felt I had to put Byron on the treatment. It really made sense to me and confirmed many of my observations and experiences. He had gotten so "puffy" and was quite lethargic. He had started out really quite well but was becoming more "Downs" all the time.

As the treatment progressed I noticed more activity, less sleeping, more purposeful play. He was able to figure things out for himself better, was more responsive and attentive. We were also doing the Doman, Delacato program during the first eight months. This was also a big help in his development--gross motor and other areas.

He has been on the treatment for two years now. He has grown 4 inches and gained 12 lbs. He has "slimmed down," his stomach is flatter, his eyes are not crossing as much, he looks more normal. The children at the pre-school he went to before the treatment and then for awhile later said they couldn't call him "flat face" anymore.

I am very thankful we have been able to have him on the U-Series. The positive things happening and the progress he is making with the help of so many makes the future look a whole lot brighter and life has had a lot more smiles and fewer tears as we see him developing far above our expectations. He is a great helper, is more co-operative, happier, healthier and behaving more normally as time goes by.

It certainly would be wonderful and such a relief if we could get the U-Series from our doctor here in California. We hope that everyone who wants to use the treatment will be able to very soon. Dear world, maybe if we all work together we can make this dream come true.

Sincerely, and with love,

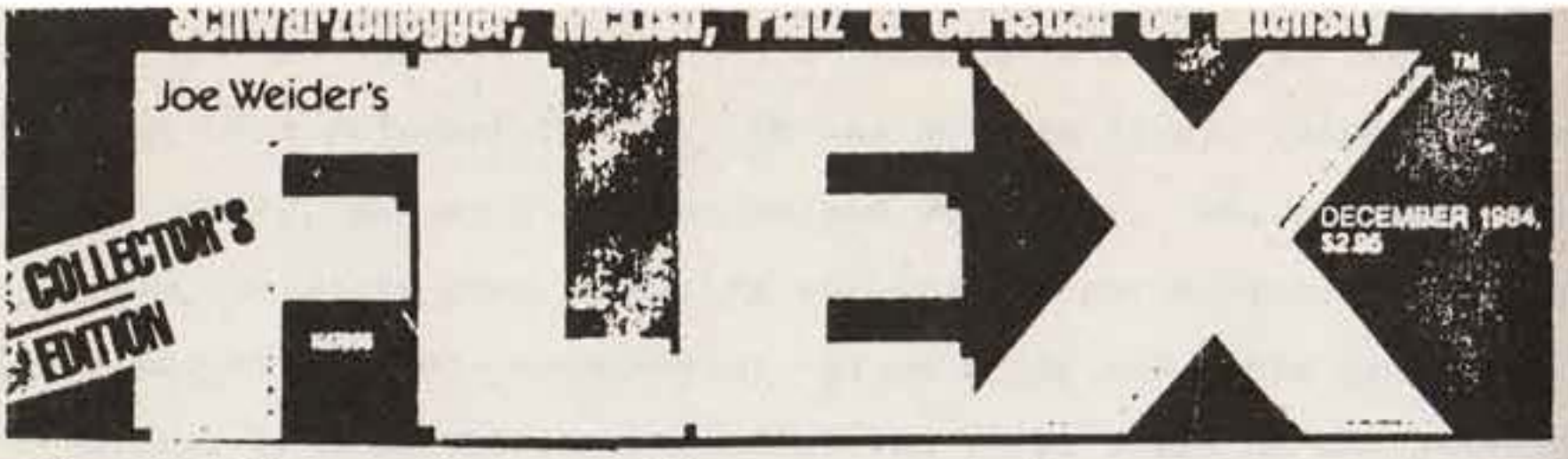
Carla Epp

Byron's mother

BEFORE

AFTER

DECEMBER 1984



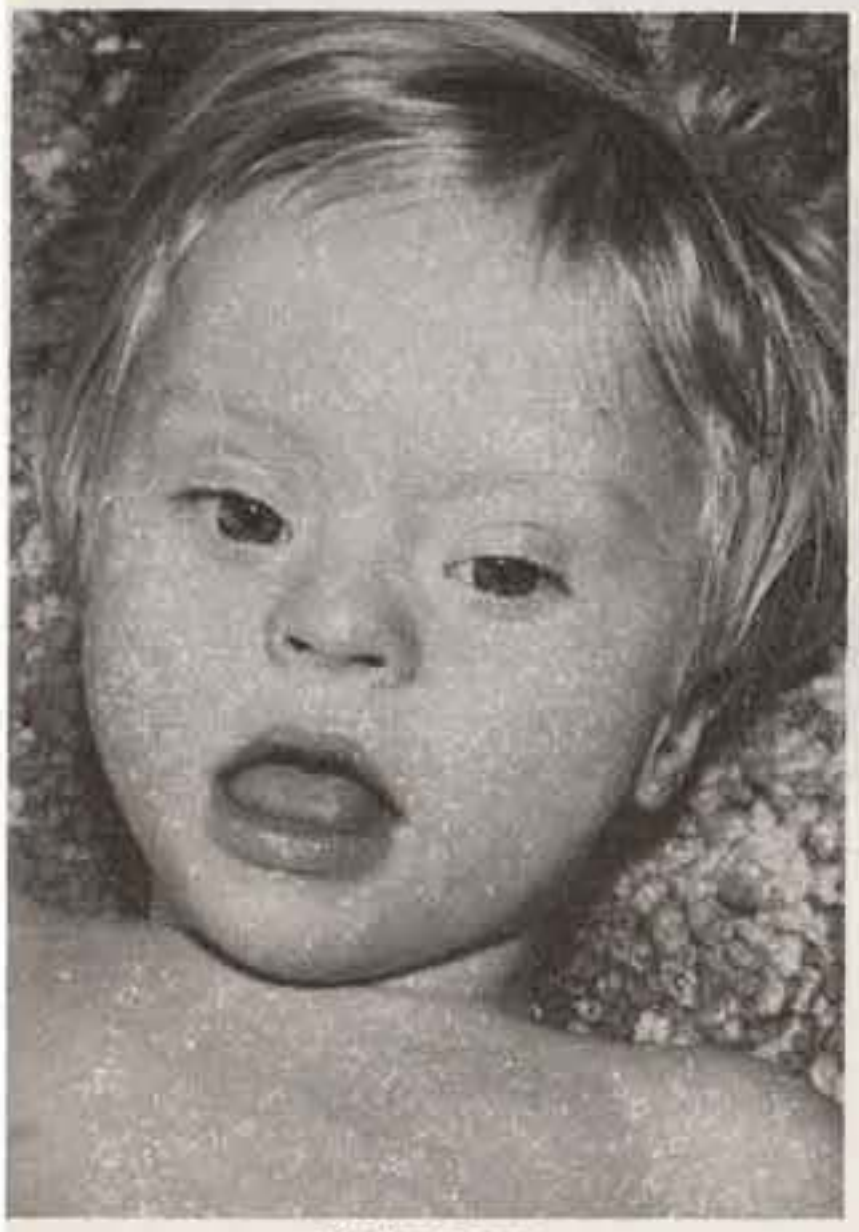
The Strong Support the Weak

The AFWB recently came to six-year-old Victor Mosch's rescue; Victor suffers from Down's syndrome and is undergoing a medical treatment called the U-Series. The cost of the treatment is $200 per month plus travel expenses to Michigan, the only state in the USA where the treatment is now being offered.

The 1984 Colorado Bodybuilding Championships dedicated this year's competition to Victor, but when they weren't able to raise the needed amount for his trip, the AFWB stepped in. The Michigan Bodybuilding Association then picked up the tab for Victor and his father once they arrived in Michigan.

The trip was a success for both father and son. The two visited the Detroit Zoo and were treated to all the ice cream and candy that they could hold. Victor spent the necessary hours with Dr. Henry Turkel, and left for home with a full one-year's supply of medication.

A special thanks to all of you in bodybuilding. Without your help, children like Victor wouldn't stand a fighting chance. We of the AFWB feel this is a worthwhile project, and would like to continue to support children like Victor.



BEFORE

AFTER

3625 Headingly NE
Albuquerque, New Mexico 87110
December 1, 1978

Dear World:

Because Dr. Turkel's success with the "U" Series was rejected, and news of it was suppressed in the United States, my daughter, Susan, was almost seventeen before I learned there was a treatment for Down's Syndrome. No local help was available twenty years ago and even now is in short supply, but she was one of the lucky ones. Our version of a balanced diet kept her in good health, and mentally and physically stimulated by a loving family and a few friends, she acquired the necessary skills for living, learned to read and learned lettering, followed by cursive writing. She learned numbers and seemed to understand the arithmetical processes, but failed to learn many number facts - sums, products, et cetera. She enjoyed drama and music and worked at arts and crafts. She went everywhere with us and learned the use of maps, calendars, and schedules - especially TV schedules which she used with her watch to find programs. She communicated ingenuously almost without language. Teaching her to read was a means of teaching speech. Her progress was slow, but she seemed bright and younger than she was.

But with the stress of puberty and a relaxed regimen, she gained weight and became lethargic and dull much of the time. She made no further progress with her studies. By this time really studying nutrition, I put her (and three of us joined her) on a strict regimen with natural food and carefully researched supplements with fruits and juices instead of other sweets and no sugar or other refined foods. With the improvement in nutrition, she found the initiative to announce that it was vacation time, and it was June. But missing schoolwork after a few days, she began to copy printed material in cursive writing. She wrote a few lines each day over a period of two weeks or so that graphically demonstrated her declining skill.

Although the new regimen would prove to reduce her weight, there were few avenues left for progress. Although she continued her personal grooming and made her bed, she did little else except watch TV or play records. She often refuse vehemently to go out with us, but when it was necessary to force her to go she did behave acceptably. It seemed reasonable to assume that her condition would worsen or at best remain static. TLC was not enough.

Before the end of the year, I had discovered Dr. Turkel's work. Susan's luck was unbelievable. Dr. Turkel was able to see her in the fall of 1975. At home there was both skepticism and enthusiasm, but everyone agreed to give "U" Series a chance. In the second year so obvious was the mental advance, the skepticism faded entirely.

Another happy circumstance was the eagerness with which Susan embarked on the treatment. She easily accepted the discipline and consistently rejects opportunities for indulgence. In six months she, who had not grown in five years, grew an inch and later another quarter inch. She became trimmer with a small weight loss and her posture improved. With a renewed interest in learning. she scored a six year increase in word comprehension in one year.

Now beginning her fourth year on US. her first interest is music, both classical and popular. She really listens, recognizes the music. and knows the performer's name. Using Dr. Turkel's Word Rummy cards in a special way, she can quickly learn to spell difficult words. She tolerates arithmetic, but has flashes of skill that are encouraging. She enjoys geography, and surprisingly, her interest in history is sustained through dry accounts. Her utilitarian speech is understandable and sometimes quite clear. However her creative conversational remarks are hard to understand, but she is patient and inventive in clarifying. She no longer withdraws with a "Forget it." And with an advance notice of an upcoming little trip, she is prepared to go out without stress. On rare occasions she has proven herself capable of handling any household chore. Next, we should find time for her to do them on a regular basis.

I am telling the World that the older DS child can be helped by the "U" Series.

Sincerely,
Julia E. Malley
Julia E. Malley

Oct. 1978

BEFORE

AFTER

Dear World

When my son Marcelle was born in 1958 in Rio de Janeiro, Brazil, nobody noticed that he was a Down syndrome boy.

I was so excited and happy, I never thought of the terrible surprise that was to come into my life.

One day, when he was more or less two or three months old, my mother came to visit me and noticed that the baby could not sit in an erect position. She was afraid to tell me that there was some possibility that the baby was not normal, and after a family reunion they decided to tell me that it was better if I took him to a pediatrician and get his opinion. After I saw several doctors and had the doctor examine my son, and saw them talk amongst themselves, for the first time in my life I heard about mongolism.

They tried to explain the problem to me. I was shocked and I cried for days; however, I thought crying won't help my baby. I tried to contact people who knew about Mongolism and one day a friend told me she heard about a School for the Retarded which was not far from my home.

Because I was a teacher of Elementary school, I decided to take courses in Special Education and started working in the program of Neurological Organization, from Doman-Delacato of Philadelphia.

2 My son started to receive this treatment that helped him to walk and speak better. But he always had respiratory problems because his nasal bones didn't develop properly and his motor development was also poor.

Because my husband had a sister living in America, we decieded to join her and try to see if it was possible to give our son a chance for better treatment and a better future.

Upon our arrival, he started going to Mac Donell Avenue School and after that Lanterman High were he is still attending today.

But he continued to have the same health problems and heavy weight, eating too much and always tired and lazy.

One day I heard about a boy in the School, who was going through a special treatment with a Doctor from Detroit and his mother was very enthusiastic with the son's improvement.

I tried contacting her, and a few days later I attended, with another mother with a Down's syndrome son, a Conference where Dr. Turkel spoke to the parents. I bought his book and read it. I became very enthusiastic. I attended several meetings of the US for DS and I became a member.

In June 8, 1978 I went to Detroit in the company of another enthused mother and her son David, who was in the program since the previous year. Two days later, my son Marcelle started his treatment.

He is now in his 6th month of treatment and he lost 27 pounds. He doesn't eat the same amount of food and he understands he cannot eat too much and does control himself.

He doesn't seem tired like before and he is more sociable and tries to converse with people. He is more assertive and will even argue to get his point across. His colds are not the same as before, although at times his nose is a bit clogged, but we live in Los Angeles where the air is quite polluted.

We thank God for the opportunity of meeting Doctor Turkel, who is really devoted to the problems of the Down's syndrome and who has really helped, not only our son, but the son's of other families all over the world thus giving them an opportunity for a new life.

God bless you, Dr. Turkel.

Dolores Gutierrez Plebani

1978

1979

II

April 13th

Sara had an evaluation done by the state just. As usual I have to wait for the written report which will probably take a month or two. I did ask for an informal report & basically was told the following:

1. Cognition: Sara was functioning above her age by a few weeks. Her receptive language is above normal. This was due to her signing and her verbalization. Also the psychologist was impressed with her level of frustration. By that he meant how she tried to master a task way above her level, she didn't give up easily. She will work on something & keep on trying.

2. Fine Motor - approximately age appropriate. Her pincher grasp (was not fully developed but is now) and she would not put cube in a cup (drinking). She thought it was a cup to drink from. She has been putting objects in a container since December. I was upset that they used a drinking cup for this task.

3. Gross Motor - functioning at 8 mos. This is her greatest delay. Mostly because she's not walking. But the physical therapist has said that in the past 3 weeks she has jumped 2 months. She is now constantly pulling herself to a standing position (and does it easily). Also about 40% of the time is crawling on all fours. She definitely is getting much stronger in the legs. Even her muscles feel firmer. Her ~~calfs~~ calves are beautifully shaped & nice & firm. Her thighs are now getting that way.

To say the least, I hate these evaluations. It was done at her nap time (1 PM) and lasted 1½ hours. It was also done by a total stranger.

I asked what the norm is for a Down's child at this age. They asked me if I wanted to compare Sara to the other Down's because of your treatment. I said yes. What they said was that Sara was exceptional. She was not the typical Down's child. She especially was advanced in her language and her receptive understanding. In fact if she didn't have the diagnosis of Down's, she would not be eligible for the program.

She's amazing sometimes. She is now signing and saying the word at the same time. Can follow 2 consecutive commands. Can identify cat, dog, baby, teddy, clock, apple, banana and phone from flash cards. Practice the language most of all in school. She is such a happy child and wants to learn so much. She is not happy to just sit and be quiet. She's very curious and doesn't miss anything. She understands everything that is said to her.

Her playing and eating is wonderful. She holds her own cup now about

35 % of the time and does quite well.

I can't get over her weight gain in the last month. It sure has jumped. As this normal? I'm careful not to give her to much starches or junk food.

Her nose is still runny. I have noticed her mouth is staying close more now. She also likes to blow bubbles

She loves herself and thinks she is terrific. Can initiate play herself with the other children. She's now trying to sing with music. She has a great deal of self confidence.

Here are the pictures. I'm a little disappointed because she just wouldn't sit still. I hope they are all right.

All I know is that I love her more each day & can honestly say now I have hope and dreams for her future. The U series has made all the difference in the world for us.

Blanks

BEFORE

AFTER

MONTHLY REPORT OF PATIENT

PLEASE ATTACH:

1. POLAROID PHOTOGRAPGH, TAKE LENGTHWISE EVERY 6 MONTHS.
2. SCHOOL REPORTS every semester.
3. 2 PAGES OF REPRESENTATIVE SCHOOL WORK every 2-6 months.

NAME OF PATIENT Sara Prestwood DATE 5/16/85

ADDRESS 6 Kingsley Rd Mt Holly NJ 08060
street city state zip

BIRTH DATE 02/07/83 HEIGHT 32" WEIGHT 24lbs

OBSERVATIONS SINCE LAST REPORT; PLEASE CHECK APPROPRIATE ANSWERS: Head-18¾"

1. Has child been ill? YES [ ]; NO [✓] If yes:

   a) With what illness? _____

   _____

   b) How many days? _____

   c) What was the treatment? _____

Please continue the "U" Series during treatment with other medicines EXCEPT SULFA. EXTRA VITAMIN C AND E MAY BE ADDED TO THE "U" SERIES AS NEEDED. Use nasal spray and teething lotion as directed.

   d) Response to treatment _____

   _____

   e) Surgery? Yes [ ]; No [✓]

2. Have others in the household been ill this month? Yes [ ]; No [✓]
   a) With what illness? _____
   b) How many days? _____
3. Does the patient have any chronic illnesses, such as:
   a) Frequent respiratory infections, colds, bronchitis, pneumonia?

   _____

   b) Congestion? Yes [✓]; No [ ]
      PLEASE USE TEETHING LOTION ON SWOLLEN GUMS.
   c) Middle ear infections? Yes [ ]; No [✓]
   d) Digestive illnesses? Yes [ ]; No [✓]
4. Have you noticed any changes in the following physical features?
   a) Eye "crossing"? Yes [ ]; No [✓]
   b) Puffiness around eyes? Yes [✓]; No [✓]
   c) Epicanthal eyefold? Yes [✓]; No [ ]
   d) Profile - shape of neck, nose? Yes [✓]; No [ ]
   e) Does the abdomen protrude? Yes [ ]; No [✓]

ADDITIONAL COMMENTS ON THE ABOVE QUESTIONS Sara appears to be getting more elongated & some bridge on nose developing

5. Is the patient:
a) Generally happy [ ]; b) apathectic [ ]; c) discontented [ ]
d) Even tempered [ ]; e) hyperactive [ ]; f) sluggish [ ]
g) Independent [ ]; h) attached to family members [ ]
i) More [ ] or Less [ ] communicative?
j) Fearful of strangers [ ] or new situations [ ]?
k) Aware of danger [ ]

6. If there have been changes in the patient's or family's routine, how well has the patient adjusted?

7. Please specify changes, if any, in eating or sleeping patterns:

8. Has the patient developed any new social skills since the last patient care report, such as sitting alone, standing or walking unassisted, feeding self with spoon or fork, new words, dressing alone, riding a tricycle or bicycle, letter recognition, reading, writing:

9. Please specify academic achievements since the last report:

10. PLEASE DESCRIBE ANY SIGNIFICANT CHANGE FOR BETTER OR WORSE IN ANY OF THE ABOVE, INCLUDING ANY NEW, UNDESIRABLE BEHAVIOR PATTERNS SINCE ENCLOSING BACK OF PAPER IF NEEDED:

NAME OF PARENTS OR GUARDIANS Diane & Roy L Pesterfield

ADDRESS 6 Kingsley Rd, Mt Holly NJ 08060

TELEPHONE 609-261-1216 OCCUPATION RN

SIGNATURES Jane E Pesterfield

50 children to service. You guessed it - she was dropped because she is doing so well!!! She has started appropriate sentence structure of 2-3 words - (talking) i.e. Dad sit here." Was furious to say the least. She is beginning to drop her sighs & wants to talk so very much & I think she is doing almost normally for a 3½ year old. Speech is her greatest achievement. I talked to the supervisor of the school assembly person etc but with no results. So I've hired a private speech therapist to see Sara ½ hr/week. If you do well they send you aside. Her mastery of the American language is astonishing. She follows triple commands, points all parts of the body, even eyes, nose, tongue, lips etc. Points to pictures in books & starts her own conversation (e.g. Dad see ball) She walks thru the house yelling for her brother & is so very independent. Eats & gets herself down diaper taken part. She even sits & pillows & lays on the floor to watch cartoons.

She has great imagination. Sets & plays house with her dolls & even sings to them. Plays with trucks & matchbox cars. She loves puzzles & knows the difference between circle & square.

Gross motor is improving more & more. She never crawls now. She plunges her derriere beautifully walks up & down hills & loves it outside - Spends the backyard to play for hours. She tries to run to keep up with her brother but hasn't mastered it yet. She climbs onto everything & is forever emptying my cabinets to play. Carries her dolls around the house. She can climb onto a small bike but only pushes herself backwards. She stoops nicely but still doesn't know walk.

Allow all Dara is wonderful. I can't wait to take her to the beach this summer.

We've had a terrible spring. My own allergies are very bad. Dr Jack I've used the nasal spray myself. I can't tell what relief it has given me. It clears my head better than anything I've ever used. The yuck that has come out of my sinuses is unbelievable Dara, too is draining a great deal from her sinuses. She even tells me when she wants more spray. Could it be possible that she has allergies?

Enclosed is a picture of the kids taken in Jan. Dara looks good don't you think? She grows more beautiful each day

Sincerely

Frank Spurlock

P.S. I've been voted Parent of the Year for 1985. ARC will present me the award in June. I can't believe it. Actually Dara has done all the work & I just supervise it. She has taught me so much & I love her dearly. I think the U-Series has developed her into what she is today. It has made her whole life work. I'm so thankful we have found you. THANKS

Sept. 1, 1983

Dear World,

I prayed for 15 years there would be someone that could help Lisa, our Down's syndrome child, to function and communicate better.

Our friends had relatives from California who came to visit them and they had a little boy who was being treated by Dr. Turkel's "W" Series. They called me to come down and the mother explained how the treatment had changed her child. She gave me Dr. Turkel's address that day.

I went home and explained it to my husband -- I was so excited, as I felt my prayers had been answered.

We began getting the medical records we needed after receiving word from Dr. Turkel that we could see him.

Our first appointment was Oct. 30, 1981 -- my husband's birthday. We will never forget that day.

Lisa's appearance has changed -- has lost that puffiness and 9lbs. She moves about better, starting to make decisions, and her health is good.

She are hoping her speech improves.

Many people have told us they can see a big difference in Lex. I wish everyone with a Down's syndrome child could use the "W" Series treatment.

Sincerely,

Eva Mae Rippe

Dear World:

During the first seven years of his life, our son, Dan, was plagued with ear infections, sore throats, and related illnesses. Every three to six weeks he was seen by the pediatrician and placed on antibiotics. We were always told this was typical of Down's Syndrome children. My husband, who is a dentist, and I both felt that there must be some way to improve Dan's ability to handle infections. Since Paul has always been interested in the effects of diet on body chemistry and tooth decay, we both continued to read everything we could find on improving health, in hopes of finding help for our son.

While reading Adelle Davis' "Let's Have Healthy Children", I came across Dr. Turkel's name, and wondered whether he might still be in the Detroit area. Since we lived in central Michigan, this would be an easy distance to travel if we decided to consult with him. Finding his name in the Detroit phone book, I called, and was immediately sent some explanatory literature. I also ordered a copy of his book "Medical Amelioration of Cytogenetic Anomalies". Paul and I both read the book and were very excited with the concept of Dr. Turkel's treatment using the "U" Series We loaned the book to our family physician so that he could read it before we asked for a referral to Dr. Turkel.

After several conversations, we finally convinced our doctor that, since he could offer nothing else to improve Dan's condition, he should let us try Dr. Turkel's method of treatment. In the summer of 1975, Dan was seen by Dr. Turkel for the first time. After that first visit, I remember very vividly the letter I wrote to a friend who was thinking of taking her baby to Dr. Turkel. That ~~xxxx~~ letter said, in part, "Betsy, this man is for real. He has something to offer our children and he has facts to back up his work."

Withina month after beginning the "U" Series, Dan had shed three inches around his waist. I had been having difficulty buying trousers to fit him because of his "pot belly" which so many Down's children have. In another three months, we noticed that Dan was running much faster and more easily when he was playing outdoors. Previously, he always appeared to have "rubbery" knees and hips, so that his running presented a very awkward looking gait. Now, he seemed to have "tightened up" in these joints, and his running looked almost like that of any normal child. During this first autumn on the "U" Series, Dan had a couple of mild ear infections which responded much more quickly than ever before to an antibiotic. In fact, our family doctor commented, "Well, Dan, I guess all those fancy pills you are taking are doing some good". At Thanksgiving, when Dan's oldest brother came home from college, he couldn't get over the change in Dan's appearance. He said Dan seemed taller and slimmer, and that even his face looked different. There also seemed to be spurts of improvement in school work.

After two years on the "U" Series, we realized that Dan was only seeing the family doctor for his annual physical and maybe one other infection per year. He had finally developed the ability to fight off minor illnesses by himself. Now into the fourth year of treatment, Dan is continuing to improve in health, alertness and physical appearance. Our latest development has been that the public school where Dan has been enrolled in the TMI(trainable mentally impaired) program has suggested that he is ready to be moved into the EMI(Educable mentally impaired) program

None of this could have happened without the "U" Series, and we are delighted to tell other parents about our experiences and the great changes Dr. Turkel's treatment has made in Dan's life.

Colette Romzick
Colette Romzick
(Mrs. Paul Romzick)
5010 Sturgeon Creek Pkwy.
Midland, Michigan 48640
December 8, 1978

October 20, 1984

Dear Dr. Turkel,

Here is a summary of what our son, Dan, has been doing the past few years.

He was in an educable level classroom(as a Trainable student) for several years after he had finished with the "U" Series. We have kept him a program of supplements, herbs, and also some cell salts as needed.

As he approached his 12th birthday, the schools wanted to return him to Ashman School, the separate building where all Trainable students were housed(age 5 - to 25). We asked that they provide a Trainable classroom in a Jr. High building, so that he could continue his casual association with non-handicapped students. The answer was "no". Then began two or three years of bitter arguments etc. between the Romzicks and Midland Public Schools. First we had a hearing, lost that and the appeal, then we went to the Office for Civil Rights with a class action suit, which eventually found Midland Schools in violation of the law for not providing a "least Restrictive" setting for those trainable students who bould benefit from it.

During those two years, Dan attended St. Louis School for Exceptional Boys in Chelsea, Michigan. Although it was a separate facility, and residential, the attitude of the staff and teachers, was so different from what we had encountered in Midland, that it was a beautiful experience for Dan and for us. He enjoyed two years of dormitory living, friends of his own age and intellectual level, lots of social occasions, including some dances with other schools, and some athletic events between St. Louis and Chelsea public schools teams. There were many male staff members, so we feel he had a real good teenage experience there. They were very cooperatibe about giving him the supplements which I packaged up and sent with him every two weeks after his weekends home. After two years, the staff felt that Dan should return home because he was at a higher level than most of the others his age, and that he was ready for more independent living. He was also beginning to ask when he would be going to a new school.

During this time, we also took him to an osteopathic physician in Lapeer, Mich. for Cranial Manipulation which resulted in the straightening of his feet which had turned in quite a bit. He still continues these. He also wears a hearing aid in the right ear, which has resulted in clearer speech.

About the time we decided to have Dan return home, we heard about NACD, and now have him on this program as well. We are seeing some very good results from this, as well.

Dan now is in a Trainable classroom at one of our Jr. High buildings. He rides the regular School Bus with the other Jr. High students, then transfers to another bus which takes him to the building where his class is located. He is very happy in school and has a very fine teacher. He mows our lawn with a power mower, rakes the leaves for us, and recently saved up $40 to buy his own set of Walkie-Talkies so that we can stay in contact when he is out in the woods behind our house. He also has been taking horseback-riding lessons thru the 4-H Tall in the Saddle program for the Handicapped. All in all, we have a happy, healthy, 16-year-old who is a kind and considerate person and a joy to have around. He still has difficulty with math and reading, but we feel the NACD Program will help a lot in this area.

Best Wishes,
Colette Romzick
Colette Romzick

He's just about 5 ft tall, weighs 136-138 lbs

17 August 1984
6901 Conservation D
Springfield, Va.
22153

Mr. Robert C. Wetherell, Jr.
Dept. of Health and Human Services
Food and Drug Administration
Rockville Maryland 20857

Dear Mr. Wetherell,

This letter is in reference to your letter of 10 August 1984, written to my daughter Beth Schwam.

As the mother of a child with Downs Syndrome, who is on Dr. Henry Turkell's U Series, I have a question I would like you to answer.

I would like you to define exactly what you (FDA) mean when you use the word effective, in relation to the U Series.

Let me define what effective means to Stephanie, age 22 months. Effective means more restful sleep- which enables her to work harder to learn physical and mental skills. Effective means having spontaneous bowel movements, after requiring over a year of digital rectal stimulation and use of laxatives to prevent more ulceration of her colon. Effective means 2 ear infections this year instead of four cases of pneumonia as she had from Feb.1983 - May 1983, plus several infections. Effectivness means increasing her skills on the Bayley Scale of Infant Development from 104 raw to 121 raw from January 25, 1984 to June 1984. Effectiv means; her occupational therapist saying, she is doing very well as we had a 3 yr.old in summer session who was content to suck her thumb, while Stephanie was walking, going through tunnels, kicking a ball, and trying to ride vehicles, at 22 months. Effective to Stephanie means going from a 10 lb. baby who could not roll over in June 1983, to a spunky 26 lb. toddler in August 1984, who walks, climbs stairs, helps empty the dishwasher, tries to run, says 12-15 words, tries to dance with her sisters and brothers, kicks a ball, and has lost all of her vacant stares.

Now effective to me means--I can sleep at night without having to check 10 times to see if she has a fever and to plan activities with the rest of my children as far as 3-4 weeks in advance, knowing that we will be able to follow through with the plans.Effective also means HOPE,- hope that Stephanie will reach <u>her</u> full potential, as a loving human being.

If effective to the FDA in regards to the U Series, means a cure for Downs Syndrome, then it is time for that agency to get its' head out of the sand.Just as people go weekly, or more often, to get allergy shots to improve the quality of their life,so I have put Stephanie on Dr. Turkell's U Series to improve the quality of hers'.

Keep in mind that the FDA will never find a more qualified expert than a mother or father of a child with Downs Syndrome to study this matter.It is all to easy for you people to procrastinate and to deny our facts, because you don't deal with the day to day realities. You take for granted the small daily occurances and look out for the biggies- such as cures for diseases.. I take my miracles in smaller doses but believe that they are no less remarkable that yours.

Japan has 20 years of records regarding the U Series, and Norway has recently allowed the U Series to be dispensed there. I find it difficult to believe that these countries are allowing things that will harm their people.I had been led to believe that under the Regan administration, the FDA would streamline their antiquated regulations, and make accesible to the Amerieaan public drugs/treatments already utilized in foreign countries.

I feel that the FDA is negligent in this matter..It is always easier to ignore things under the guise of "administrative proceedings".

My daughter Beth, wrote to President Regan, to gain his support of House Resolution 5824, as proposed by Congressman Goodling . Hopefully the President will support 5824 if it passes legislation and remove some of the awful power the FDA now possesses.

Please reply in a more definitive manner.

Sincerely Yours,

Mary J.Schwam

Courtesy Copies:

President Ronald Regan
Mr. Stan Parris
The Washington Pos - Letters to the Editor
Dr.Henry Turkell

On September 17, 1984, Tom started working at a hospital. There are several other places he will be taking training throughout the year. He will graduate from school in the spring of 1986.

March 29, 1979

Dear World:

Our Down's Syndrome son, Andy, was born June 20, 1978. He has so far developed no heart problems and has been a healthy baby.

In August, 1978, a friend of our family saw an article about Dr. Henry Turkel in a newspaper while visiting Hawaii. The article referred to his U-Series Treatment for Down's Syndrome. The friend sent the article to us, and immediately we began looking into the possibility of going to Detroit to see Dr. Turkel. Our pediatrician looked over the list of medications used by Dr. Turkel and assured us there was nothing that could hurt him. Accompanied by a physician relative, we took our son to Dr. Turkel--not really knowing what to expect. After spending a day talking with him about our son's condition we decided to go ahead with the treatment. Dr. Turkel's knowledge of the physical complaints of a Down's Syndrome child and his explanation of the many facets of this disease helped us immensely to understand all that was involved. Our pediatrician doesn't really see enough Down's Syndrome children to be aware of all their symptoms and problems in development.

In September we gradually introduced Andy to his new medicine. After 4-6 weeks we noticed that his skin color was better--rosy cheeks and a sheen to his skin. His stomach looked like it had a balloon inflated in it when we took him to Detroit, and after only a few weeks of the medicine his stomach flattened out. Andy's muscle development seemed slow after birth, but after starting the medication his development has been steady. He is healthy, alert, active, and happy. He was sitting up when he was seven months old--quite an accomplishment for a Down's Syndrome baby.

We are very pleased with Andy's progress, and although we don't know what the future holds for him (9 months old now), we feel that Dr. Turkel's medicine has made his life better than it would have been without it. When Andy wakes up in the morning with a stuffy nose we give him his nose medicine and he breathes freely again. When he awakens during the night with teething pain, we put his gum medicine on his gums and he falls right back to sleep. When he gives us kisses, says hi, babbles endlessly, and pushes himself all around our house in his walker we can't help but think Dr. Turkel's medicine played a major part in his progress.

We don't feel that it is fair for the F.D.A. to make Dr. Turkel's medicine and knowledge almost totally unavailable to Down's Syndrome patients. We are fortunate and were able to make the trip to Detroit. Most people could not. So please World, listen to our story and

<u>DO SOMETHING</u>.

Sincerely,

Charlie + Carmine Jordan

Charlie & Carmine Jordan

Dear World:

We have now been serving on the Board of Directors for US for DS since its beginning in 1975. We have seen a great deal of change in public attitudes and treatment of children with Downs' Syndrome. The use of vitamins and many of the ingredients used by Dr. Turkel in his U Series are being incorporated more and more by doctors. Insurance companies are finally becoming more willing to cover the ~~cost~~ cost of the treatment. Parents and concerned citizens are more demanding as they realize that there is an effective treatment available to victims of Downs' Syndrome.

We feel that US for DS has played an important role in many of the changes taking place. We have actively participated in several court cases involving the use of the U Series, effectively putting pressure on large insurance companies to accept the treatment as beneficial. We have seen new chapters form in several states.

We foresee in the future a time when the "U Series" will be routinely used by doctors for their Downs' patients. We hope that time arrives during Dr. Turkel's lifetime so that he may have the satisfaction of knowing his work for many, many years is recognized for its value.

Sincerely,

Mr. & Mrs. Nelson Hao
Coalinga, Ca 93210

Dear World,

Our son will soon be celebrating his 7th birthday. When we think back to those first few days of his birth, it is with happy thoughts and grateful acknowledgement to God for allowing him to be a part of our lives. Through this one child our lives have expanded to include friends all over the nation who have faced a similar situation.

Lee was born on January 25, 1972, and we were told that he was mongoloid shortly after birth. We were very ignorant and little informed about mongolism as our pediatrician very matter of factly told us that our son might have a very limited life span, could be very sickly, would never go beyond a first grade level of intelligence, if that. He advised us to love him and accept his handicap as something we would never be able to do anything about.

We took our son home and began trying to absorb all we could find out about Down's Syndrome and how to cope with the changes it was to bring to us.

The first two years of our son's life passed by with little problem. We had to deal with a few flare-ups with ear infections but no major health problems as we learned so many children afflicted with Down's Syndrome have. Lee sat up at 6 months, walked at 18 months, and for the most part progressed almost normally. He was and still is a very alert child, always busy and always active.

When Lee was about two, a cousin sent us an article that she had come across in an old magazine from the teachers' lounge at

her school. The article gave a little information about the "U" Series and Dr. Turkel, stating that the FDA would not allow the medication to be sent from the state of Michigan, and that parents had to travel to Detroit with their children if they felt they wanted their child to have the treatment. The article gave a brief description of the ingredients used in the "U" series and how they seemed to benefit the health and growth of the Down's child.

We wanted to know more! By this time we had pretty much decided there was nothing but our love and attention to help our son achieve his fullest potential. Every article we had read up to that point had only reaffirmed what our pediatrician had said. There seemed to be no more to do and we had not even really looked for anything as the "black and white" of it just seemed so unchangeable. After all, when doctors so wholeheartedly agreed there was nothing to be done, how could we question such learned men. We did not believe in miracle cures or drugs either and their statements made sense.

Dr. Turkel's treatment seemed also to make sense. We wrote to him and right away received information about the "U" series. We asked for a reference, someone whose child was on the treatment and were told that Mrs. Arline Burman's son Dale in Los Angeles was probably the closest to our area. We called her one evening and through her enthusiasm over her son's progress, we determined to look closer into the "U" series and try to schedule an appointment with Dr. Turkel.

While waiting for our appointment (several months away), we took the information we had about the "U" series to our pediatrician. His reaction and response were typical. He advised us not to waste our time and money. He felt there could be no benefit to our child, although he admitted he could find nothing in the treatment that

would cause harm. He referred to Dr. Turkel as a quack who was ripping off desperate miracle-seeking parents and hinted it would be extremely foolish for us to pursue the matter.

We examined our feelings and carefully went over the pros and cons, finally determining that we would rely on our own intelligence and judgement which told us to proceed with the treatment. It was our time and our money and if we were willing to use it in that manner we felt that we must certainly try to help our son achieve his fullest potential.

The rest is all history--we went to Detroit, were amazed by Dr. Turkel and his compassion and deep concern for all Down's children. His vast knowledge of almost any medical problems were very apparent. This man was truly gifted and sincere in his efforts! He was so willing to explain and answer all our queries about the "U" series. He was most understanding of our financial situation and arranged for us to have a years supply of medication when we left his office so that we would not have to pay for another plane trip within that year. We took our son home and after a few days of frustration in finding the right method to administer the pills to our son, we settled into the routine of pills with every meal.

Lee did not change overnight. He was 3 years old and growing and changing as any normal child does throughout his life. He did have fewer colds and is such a happy, healthy child, we cannot question but that the "U" Series has benefited him. Teachers at school notice his progress and the difference in him and other Down"s children. He is unmistakably retarded, but he demonstrates such imagination and eagerness to learn new things. He amazes us with all the minor details he notices in things we take for granted.

His coordiation and growth are not too far from normal. He is slowly improving in his speech, the area we feel he needs improvement in most.

We have been so fortunate to have friends and family who have wholeheartedly supported our efforts to help our son. Just before we made our first trip to Michigan many of our friends surprised us on our sons third birthday with a lovely party and money tree to help with expenses. Our son has many honorary aunts, uncles, moms, dads, grandma's, and grandpa's. He has a way of capturing everyone's heart. He is constantly into mischief, is very demanding of attention, and can be so loveable! He has one sister who was 12 when he was born and has always acted as second mother to him. She is absolutely his #1 fan and delights in watching him grow. She recently made Lee a very young uncle and transformed him into a self-made babysitter. He is constantly trying to care for the baby's needs and delights in watching her every movement. He wants to go see the baby as soon as he arrives home from school and gets angry when sister takes her home after a visit.

We are so proud of our son and what he accomplishes. He is a precious part of our lives and we are so grateful to Dr. Turkel and his persistent efforts to make the "U" series available to all Down's children at a minimum cost. We have witnessed the changes and improvements in children who have started the treatment after our son. Lee was the first child in the San Joaquin Valley to begin the treatment but now has a number of children, three in his own school, who are on the treatment.

May God bless Dr. Turkel, his family, and his staff. They all have been so kind and good to the Down's children they have worked with.

Sincerely,
Mrs Eunice F. Ahn
Mr. Nelson N. Ahn

Hello World, my name is Pam; I'm a Downs Syndrome child, - you call me Mongoloid. I never had the chance to learn to write so my mom is doing it for me. Maybe next year I'll go to school and learn to read and write, but I'll tell you more about that later on.
Mom had had four miscarriages before I came along so when she became pregnant with me her doctor made her stay in bed, with the feet raised, most of the time. It was pretty boring but she felt it was worth it to have a child. Then the night I made my entrance into the world her doctor was horrified, afraid to tell mom she had a 'defective' child. He decided he better wait a few days so he and the nurses just kept saying that I was very weak but "doing as well as can be expected". Since mom had no real idea what was wrong she didn't know how "well" i could be "expected" to be doing so daily she became more upset. Finally Grandma, who knew from the start about me, told mom that I was 'mongoloid'. Next day the doctor came in and mom said, "I know my baby is mongoloid, now tell me the truth about what is wrong with her." Doctor was amazed that mom was so calm about it but he didn't realize that all those miscarriages made mom glad just to have a live child, and she had spent a great deal of time with another Downs Syndrome child and know how loving and affectionate we are. So he told her that I was having respiratory problems and he felt I should be kept in an incubator a few more days. This was back in 1952 and at that time most doctors would recommend to parents of 'retarded' babies that the child be immediately put in an institution.. moms doctor never made such a suggestion.
I was only three months old when I experienced our first move. I was born in Pennsylvania in December of '52 and the following April we moved to Oklahoma. In May I had my first bout with pneumonia and in the following two years I spent about as much time in the hospital as I did at home. During the cold months I had repeated bouts of pneumonia and bronchitis, during the hot months I dehydrated seriously. Luckily I had the worlds greatest pediatrician, he loved me like his own daughter. And at the hospital I was cuddled by the nun who was in charge of the pediatric department. There was a strict rule that babies were not to be held or cuddled by the nurses, but often mom would come to visit and find that the head nun would have a chair in my room and she would be rocking me in her arms and singing to me. If it hadn't been for all this love I probably would not have made it thru these two years.
Mom never had any problem in accepting the truth about my condition but poor dad just couldn't face the fact that his child was less than perfect. For the first couple years when people remarked about my not being able to walk or talk he would make excuses that I was sick a lot, but as I grew and my third and fourth birthdays came along and I made no significant progress it became harder to find some excuse and he began drinking very heavily. Several people tried to talk to him, mom, the doctor, friends, other relatives, but he still would not listen - he said they were all 'nuts'. He would come home very late, sometimes after midnight, get me out of bed and prop me in a corner of the couch and try to teach me the A B C's. This was very upsetting and he and mom would get into terrible arguments when mom would try to stop him. It got so I hated when he came home and I'd become hysterical when I'd hear his car pulling in the driveway. Mom had to tell the doctor what was happening and doctor said mom would either have to leave daddy or put me in an institution. She did not hesitate, she packed all dads things and when he came home from work she said he would have to find another place to live. Afew weeks later she filed for divorce.
When it first becamme evident that dad couldn't accept my 'condition' mom had gone back to work and shortly after her divorce we moved from Tulsa to Oklahoma City. Mom was working for the Air Force and the move resulted in a promotion; she knew it would take a considerable amount

of money to provide for me properly so she had to be alert to any chance to improve our income. But before we left Tulsa she had become a member of a small group of parents who were trying to establish a school for their retarded children. At that time there were no facilities available, other than the state institutions, and many parents were coming to the

conclusion that their children had some learning ability and should have the opportunity to make the most of that ability, no matter how limited. Mom was working nights at that time so she volunteered to help at the school during the day. At first there were just a few children and the school was in the garage of one of the parents, but as more parents became involved the group expanded and then the Junior League of Tulsa became interested and decided to 'back' the project. This brought in a considerable amount of money and a real school was built. Mom would take me along and I became the youngest child enrolled in the school. I proved that it was beneficial to start teaching 'retarded' children at a very early age.

We were only in Oklahoma City a short time then mom transferred to Tacoma, Washington. The public school there had classes for special children so mom enrolled me. At that school children were tested to try to determine their learning capacity and they were put in classes tailored to their ability. I was considered educable so they started to teach me to read and write. But winter came along, and with it, my old enemy, pneumonia. That put an end to my going to school there.

When Spring came mom had an opportunity to move to California so off we went, to Edwards A.F.B. up in the Mojave desert. The summer there was terribly hot and I had a problem with dehydration. While we were there I caught the measles and was very, very sick. In the Fall mom heard there were some openings at Norton A.F.B., she applied for a transfer and we moved to San Bernadine. She wanted to have me start school again but my doctor advised against it. We liked living there but after a few months mom had an opportunity for promotion by moving to the Stockton (Calif.) area so we went north. We were there a year and mom felt that maybe I could go back to school, so she enrolled me in the special ~~ed~~ class and for the next three years I went to school when I was well enough. My teachers were nice but at these schools they only taught manual subjects. We learned a bit about housework and helping in the garden. Girls learned to wash and iron clothes and a bit about sewing. No attempt was made to teach us academic subjects, except to print our first name. This was discouraging to mom who felt that those of us who could learn reading and writing should have the chance.

My schooling was frequently interrupted by illness and finally my doctor said he felt that what I was learning was not worth the risk to my health, when another child came to school with a slight cold I would get it and it would develop into something serious enough for me to be hospitalized. By this time they were aware that I had a serious heart condition too. So, reluctantly, mom took me out of school and I never went back.

During the next few years my health slowly worsened. My grandmother was living with us, taking care of me while mom worked. Grandma had a bad heart too, and our doctor thought maybe she should have an operation so he sent her to Stanford. After a few days there the doctors decided that for the time being, at least, an operation was not needed, but they wanted to check her at regular intervals. It was when we were there for one of her check-ups that I had an attack. You must admit that was very smart of me in a way, if you are going to have a heart attack what better place to have it than a hospital where they have the best "heart" doctors in the country!

I was admitted to the hospital and watched very carefully for a few days. The doctors finally decided that there were several things wrong with my heart and that the only way they could positively identify these problems was by a heart catheterization. This was very risky. my blood vessels were so small and the walls so fragile there was a chance of puncturing one and causing a
hemoraghe that could kill me, but, on the other hand, there was the possibility that what they might learn would be helpful in treating me. They explained all this to mom and told her there was a 50-50 chance of my surviving - it was a tough decision - but mom decided to have them go ahead.
The doctor who performed the procedure really 'sweated it out', but I had a fine time. I lay there watching the screen where we could see the catheter inching its way to my heart, and as the doctor worked I told him all about my favorite T.V. program. He said later that I helped him because I was so casual about the whole affair.
They learned a lot from the procedure, seems there were three holes in the wall that divides the heart and my blood kind of slushes back and forth from one side to the other. Since all of the blood never gets into circulation there is a lack of oxygenation; this is why my fingers and toes are clubbed and blue in color. There is also a marked enlargement of the upper left chamber of the heart and my poor lungs are terribly scarred from all these bouts with pneumonia. The doctors said that had my lungs been in better condition they could repair the holes in my heart but with such bad lungs it was very doubtful I could take an anesthesia. They said that my condition would continue to deteriorate and estimated that I only had a few more years to live.
Stockton is located in the middle of a very fertile agricultural area and the farmers hire planes to dust their crops with pesticides. Those who live in the area cannot help breathing this pollution and I was no exception. Shortly after I got out of Stanford I developed a chronic cough. Even when I was sleeping I would cough, like a baby with 'croup'. My doctor was very disturbed by this, there was nothing he could do to help me and this constant hacking was putting a strain on my heart. My living time was being shortened by conditions beyond control.
My favorite T.V. program was "Hawaii Five-O" and I kept telling mom I wanted to go to Hawaii and meet the star of that show, Jack Lord. When my health started deteriorating mom decided that no matter what the cost she would try to take me to Hawaii, so she borrowed the money and off we went. Before leaving she wrote to the chief of police there and asked if he could help me meet Jack Lord. She sent a letter from my doctor which explained how sick I was. The chief wrote back and said he would try to arrange it for me, and when our plane landed there were two police officers to meet us! During our stay they took us to dinner at a famous restaurant and showed us around the island, but what delighted me most was that I was able to go to the set where the "Hawaii Five-O" program was filmed and Jack Lord came there to show me around and to talk with me! It was the biggest thrill of my life.
We were there ten days and mom noticed that my cough seemed to lessen. When we went home she mentioned this to my doctor and he said it was because the air in Hawaii was so clean. He said that it would be beneficial if I could live there. Mom had been having trouble for several years with arthritis, she was losing a lot of time from work and her bosses were encouraging her to take a disability retirement. She tried to put it off because she worried about how we would live on a small pension, but when the doctor said it would probably help if I could live in Hawaii she applied for retirement which was quickly approved; she sold our house and we moved again.

We found a nice little house to rent, located on the leeward side of Oahu, and we settled down. When mom took me to the doctor he was quite fascinated by my heart problem, seems the combination of defects is quite rare. In a way this has worked to my advantage, I get a lot of extra attention from medical people because they don't usually see patients with such interesting (to them) conditions. The clean air of Hawaii did its work and in a few months my chronic cough was gone. I felt much better. Although I still tired easily and tended to have a blue tinge to my skin due to improper oxygenation my condition did stabilize for a time. Then early in '78 a new problem developed. Tiny spots began to appear around my ankles and mom thought I was being bitten by sand fleas so we stopped going to the beach. But the spots kept appearing so mom asked the doctor about them. This was something that my doctor had never seen so he consulted with other doctors, none had seen such a thing but several had read about it in medical journals. A biopsy was done to positively identify the spots, and it was shown that they were small ruptures, an unusual thickening of my blood was causing small blood vessels to rupture. Because of my complicated heart-lung condition the doctors all agreed nothing could be done. Soon mom noticed my eyes seemed to be unusually red so she took me to an eye specialist. He said that the tiny blood vessels in my eyes were rupturing and there was no doubt that I would, sooner or later, go blind. I was, in a sense, sitting on a time bomb, there was no telling when the blood vessel that would cause blindness would rupture, it could happen any day. Dark glasses would give a little protection from light, which was a strain on my eyes, but otherwise there was no help available. The future never looked worse.

One day in July we stopped to visit a friend and just as we were leaving she recalled seeing an article in the paper about a doctor who was going to give a lecture about some kind of program to help Downs Syndrome children. She ran back into the house, got the paper and brought it out to the car. When we got home mom read the article about a Dr. Turkel, who was on his way home from KMM Japan and who was going to give a lecture about a treatment he had devised many years ago and which had benefited many Downs Syndrome children. Mom thought she might learn something that would help me so the night of the lecture we were amoung the first ones there.

She listended closely as Dr. Turkel explained how the extra chromosome that causes Downs Syndrome created the retarded condition by causing various accumulations that prevented these children from developing normally. When the lecture was over mom spoke to the lady who was responsible for Dr. Turkel stopping here to give his lecture. Mrs. Burman was very sympathetic and told mom to wait a bit and speak to to doctor. When Dr. Turkel heard about my problems he said he felt his treatment could help me but he had so many patients he could not take any more. We were very discouraged but as we were leaving Mrs. Burman said she would try to get the doctor to take a few cases from Hawaii for his treatment. A day later she called and said he had agreed but the children would have to come to Michigan, as the treatment was only available in that state in the U.S. due to its being banned by the FDA. It was estimated that going to Michigan would cost about $4000 or more, counting the medical workup needed, the air fare, hotel, meals and a years supply of the medication. Where in the world could we come up with such a sum?

Mrs. Burman suggested that the reporter who had interviewed Dr. Turkel might be able to help so mom and I went to see her. Pat Hunter, of the Honolulu Advertiser proved to be a very sympathetic lady. She had some pictures taken and discussed the situation with mom. A few weeks later a story appeared in the paper, it explained that there might be help for my threatened blindness but that we did not have the money needed to go to the mainland to see the doctor.

Some of the people who saw the story were touched by my plight and sent money to help, but in a few days the contributions stopped and we had less than half what we needed. Even mom, who doesn't give up easily, was beginning to be discouraged, it seemed as the we weren't going to be able to make the trip after all. Then one evening, just when things seemed to have come to an absolute standstill, the phone rang. The lady caller said she was a tourist from California, she had read the article and wanted to know more about me. Mom went into more detail about my problems and told the lady we had only gotten less than half of what we needed to go to Michigan; the lady said not to worry, she would be returning home the next day and would send what we needed. A few days later mom was wakened very early by our dogs barking. She went out front to make them hush and there was a Loomis courier with the check from our caller.

That same day mom took me to the doctor and started getting together the information she knew Dr. Turkel would need and she wrote asking him to let us know what special records or X-Rays would be needed. For the next couple weeks letters went back and forth as she acquainted him with specific problems and he would answer requesting further data. Finally a definite appointment day and time was set. We got our plane tickets and packed for the trip, we were to leave on election day, in the late afternoon.

We were up bright and early, went to vote then took our baggage to the airport and got it checked; came home, showered, changed into traveling clothes and left again, this time taking the bus to the airport.

It was a very pleasant nine hour, non-stop trip to Chicago, then a short trip to Detroit. Mom had reserved a car and we went to get it. Living in Hawaii for five years had made us forgetful of late fall weather on the mainland so we weren't quite prepared for the cold. We had brought our warmest jackets but when we left the airport terminal our ears and noses just about turned to icicles!! First thing we did was hunt a store where we bought wool caps, scarves and gloves. Then we went looking for Dr. Turkels place and having found it sought a motel close by. We spent the rest of that day exploring the area. Next morning we were up early, had breakfast, then went for our much anticipated appointment.

I was at ease right away with Dr. Turkel and his two lady helpers. His office didn't look much like the usual doctors office, there was none of the equipment one usually sees in an examining room. Doctor talked with me and mom, then he measured my waist, hips and chest. He weighed me and then took me into another room where a lady showed me a lot of pictures and asked my to fit spoken words to the pictures. I did the best I could but tho some of the pictures were of familiar things the words were strange. But in spite of that problem I did pretty well on the test. They said I have the intelligence to learn up to fourth grade regular school work.

Doctor went into great detail about how his treatment works, what improvement we could expect and said that because I was getting such a late start I would need to be on the program for five years. The time passed quickly and when we were ready to leave he put all my medication into a big shopping bag and we departed.

When we got home mom started me on the medication, that was almost eight weeks ago. Already we have noticed some improvement. Altho I am still having the rupturing blood vessels occur the new ones are all below my knees, and they are occuring less frequently. Since I was very young I have had terrible patches of psoriasis on my knees and elbows, during the winter they usually got so bad I would have to go to the dermatologist for shots but since I started Dr. Turkels "U Series" treatment the psoriasis has cleared up a great deal.

As is common with Downs Syndrome children, I had a weight problem, and the extra weight added to the heart problem. Even before we went to Michigan Dr. Turkel had suggested some changes in my diet and I have lost 12 pounds. Before the treatment I was a big eater, I was almost always hungry, but didn't seem to benefit by eating, now I eat about a third less and have more pep. The other day I was to my doctor for a routine check-up and he noted that my fingertips are less blue than was usual. With this much improvement in such a short time we have great hope for the future.

Right after Dr. Turkel lectured here the parents and others concerned about Downs Syndrome children decided to form a local chapter of the 'U.S. for D.S'. There is a chapter on the mainland, its headquarters are in California. The members are trying to make Dr. Turkels U Series available to Downs Syndrome children everywhere in the country. Because of a ban by the FDA parents who want the treatment have to take their children to Dr. Turkel and because he is the only doctor in America using this treatment only a very few children have access to it. One man can only treat a very limited number of patients and other doctors are 'scared off' by the FDA ban.

When the Hawaii chapter of U.S. for D..S was formed mom was elected vice president of the chapter and also made chairlady of the committee set up to try to get legislative action to legalize the treatment in our state.

We are very fortunate here because the smallness of our state makes for more personal relations between the people and the elected officials. The members of the legislature are much more responsive to the needs and desires of those who elected them.

Mom had talked to our state house representatives even before we went to Michigan and had gotten a promise that they would try to help if they got re-elected. When they were returned to office they said they would keep their promise. When the legislature convenes in January a bill will be introduced in the state house of representatives which will, if passed, legalize the treatment here. An almost identical bill will be introduced in the state senate. In addition to this our two national senators, Sen. Dan Inouye and Sen. Spark Matsunaga are going to investigate the FDA ban and determine if something can be done to make the treatment available nationally.

We anticipate much opposition, from the FDA and from doctors who are intimidated by it and the AMA. But we hope that the wishes of the parents will finally prevail. This is the only treatment that offers any hope for us. Our parents feel that is our legal right to have the opportunity to take advantage of it.

In view of the results of my intelligence test mom has decided that next school year she is going to try to enroll me in the first grade in the regular school. I CAN learn, and she feels I should have the chance. It may mean a fight, I am 26 now and they may not want to let me start school at my age, but if they stop me mom is ready to go to battle.

Who knows - one day I may be able to write a sequel to this story,- all by myself, without the help of a ghostwriter.

Wish me luck.

With love,

Pamela Hollahan

This story may be reprinted and used in any way That will benefit Downs Syndrome children. Love, Pamela Hollahan

Dear World:

The extremely cold and snowy January 1977, a child was conceived within our family circle. We were pleased that we were to be parents again, even though I would be 45 and my husband 56 before the expected birth. The baby would be welcomed by four brothers and four sisters, ranging in age from 22 to 5 years. As soon as I suspected pregnancy, I quit sledding down our snowy hills, and began taking vitamins and following Adelle Davis' pregnancy diet recommendations. We prayed that God would oversee the development of this child,and I began counting protein grams and calories daily, to assure adequate nutrition. We were determined to do all we could for the health of our unborn child.

The following Spring was especially rewarding. Our oldest child Cathryn graduated Magna Cum Laude from Mississippi University for Women. Our oldest son Henry won a second scholarship, based on his academic record, at Indiana Institute of Technology during National Engineer's Week. And, our third child Rodney was named a Finalist in the National Merit Competition. Except for a cold and congestion just before Easter, my health remained good.

In August I developed a severe itch and rash, mostly on my arms and legs. We tried many preparations to relieve it, but relief would only be temporary.

Our baby was born one month early September 8, 1977. It was an easy birth with no medication, and she breathed right away. We were pleased that her weight was 7 lb. 3 oz. But something seemed wrong, and she wasn't interested in breastfeeding right after birth. Later she nursed, but became jaundiced. This led to hospitalization in a large city Children's Hospital for examination. There, several Doctors

diagnosed her as having Down's Syndrome, and a chromosome study later confirmed this. A heart study by specialists found that she had a strong heart. My husband baptized her during this hospital stay. My skin rash began to heal after her birth, but it took four weeks to heal completely.

It is hard to write all the sad feelings and thoughts parents have when they realize their child has a health problem. We began reading all we could about Down's Syndrome. So much was negative. My husband said "These Doctors really don't have much to offer her." I caught the attitude "She will be sick a lot, but we can hospitalize her again whenever she is ill." We were already shocked by the bill from four days of tests and hospitalization ($1,379.75), and didn't feel we could afford a great deal more of that. Valerie hated the taking of blood samples, the punctures for constantly administered antibiotics, and the blindfold for bilirubin lights. Hospitalization had interrupted our breastfeeding relationship also, as she was given Similac because of the jaundice. I stayed with her in the hospital the entire four days. So, we knew we wanted a Doctor who would treat her at home.

We named our baby Valerie Rose. Valerie means healthy, robust and valiant. The rose is a symbol of love. She was a sleepy baby until the day before she was due to be born. It was difficult getting a good supply of breast milk again, after having baby on the bottle in the hospital most of the time. I expressed milk into bottles between nursings to increase her milk supply. I would feed her every two hours, and oftener if she wanted. I would set our alarm to see that she nursed regularly through the night, that hard winter. How frustrating the next months were, because in spite of all our efforts, which included even my eating more food to hopefully produce more milk

for her, Valerie gained weight ever so slowly, while my weight increased easily. At Christmas time, when she was 3½ months old, she had just then regained her birth weight of 7 lb. 3 oz. We gave her vitamins, fresh orange juice, brewer's yeast, prune juice, and started fruits and vegetables and meats early to help her grow. Her smallness and slow growth were the distinguishing features that showed she was "different".

We read of Dr. Henry Turkel and the U Series Medication for Down's Syndrome in two books which we had in our home library. One was "Let's Have Healthy Children" by Adelle Davis, who mentioned it briefly. The second was "The Encyclopedia of Common Diseases" by Rodale Press, which had five pages on this treatment. Of course we were interested. The books had said "a Detroit, Michigan physician". The telephone information service was of no help, because the city was actually Southfield, a part of Detroit. Finally, before Thanksgiving Day, we received Dr. Turkel's address and telephone number by writing to Prevention magazine. Then began some phone calls and correspondence, and our preparing Valerie's case history for Dr. Turkel. We also read Dr. Turkel's book about the treatment "Medical Amelioration of Cytogenetic Anomalies". We wrote to four different Down's Syndrome organizations in our area (none were US for DS), requesting to hear from any of their members who had tried the U Series treatment for their children. From those four letters we received two letters and one phone call from families who had children currently on the U Series. All three reported improvements, and satisfaction with the treatment. One of these reported that before starting his son on the treatment, he had obtained names and addresses of eight former patients in his general area from Dr. Turkel. He wrote eight letters to these families, and received six replies, all positive

about the treatment. This made a total of nine "satisfied customers", and influenced our final decision to make an appointment for Valerie, which we did in February. Only two men were skeptical about the U Series treatment, and interestingly they were both Medical Doctors who had no first hand knowledge of the treatment.

When we arrived at Dr. Turkel's office March 20, 1978, Valerie weighed only 9 lb. 8 oz., and was 6 months and 12 days old! Dr. Turkel explained that putting food into her had been about like putting food into a sieve - it had gone right through her because her organs were too immature to metabolize them properly. The treatment would help her organs to mature. Dr. Turkel was very friendly, kindly, and explicit in explaining the U Series Treatment, and what results might be expected. So, we left with a year's supply of medicine, report forms, and other instructions. We hoped that the U Series would help her to grow.

Imagine our happiness when, the very first week on the U Series, she gained 13 ounces! Before beginning the U Series, she had gained only 2 lbs. 5 oz. over her birth weight in 6 months and 12 days. She gained 2 lbs. the very first month she was on the U Series, and might have gained even more if she had not been ill with fever and diarrhea about 6 or 7 days in April. She missed three days of medication (U Series) during her illness because she did not want her food. Her weight record after beginning the U Series is as follows:

at beginning	Mar.21, '78	9 lb. 8 oz.	
1st week	Mar.28, '78	10 lb. 5 oz.	(13 oz. gain)
2nd week	Apr. 4, '78	11 lb. 0 oz.	(11 oz. gain)
3rd week	Apr.11, '78	11 lb. 8 oz.	(8 oz. gain)
4th week	Apr.18, '78	11 lb. 0 oz.(was ill)	(8 oz. loss)
1 month	Apr. 21,'78	11 lb. 8 oz.	(8 oz. gain)
2nd month	May 21, '78	13 lb. 1 oz.	(1 lb. 9 oz. gain)
3rd month	June21, '78	14 lb. 13 oz.	(1 lb. 12 oz. gain)
4th month	July21, '78	15 lb. 14 oz.	(1 lb. 1 oz. gain)
5th month	Aug.21, '78	17 lb. 0 oz.	(1 lb. 2 oz. gain)
6th month	Sep.21, '78	18 lb. 0 oz.	(1 lb. gain)
7th month	Oct.21, '78	17 lb. 14 oz.(was ill)	(2 oz. loss)
8th month	Nov.21, '78	18 lb. 9 oz.	(11 oz. gain)

and her record of length:

Birth 20½ inches
4 mo. 22 "
6 mo. 23½ "

U Series began

7 mo. 24½ "
8 mo. 26 "
9 mo. 26¼ "
10 mo. 27 "
11 mo. 29 "
1 year 29 3/4 "

Even before beginning the U Series treatment, we felt Valerie had lots of vigor physically, and emotional response. She loved to nurse, watch others and look around, be talked to, and receive attention. Her hands are normal, and she likes to use them. She had been smiling for us since she was 2 months of age. She seemed to nurse well, and have plenty of wet diapers and bowel movements. But she was often sick, had chronic nasal congestion, and was not growing normally.

After treatment began she seemed happier, and also would sleep more in the daytime. She slept very little in daytime before being on the U Series. It was also easier to get her to laugh out loud.

As far as personality is concerned, I can't tell any difference between Valerie and our "normal" children. Valerie is spirited, loving, kind, curious, and plays and teases. She has very sensitive feelings. She communicates well without using words, although she can say "DaDa", "MaMa" and "Bye". She can judge strangers- likes most and is afraid of others (cries). Her health problems and poor weight gain have been the main difference.

The third month she was on U Series, she had no nasal congestion, nor any constipation. We began her DPT shots and polio vaccines when she was 9 months old. She had no illness or reactions from the immunizations. Before being on U Series, I did not feel she was strong

enough or healthy enough to get shots.

She could sit up alone at 10 months. She learned to crawl forward at 12 months. At 13 months she could pull up to a standing position holding onto furniture, and also learned to wave bye bye with her hands. At 14 months she likes to clap her own hands. Also, she can move sideways while in a standing position, holding onto furniture with her hands. She crawls very well, and fast. She is a pleasant child.

When Valerie began the U Series treatment she was 6 months and 13 days old and weighed only 9 lb. 8 oz. After six months on the U Series she weighed 18 lbs. She gained only 2 lb. 5 oz. her first six months, without the U Series. The next six months she gained 8 lb. 8 oz. while on the U Series. Most babies have their fastest rate of growth in their earliest months.

Our friends keep exclaiming how changed she is, how much she has grown, and how she looks like any other normal baby. Strangers often tell me that I have a pretty baby, which of course all mothers like to hear.

We are grateful to Dr. Turkel for his 40 years of studies, and effort in helping children with Down's Syndrome. The bridge had already been built, before we ever knew Valerie Rose, and we thank God for helping us to find it.

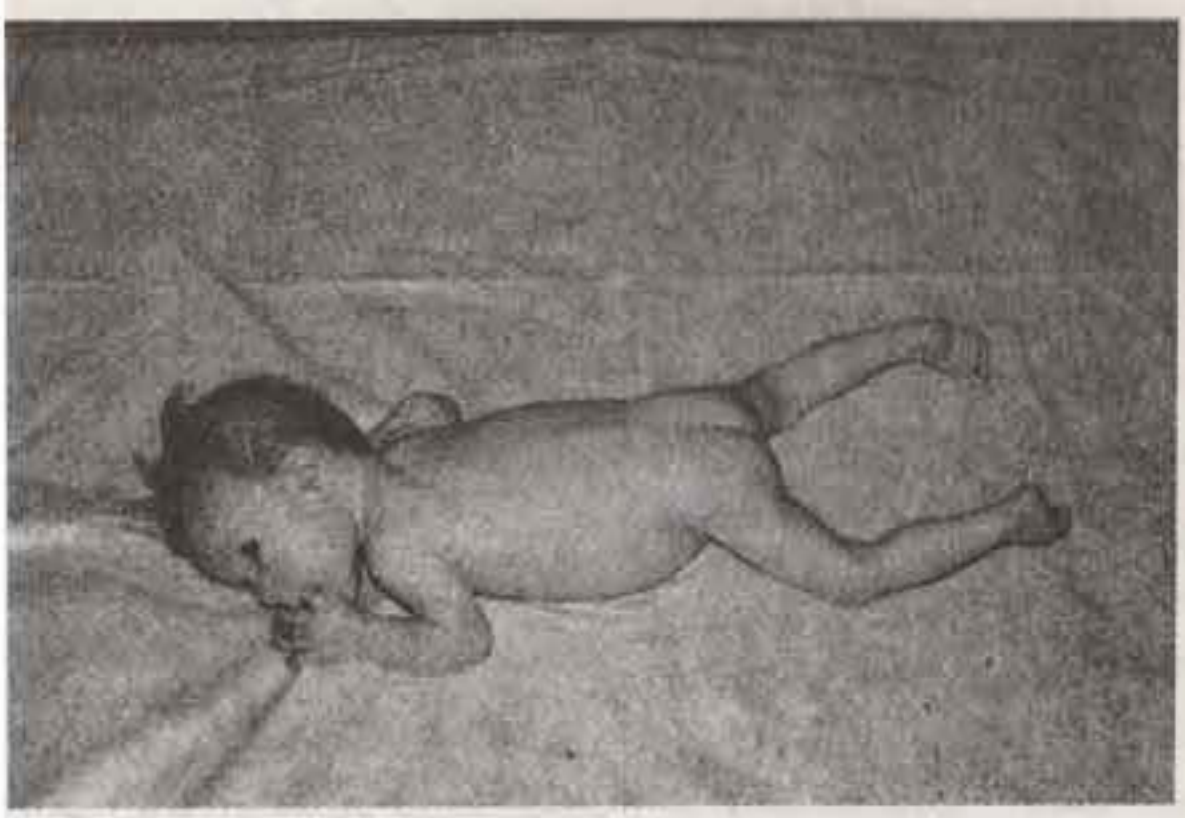
Sincerely,

Mrs Richard H. Hoffman

Mrs. Richard H. Hoffman
Star Route 288, Box 80
Steelville, Missouri 65565

Valerie Rose Hoffman

Before "K" Series



7 months later

10/15/83

Dear Harold

Dr Turkel first saw our son, Karl, at the age of 12 months. At this time Karl was growing very slowly, was listless and not very active. His development had slowed considerably.

After two weeks on Dr Turkel's "U" series Karl was growing again. A light came to his eyes and his life changed for the better. The "U" series helped him overcome many physical problems common to Down's Syndrome children.

Today Karl is taller than the average 9 year old and his weight is ideal at 70 lbs. He is in 3rd grade; He is in a class for the mildly retarded part of the day and in a regular classroom part of the day. He reads, uses cursive writing and is doing two column addition in math.

Dr Turkel has helped us as well as helping our son. He gave us hope. Instead of the usual lingo we heard such as "take him home and love him" and "do not expect anything from him", Dr Turkel told us what was wrong and how to normalize it. How to handle all the little problems of Down Syndrome children was part of the help we received.

The "U" series has given our son a better life than he would have had. Dr Turkel is truly a great doctor who has devoted

his life to the problems of Down Syndrome children. I thank God for him and for the opportunity we have had to have our son under Dr. Tuttle's care.

Sincerely
Karen Kautz

4555 Columbia Road
Medina, OH 44256
1-725-0381

October 25, 1983

Dear World,

Our daughter, Carrie, was born on July 15, 1981, my 31st birthday. We were so happy! Carrie was our second child, and we were sure she would be the image of her older sister, Katie. Dick left to tell everyone the good news. Then our pediatrician and two nurses came in to tell me Carrie had Down's syndrome. It was such a shock; I had to tell my husband on the telephone, that was so hard. I contacted our local school for the handicapped (Medina County Achievement Center) at once. My talk with the head of the education department, Chuck Teter, helped keep me sane. He told me that many good things had been happening in the treatment of Down's children. And, he stressed, so much had been accomplished in the last five years, who could say what would happen in the next ten years. That statement gave me hope, and I still think of his words.

We had many bad moments. When Carrie was at Akron Children's Hospital for her blood work a "specialist" falsely told us that if she didn't get leukemia as a child, she would as an adult. He added, that it would be a fatal type. Our baby was only two days old, I felt that I had aged thirty years in those two days. It was several weeks before I found out that the doctor was mistaken, Down's syndrome children have a tendancy to develop leukemia more than normal children, but that doesn't mean that they will develop it.

Our former pediatrician was too busy to discuss Carrie's hospital report with me. His receptionist just gave it to me with no explanation. This report described our baby as "fishmouth" and confirmed that she was retarded. I sobbed as I read it alone in the parking lot. The same physician didn't bother to tell me how lucky we were Carrie had no heart problems, or any physical problems at all. Mothers of handicapped children need to hear some good news once in a while!

Our daughter has been taking megavitamins for two years. She is very healthy. She has had tubes in her ears since June of this year. Her speech is slow, but steadily increasing. She has walked independently for about two months. Carrie enjoys brushing her teeth and "helps" when it's time to get dressed. We think she has a good sense of humor--she has a real "belly laugh". As parents, we are biased, but we feel the vitamins have really helped. She was an infant when she started taking them.

Her stool was always black and "snakelike". Her feet peeled and were always cold. Her coloring was "mottled". She was chubby from edema; her face looked like a pumpkin. Within a few days after taking the vitamins her coloring had improved and her feet were warm. (I took off the extra socks.) She held her head up within two days after starting vitamin therapy, but I couldn't say the vitamins were the sole reason. Along with the vitamins and other nutrients, she takes a diuretic and Metamucil (or an off brand). Her stool is now more frequent and of a normal consistency. She is still edematous, but not nearly what she was before the vitamin therapy.

Carrie started school last fall (1982). She has her own car seat on the bus. She goes four half-days per week. Next year she will be three and will go to school five full days per week. It is hard to think of a baby being in school, but Infant Stimulation is the only way to go! Carrie learns so much in school that I would not be able to teach her. I am not trained to work with a handicapped child. These teachers are, and it is for your child's best interests that you take advantage of any/all programs offered for your child. We take Carrie to speech after school twice a week through an Easter Seals program. She swims at least twice a week at the YMCA, she is in Shrimp I. Normal children are alone with the instructor in that class, but I get in the water with Carrie as she is not coordinated enough to sit alone on the side of the pool. She swims as well, if not better, than everyone in her class.

I think the most important thing to remember is the long-range planning for your child. Don't let anyone tell you your child is not able to participate in a program. If you truly feel that your child is capable of an activity, fight for it! If you feel your child needs special help, seek it out! Do it while the child is young, when "he's a little older" may be too late. It may mean the difference between being able to live alone or needing constant supervision. It's a long road and these children need every break we can give them. Thank God that you are strong enough to do the job at hand. If you feel you are not able to cope with your problems, seek help. Talk to your minister, a friend, or your local social services group. Many days I feel and look as though I am on a tread mill, but when I think of the benefits my daughter has, it is well worth the effort.

You must have a good relationship with your doctor. I made sure the doctor that treats my daughter would at least go along with vitamin therapy, even if he couldn't say it would help her. Our physician is in Family Practice, and he treats us all. He worked with Down's syndrome children in a workshop atmosphere which is a super recommendation as far as I am concerned. He knows as much about little children as any pediatrician, and truly cares about our little girl.

We were very fortunate in finding out about Dr. Turkel while our child was very young. My aunt and uncle had been transferred to Michigan with his company. They had read about his work in the Detroit Free Press in 1979. They had saved the article and mailed the information to me after Carrie's birth. I was very skeptical and wrote to Dr. Turkel asking for names of parents I could correspond with regarding vitamin therapy. He complied with my request, as he has answered any question I have had regarding Carrie's treatment. I received letters from parents that I consider treasures. No one could imagine the trauma some of the parents have been through. I knew these letters were heart wrenching for the parents to write--I've experienced the same feelings. If anyone wants to write to me I would be happy to share any information about our daughter and her vitamin therapy. We were lucky enough to have parents who lived several hours from us come to our home with their son to talk about Dr. Turkel and what to expect when we made our trip to Southfield. No one can put a price on what that visit meant to us.

I gave Carrie her vitamins in applesauce and mashed bananas when she was an infant. She now takes them mixed in yogurt, potato salad, or whatever I am sure she will eat. I give her the vitamins without fail. She has only missed a few times and that was because of illness; never more than one mealtime dosage has been missed. I feel that this is very important--I do exactly what Dr. Turkel has told me to do. If I have a question I ask him about it. He always replies promptly. The Metamucil and diuretic are very necessary. Carrie's teacher asked me if I wasn't concerned that she would have to take them forever. I replied, "What if she does?" The child's comfort is what I am striving for. (Metamucil is a natural laxative, she isn't hooked on it.) My point is, the child will not improve without these substances, why not use them?

I could relate many other stories about experiences we have had with people regarding Carrie and her condition. We have met many wonderful people because of our association with her school and her vitamin therapy. Please contact me if you need any information, or just need to talk or write to someone.

Sincerely,

Frances L. Koenig

Frances L. Koenig (Mrs. Richard A. Koenig)

Worthington, Ohio
February 22, 1979

Dear World:

Our son, Jimmy, began the "U" Series not a year and a half ago. Diagnosed Downs Syndrome as an infant he was a loving but impossibly hyperactive child by 11 years of age. He tested as having an I.Q. of 39.

Today his I.Q. is 66. He is no longer hyperactive; he attends a public school EMR class, mainstreaming, in a trial year. (After a rocky adjustment period he has maintained a good pregress record.)

People who have not seen him for some time remark on his changed appearance as well as behavior and attitude. He has gained 4 inches in height; he is slim now instead of chubby. Instead of despair we now have hope.

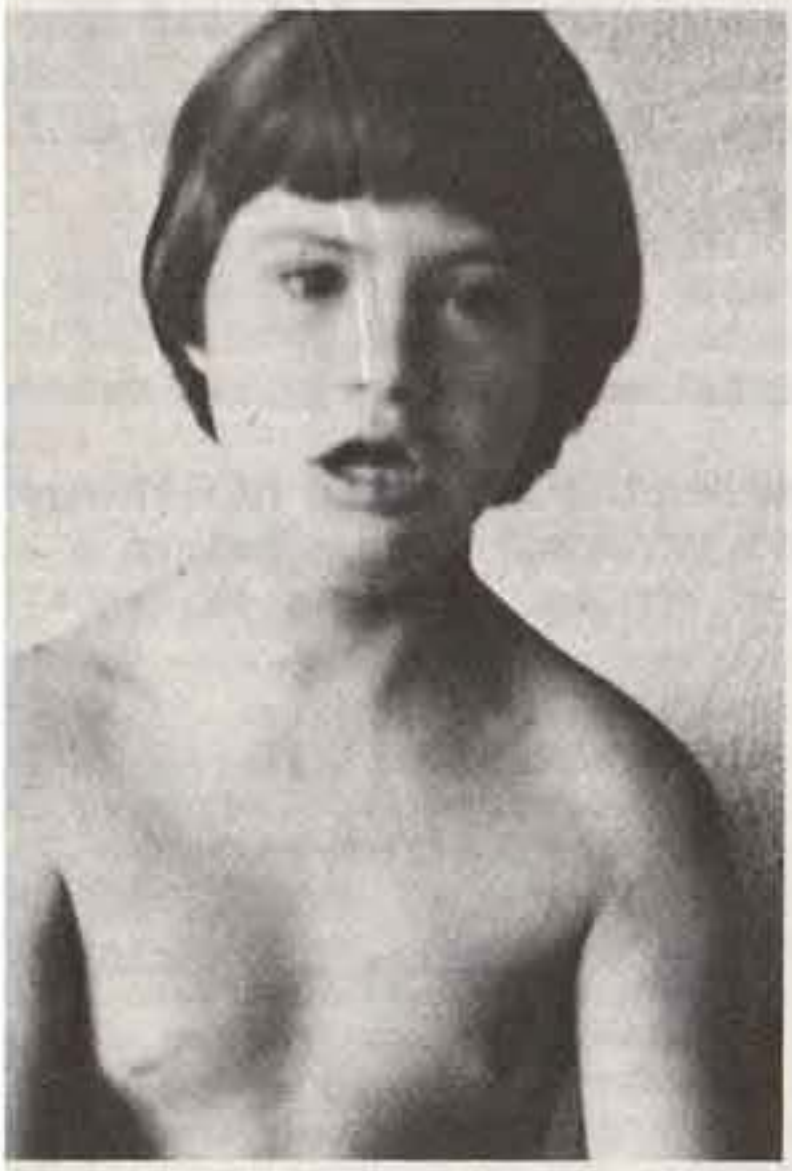
Sincerely,

Marjorie Henninge

Mr. & Mrs. James L. Henninge

US for DS: This is to give you permission to publish this letter and the photographs if you wish, In a "Dear World-type book" only. Or Update. Marjorie Henninge

Jimmy Heninge



Beginning "A" Series
treatment Sept. 1977

Fall 1978

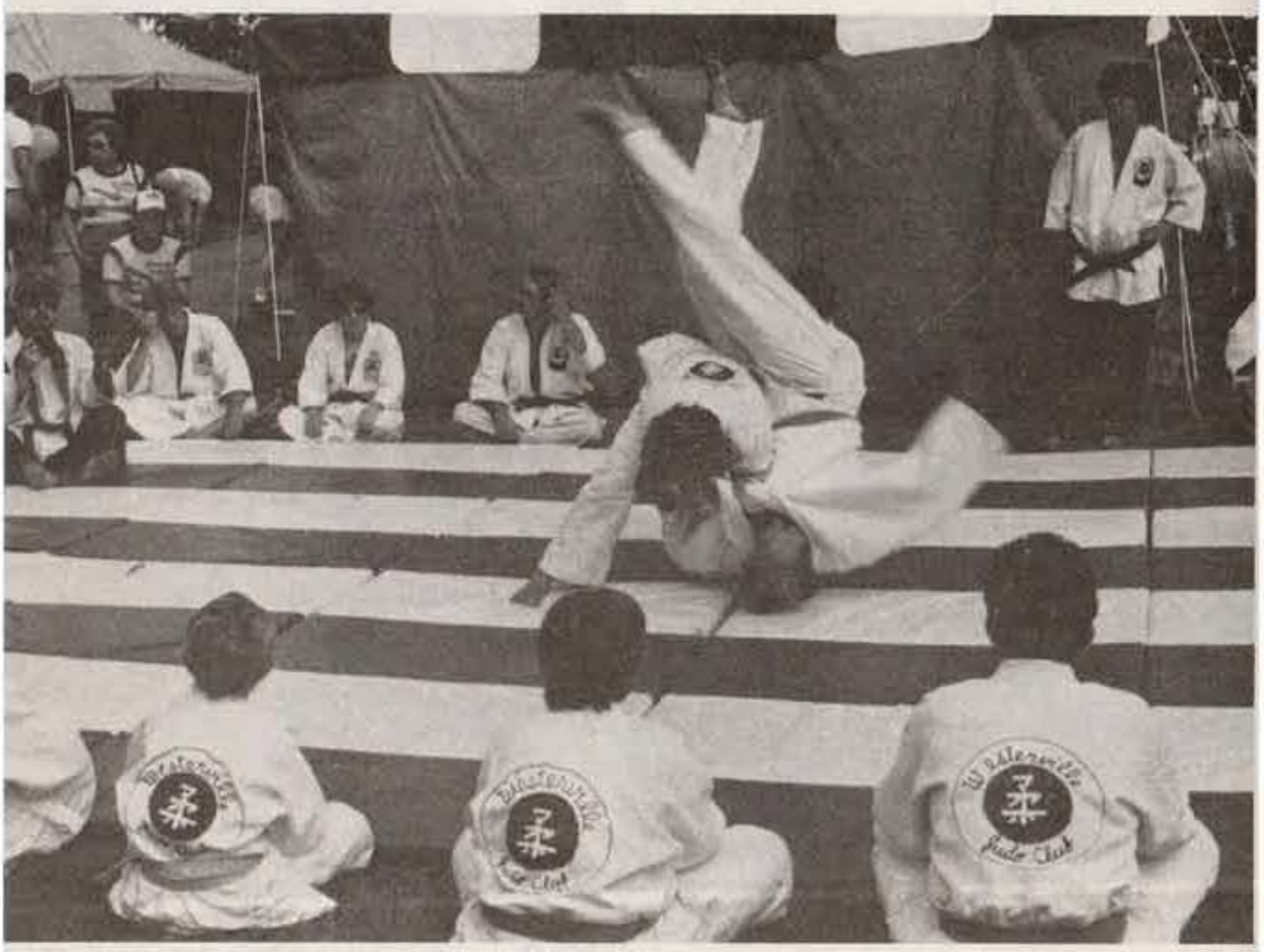
Oct. 31, 1983

Dear World,

Enclosed is picture of Jimmy taken by a classmate at the high school where he's in the special education classes. He has been off the U-Series more than a year after having been treated from age 11 to age 15. He used to hate school; now he's eager to go each morning.

He never could understand the value of money - the concept; Example of growth in his understanding: To obtain this photo I had to pay him for it.

Sincerely,
Maxine Hennige



Mariann

Lørenskog, 21.12.83

Dear Dr. Henry Turkel,

We hereby would like to send you our best wishes for the X-mas and the new year.

We hope you reconize the girl on the picture that visited you in the Grand Hotel this summer. Mariann has now been treated with U-series for one year. She goes to her 1.st year in grammar school and she reads words, writes and does her maths. just as the 22 other "normal" children do. Everyone is puzzled by her developements.

We have also taken new X-rays and when the doctor comparred them with the ones taken before the treatment started, we could clearly see the difference. The doctor examining the pictures this time had not heard of the treatment before, but he believed what he saw, and since he had a mongloid child in his family, he wanted the information IFAB is submitting.

We have heared from Phyllis that you are planning to visit Oslo in January to get the blind test started. We look forward to see you once again.

Yours sincerely

Eva and Arne Håkon.

SENTRALSYKEHUSET I AKERSHUS

KRYSS FOR B.HJ. [ ] BEKV.KL.

JA [ ] NEI [ ]

JA [ ] NEI [ ]

010975 38235

TUNHEIM MARIANN
HRKONSVN 81.
1470 LØRENSKOG

PEDIATRISK POLIKLINIKK
SENTRALSYKEHUSET I
AKERSHUS
1474 NORDBYHAGEN

Pac. har Downs syndrom og [illegible] viet store forandringer siste år etterat hun startet et behandlings program med Turkel U serier (vita miner, enzymer, hormoner etc.). Hun har bl.a. fått endre hode/ ansiktsfysiognomi med slankere nese og mer markerte tubera frontalis og protub. occipitalis. Hendene er er blitt slankere med mindre clino dactyli. 4 år og 4 mnd.er gml. var skjelettalder 3 år og 6 mnd.er.

Skjelettalder. Registrering av skjelettutviklingen i hode/hender.

Rtg. caput, front+side
Rtg. hånd + håndrot (ve. side)

1.12.83 | dr. H. Vogt, Ped.avd.

15/12.83 | Tunheim, Mariann | K | 01 09 75

KB | JW | KCA/m | RHA.E./gl

Caput, den 21.12.:
Det er tatt front og sidebilde som viser normal kalkholdighet. Det sees fortsatt impressiones digitatae sutura lambdoidea, sutura coronaria og sutura frontales er fortsatt åpne. Utvikling av bihuler tilsvarende kronologisk alder.

R: INTET PATOLOGISK PÅVIST.

Begge hender, den 21.12.:
med skjelettalderbestemmelse.

Utviklingen i håndleddet og håndrotsregionen tilsvarer 8 år og 10 mndr mens det i perifere deler er skjelettalder svarende til 7 år og 10 mnd Phalangene er noe kortere enn normalt og det er antydet clinodactili. Det er normal kalkholdighet i skjelettet. Det er symmetriske forandrin er i hendene.

R: SKJELETTALDER KUN LETT FORSINKET I FORHOLD TIL KRONOLOGISK ALDER.
KONFERER BESKRIVELSE.

J. Westvik/gkl

B 3.5
HL

Dear World:

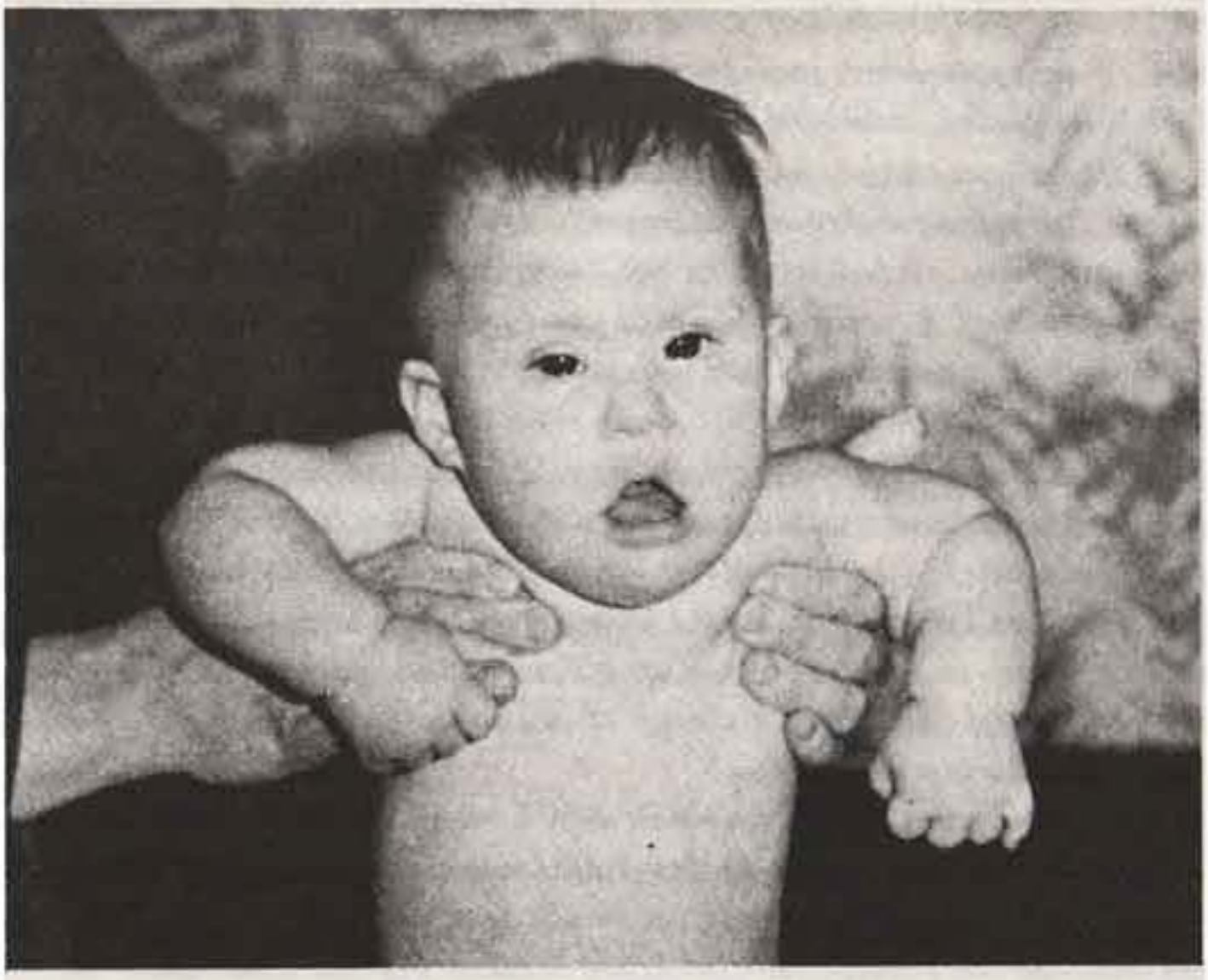
My 21 month old son was born with Down's Syndrome. Although I had heard of the disease and also read about it previously, I knew nothing of the physical complications that could come with it. My husband and I heard about Dr. Turkel through a friend whose Aunt had improved both physically and mentally with the U-series. We were impressed by the program and rationale behind it, so in Feb. 1978 when our son was 8 months old, we made the first trip to Detroit.

Since he began the program we have noticed many improvements. The first thing we noticed was that he stopped holding his tongue out of his mouth. Secondly, he lost about three inches around his waist along with some weight. He is now better proportioned in his arms and legs and is slightly over 30 inches tall (an increase of 4 inches since he first began the U-series). He has had colds but has not had serious trouble and is very alert and active. He is doing well at school in the infant program and although he doesn't fluently or walk independently yet, he says at least five words and along with having good balance he is taking many steps alone. I think the one comment that most people have made is the fact that our son is so active.

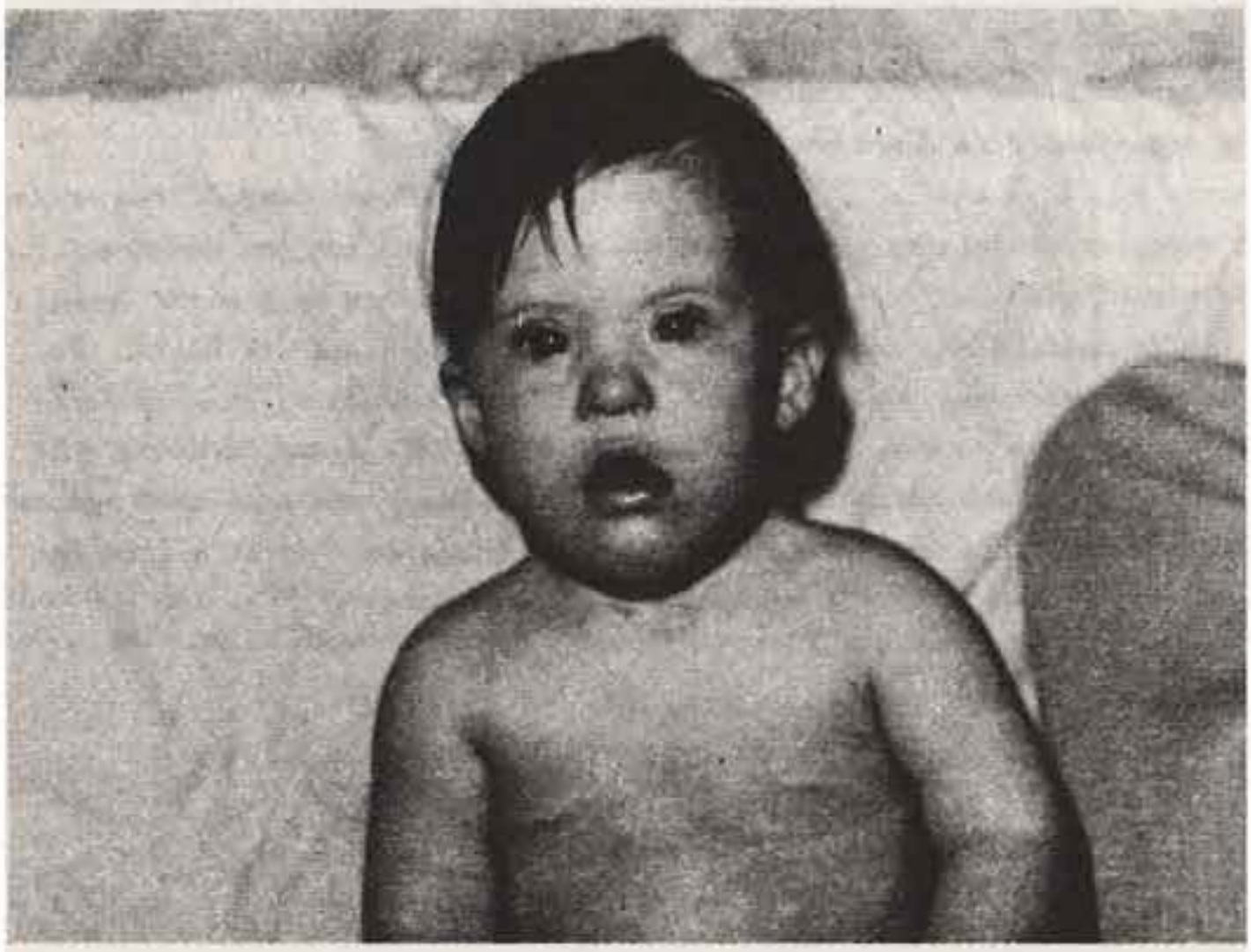
We feel that the U-series has given our son a good start in life and that he will continue to make progress with it. Our plans include continuing the U-series as long as Dr. Turkel feels it's necessary.

Sincerely
Jan Pool

Craig Hool



Feb. 1978 8 months



Sept. 1978 15½ months

Dear World,

I was 38 years old when my fourth child, Liz, was born. I had a normal pregnancy, no morning sickness, and no sign of any difficulty. I went into labor about 4:00 a.m. and at 8:30 Liz was born - an easy delivery. I realized something was wrong when I saw Liz in the delivery room. She had the red-violet color of the top of a turnip. A young resident pediatrician, who came in with a permission slip to allow a blood transfusion, admitted to me that Liz was possibly "borderline" Downs Syndrome. Liz was jaundiced, was placed under lights in an incubator in the nursery, and being force fed (whatever that meant), and remained in the hospital a few days after I went home. I had to go in and learn how to give her formula.

Like most parents of a handicapped child, my husband and I were stunned to learn our daughter was not normal and have attempted to learn as much as we possibly could about Downs Syndrome. We found the common response was that nothing could be done about a genetic defect. We were told to keep Liz warm and happy, that she would have a placid disposition, some training was available for her limited I.Q. and, that if we wished, we could put her in an institution and she would never miss us. I could not be happy with that so, when other babies were in walkers, so was Liz even though she was perfectly content in bed. I rolled up a blanket and wrapped it around her to keep her upright so she could have a change of position, look aroung and possibly be stimulated by the activity around her.

At seven months Liz was in the hospital with a strep infection. The Dr. who attended her had much experience treating Downs children and cautioned me not to allow her to form bad habits as they would be doubly hard to change. I believe it was some of the best advice I could have received because Liz has known what "No" means from the time she started pushing herself around in her walker. Many people have the misconception that Downs children cannot understand, are stubborn and even mean. However, I believe they understand and are simply trying to convey their wants and deisres just like "normal" children do. Liz has been treated as normally as her abilities will allow by the entire family. We are making every effort to assure Liz the opportunity to function at her maximum level.

We learned of Dr. Turkel's "U" Series through a friend who brought two copies of Prevention magazine containing articles covering the medication and treatment. At our first appointment with Dr. Turkel in August 1976, we learned more about Downs Syndrome and Liz in particular, than we had in the six years since her birth. We learned her body was retaining a great deal of fluid, the sockets of her hip bones were not developed as they should, her heart was enlarged, her sinus cavaties were under developed (which causes the mongoloid look to the eyes), her soft-spot had not closed, and that constipation was much greater than we realized. After a trip for complete body X-rays for Dr. Turkel's analysis, and six hours with Dr. Turkel learning about the "U" Series, my husband and I were so filled with information we were physically

and mentally exhausted.

Liz remained on the "U" Series for four years. During that time her trips to our local Dr. for treatment of upper respiratory infections went from 2-3 times per month to about once every six months. She has been very healthy in comparison to many Downs children in our acquaintance and doing very well in the 04-Unit at our local elementary school. She is very adept at taking care of her personal needs i.e., bathing, dressing, eating, playing her records, reading books, picking up her room, brushing her teeth, etc. She helps put groceries away, clears the table, helps with many chores around the house, and has earned many badges in her Girl Scout troop. She has a very large vocabulary she can read, write, and understand the meaning but has difficulty with sentence structure at present.

I believe the "U" Series has helped Liz become healthier both physically and mentally. Dr. Turkel has been able to give us advice about the many difficulties and phases Liz has gone through during the past seven years. Dr. Turkel is quick to point out the "U" Series is NOT A CURE for Downs individuals since the cause, the extra chromosome, cannot be removed, but ameloriates many of the symptoms.

I urge every reader to investigate Dr. Turkel's credentials, the "U" Series, the improvements in Downs individuals being treated, and then write, call, or wire your Congressmen for action to make the "U" Series available through your local physician at a reasonable cost.

Sincerely,

Laura + Nicholas Kronz

Laura and Nicholas Kronz

To the Editor:

Yes it works, but not for all of us.

This is in no way intended to decry the good accomplished by the United Fund, but at this time when everyone is urged to give to those in need, I would like to speak for those less fortunate, at least 100,000 of them tucked away in institutions to be forgotten and to die young. Those with Down's Syndrome, or more commonly known as Mongoloids. These are not denied help by the United Fund, but by our own American Medical Association, and our own United States Food and Drug Administration.

If you were told that a Mongoloid through medication could be taught to read and write, to speak intelligently, to become self-supporting even to the point where they can marry, take care of a home and bear "normal" children, would you believe it? Probably not, because the medical profession has diagnosed it as incurable, a genetic defect, an extra chromosome, and refuses to acknowledge any treatment.

But I have seen it work,

Who am I? I am the foster parent of a two and one half year old Mongoloid boy who received this treatment for four months. I saw him change from an almost helpless, spineless, pathetic little thing, to an alert and happy little boy who could sit alone, stand alone, and take steps by holding his hands. I saw his appearance change to almost normal, he became aggressive and playful. Then he was found to be diabetic, and his pediatrician refused to let us continue the medication. I saw him regress to the point where he could no longer stand, no longer laugh and play, but only make groaning sounds and stare at his hands.

Over four months ago his pediatrician diagnosed him as unteachable, and untrainable, and he was taken to the State Home at Coldwater for

what? To be forgotten and die.

Yes there is help for the Mongoloid, Dr. Henry Turkel, M.D., of Detroit, has devoted his whole life to the amelioration of Down's Syndrome, and the results of his work are truly amazing. But because the medication is a combination of harmless drugs and vitamins, which the Mongoloid definately needs for growth, the American Medical Association refuses to acknowledge it.

Do we have a polio foundation only because an important person, a Roosevelt needed it? Do we have a foundation for the retarded only because of the Kennedy family? How many tax dollars are spent to care for these forgotten ones? Or do you care where your tax dollars go?

I readily admit that 2½ years ago, I too was unconcerned, because my loved ones were not affected by Mongolism, or polio, or cancer, or sclerosis, or retardation etc., but today all but **Mongoloids are receiving** help, why? If it takes unity to help these others, why can't we unite for the Mongoloid?

We love this little boy very much, as much as we love our very own, and we visit him in Coldwater every week, but it breaks our hearts to know that there is help available for him that he cannot have, and because we are not his legal parents, our hands are tired. We continue to pray that with God's help this injustice might be made right.

Space does not permit me to go into detail about Dr. Turkel and his work with the Mongoloid, but if you are interested and would like to hear some heartwarming letters from mothers of Mongoloid children, please write to me or call me.

Wendell K. Lammers
127 N. Market St.
Hastings, Michigan 49058
Phone 945-4291

or

Wendell K. Lammers
8520 Pennfield Rd.
Battle Creek, MI 49017
Phone 963-3801

——:——

April 3, 1980

My son John Michael Lopez was born August 9, 1978. After several consultations with various physicians, I was informed that John is Down Syndrome, Trisomy 21, is mentally retarded and will be physically handicapped. At this time I was told there was absolutely nothing that could be done about his condition. My alternatives were to institutionalise him or take him home and love him. Although I have always accepted the diagnosis of John's condition, I refused to accept the fact that in this day and age of advanced medical technology the medical profession could not offer more. I have taken advantage of every educational program offered to John through the school system; but I still did not stop searching for an alternative to further develope John's physical and mental abilities.

Throughout the first six months of infancy, John progressed as any other "normal" child. During this period I had heard about Dr. Henry Turkel and his treatment for Downs Syndrome children. Because I was told by a pediatric cardiologist that John's life span would be short, I felt I had nothing to lose. I attended lectures given by Dr. Turkel and immediately became interested. At seven months John was not progressing as well as he did up to this point. I then attempted to make an appointment with Dr. Turkel, only to find a waiting list. Because of John's so-called "short life span" I took the list of medications and information about the "U Series" to my family physician. He studied it and agreed that I should try it. I then proceeded to take the prescription to my family pharmacist to have it filled. After numerous attempts, the pharmacist failed because of the non-availability of the medications. John was finally accepted as a patient by Dr. Turkel on July 19, 1979. At this time John showed definate signs of Down's Syndrome. I witnessed through X-rays his underdeveloped

hips, enlarged heart, and accumulations throughout the body including the brain, and underdeveloped sinus cavities. His motor capabilities were not that of a eleven month old child. John was content with too much sleep, not alert, and had poor eating habits.

After being on the medication one month he became more alert and much more aware of his surroundings. By the second month John's eating habits had improved and his problem of congestion had been solved. By the third month John's motor development progressed. He sat up unaccompanied by support; he was able to stand in his crib; he waved bye-bye and played patty cake; walked around furniture and finger fed himself. It was very obvious that John was progressing from the typical capabilities of a Down's Syndrome child, toward a more normal pace. By the fourth month John had stood by himself; became more vocal, such as mama and dada.

It was suggested to me by various professionals that John would have accomplished these tasks anyway. This instilled many doubts in my mind. Because of monetary problems and doubts, in November, I started to stretch John's medication on a every other day basis. By the following month he was entirely taken off the medication. During this time, family members and friends began to ask questions. "Does Johnny have a cold?"; he had become very congested. "Why is Johnny always so tired?"; he became more lethargic. "Doesn't John recognize me anymore?"; he was becoming unalert. "Whats wrong with Johnny?". Only my husband and I knew the answer to that question. We realized without a doubt that John definitely needed this medication. Immediately after the holidays, we started John on his medication as required. Again, during the first month of medication, John became more alert and uncongested. We renewed his prescription in February and have been administering it ever since. He has been tested through the intermediate school system up to the 56 week level and has passed with flying colors. Because of personal reasons, John has not attended his

school sessions during the last few months. I can verify, at this time, that John has continued to progress to the expectations of the schooling program. He can push cars back and forth; easily remove rings from peg; point to three parts of his body (only one is required); imitates scribbling with crayon; turns pages of a book; climbs stairs; taken five steps unaided; shakes his finger and says no-no; uses fork and spoon to feed himself. John shows all emotions of a twenty month old child; anger- when you tell him no; excitement- when people enter a room whom he recognises; shy- with peoples he does not know; pride- feels satisfied by accomplishing a deed by applauding himself. John not only plays well with other children but also entertains himself. I want to state at this time, that tasks, such as standing, was not encouraged by family members. It was through John's own determination that he accomplished these motor skills. Because of his own attempts, we now encourage and practice with him.

Because of my whole-hearted support and belief in the "U Series" and its effectiveness of this treatment I decided to make more people aware. I recently started an organization of concerned citizens here in Michigan. We firmly support the approval and the use of the "U Series". We stand firmly committed to do anything possible to give parents and our children the right to choose a safe, non toxic, effective treatment for certain genetic defects. We cannot understand the negative attitude of the F.D.A. concerning this medication. We intend to persevere in this matter until our accomplishments are finalized. We hope, through investigation and findings, the F.D.A. will reconsider their standings.

We have been very disappointed in our few dealings with the F.D.A.. We inquired about information on the "U Series" and had to speak to five different people before they even knew what the term F.D.A. meant. It is very discouraging to see how our governmental agencies are run. I also asked for the most current information on the "U Series". What I received was a paper that dated

back to 1974. I hope you can now understand and agree with my feelings of disappointment.

Attached to my testimonial are a few letters of confirmation:

1. A progress report from the Intermediate School System
2. A doctors, pharmicists, and mothers account of a child with Down's Syndrome, run by the Macomb Daily. That child is my son, John.
3. A standard letter to be sent, along with information and many supportive signatures, to people in public office.
4. A letter of conformation supporting the "U Series" by a director of special education.

We are extremely confident that through massive public support, we will be heard and answered by the F.D.A. in a most positive manner.

Rosemarie Lopez

Rosemarie Lopez

On April 3, 1980
Appeared Rosemarie Lopez

Robin Werth

ROBIN WERTH
Notary Public, Oakland County, Michigan
Acting in Macomb County, Michigan
My Commission Expires January 23, 1983

December
(12-1973)

Nov 27, 1974

[illegible]
Williamson, WV 25692

Re:
Philip Wayne Hornbuckle

Dear World:

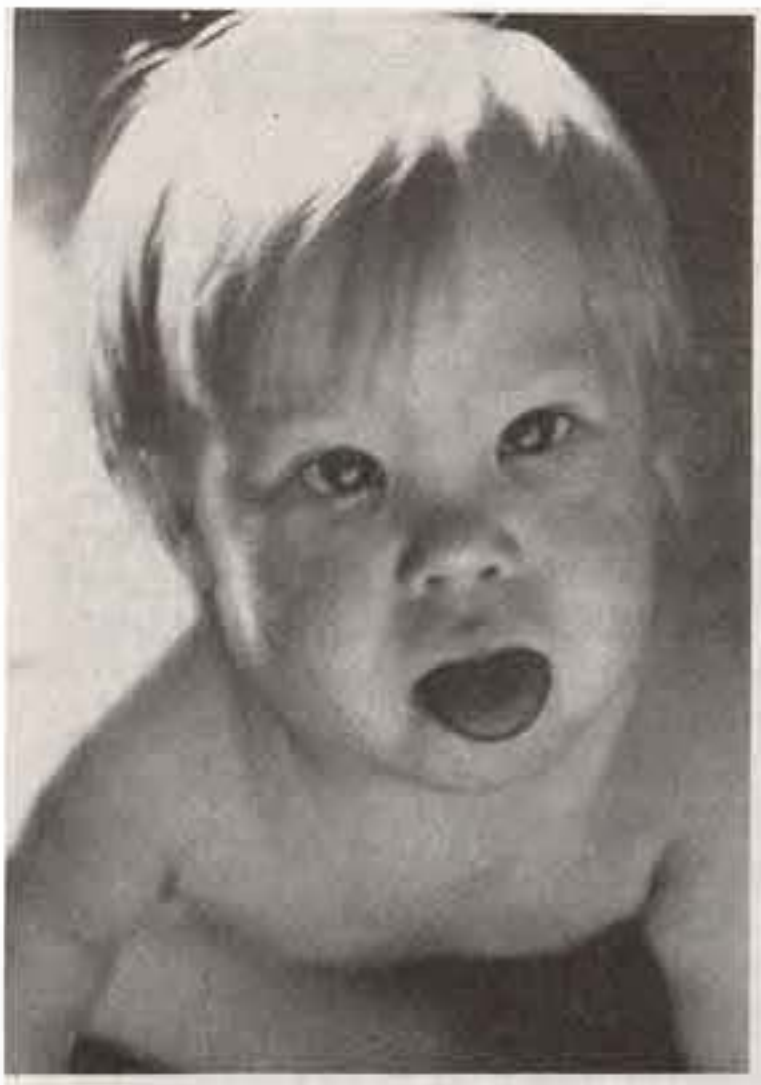
Our son, Philip, was born Aug 14, 1973. His weight was 7# 14 oz and length was 19 1/2". He was diagnosed as having Down's Syndrome at that time.

Philip was hospitalized in Feb. 1974 with pneumonia and again in March 1974 with bronchitis; but since receiving Dr. Turkel's U-Drug Series beginning in Nov. 1974, he has not had any serious illness.

We are very thankful for Dr. Turkel's treatment of Philip and feel it has helped him both physically and mentally. He is alert and energetic and has learning potential. He is presently enrolled at Guyan Elementary School in special education.

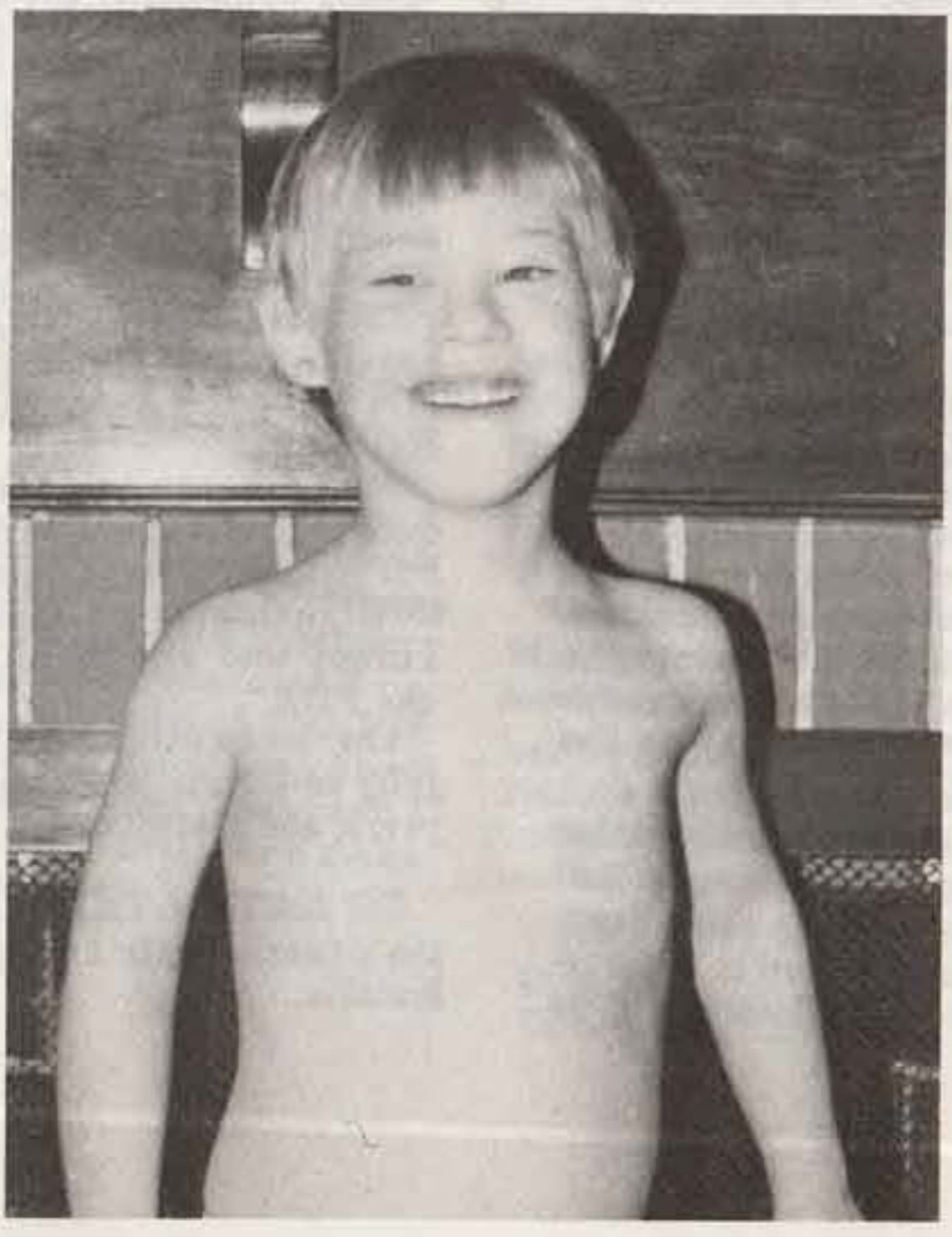
His weight is now 34# and his height is 46".

Enclosed are pictures taken of Philip before and after treatment which clearly indicate a marked improvement in physical features.



Philip 11/74

Philip 5/78



Philip 1/80

Mother disregards federal

by KATHY BROWN

Natalie Atkins is taking a gamble.

The eight year old Green River girl, suffering from Downs Syndrome (mongolism), is taking a controversial medication to fight her illness. The medication, called 'U Series' by a Michigan physician, has not been approved by the federal Food and Drug Administration (FDA) despite attempts over a 30 year period.

Despite the possible dangers of the drug, something the FDA warns against, Natalie's mother said it has turned her and her daughter's life around.

Katy Atkins, a lifetime Green River resident, said yesterday she's never seen any side effects associated with the drug in her daughter. That doesn't eliminate the possibility of side effects occurring with others, she added.

Her daughter has been under the medication since Dec. 3, 1981, the first child in Wyoming to do so. Atkins calls the results "a miracle. It's like having a new child."

Atkins said she waited one year before telling others of the medication because she wanted to see the results.

She recently spoke with a group of Green River mothers about the medication, and some of those mothers may also take a gamble and visit the Michigan doctor.

ACCORDING TO Faye Peterson, of the Food and Drug Administration in Washington, D.C., the medication for treatment of mongolism hasn't been approved because there is no scientific evidence establishing the safety or merits of the vitamins, enzymes and minerals in treating the genetic disorder.

Peterson said the U Series contains vitamins, enzymes and some potent drugs, such as thyroid. As a new drug, she added, the medication is "not recognized as safe and effective for its proposed use."

The public information officer said she is not sure what specific effects the U Series may have, but added that it's not adequately tested for safety and the FDA doesn't approve of the treatment and can't recommend it be used.

Because of this, the federal agency can't permit interstate distribution of the U Series by the Michigan doctor who developed the medication.

Another source said the physician would violate the law if he packaged or promoted his medication in interstate commerce.

The doctor, according to the FDA information, disagrees with that agency's findings, and is able to practice medicine since he is licensed to do so.

FOR NATALIE and Katy Atkins and for Cindy and Sarah Johnson, however, those warnings may not stop them from seeking help for Downs Syndrome.

Cindy Johnson is the mother of infant Sarah, who also suffers from Downs Syndrome. She and her husband are planning to visit the Michigan doctor to see what can be done for their daughter, despite the FDA warnings.

"When I look at Natalie, I know I have to go and try to do something," Mrs. Johnson said. "I can't ignore Natalie."

Mrs. Johnson said the effort will be difficult and expensive for the family, but she has investigated the matter through literature from Japan and Europe and she doesn't understand the FDA."

The medication has been used legally in Europe and Japan for several years, she claimed.

TO KATY ATKINS, the reality of the situation exists with her daughter Natalie.

warnings to treat child

Her daughter entered first grade in Wilson School this year, and made straight A's on her first report card. Atkins credits the U Series for the 'miraculous' improvement in her daughter over a one year time period.

"If anybody could have lived with her for a week last year, compared to this year, she's like a different child," Atkins said.

Most Downs Syndrome children never are able to attend the public school system, she claimed, so the step taken by her daughter is seen as the promise of more to come.

Atkins credits the medication with improving her daughter's eyesight, her breathing, her speech, her physical abilities and her mental abilities. She also said her daughter has grown 10 inches in the past year and the medication has helped her overall posture.

Looking at a one year difference in her child, she said, "it gets better and better every day. In every aspect, everything has improved."

Atkins said she walked out of the doctor's office last year in December and "cried for three days. God, what a miracle, what a Christmas present."

The Green River native added, "I'd pay $10,000 if that was the price. I'd pack everything I own."

To Atkins, when she first heard the news after Natalie was born, "I was crushed."

THE MOTHER of the Downs child said "anything's worth a try," when dealing with that genetic disorder. "It's the best gamble I ever took."

Atkins said she's worked with her daughter and pushed her hard throughout her life. But "last year I was at wit's end, and this year it's like a ton off my shoulders."

All this wouldn't have happened, however, if she hadn't "by chance" saw a documentary on television about the medication.

After finding the name of the physician, and getting the medication, she waited one year before telling others "before I stuck my foot in my mouth. I want my results. I got her sitting right next to me.

Atkins said she is telling about the U Series and the possible help it may offer to families because "I want to see other children have the same chance Natalie had, and have other parents feel like I do.

Before, without the treatment, a doctor told her to enjoy her child while she could.

"Every morning you go in there and pray she'll wake up and she's alive." For seven years she had to have that courage, Atkins said. "And now I know she's gonna wake me up and it's going to be alright. You can't keep her down now."

Atkins said if Natalie keeps progressing as she has so far, "I'm sure she'll graduate and do just great, and be self-supporting."

SHE DESCRIBED her child as being introverted, not interested or active and somewhat listless before receiving the medication. Now, however, she has an active, interested, curious friendly daughter who gets excited.

On the airplane ride to see the Michigan doctor the first time, Atkins said, her daughter just sat there and hardly had any reaction. The last time Natalie went, however, she "had to try out everything, she was so excited, and she had a great time."

On the agenda for Natalie this year is an unusual activity for a child afflicted with Downs, skiing.

Dr. William E. Lund, D.C. Oct. 17, 1978

851 East Grand
Escondido, California 92025
Phone (714) 745-7251

Dear World

Our son Matthew has been receiving Dr Dunkle's treatment since he was 3 mo old. We noticed a change in his strength within a week. Although his growth is slow, he is developing in a very normal pattern. Most people do not realize that he has Down's because he looks and acts normal. He is very alert.

Because of his low tone we are very interested in adopting a baby girl who has Down's.

We would encourage parents to use this treatment.

Sincerely
Dr. Wm. Tom E. Lund

BIO MECHANICS • PAINLESS BODY CORRECTION •

Dear World:

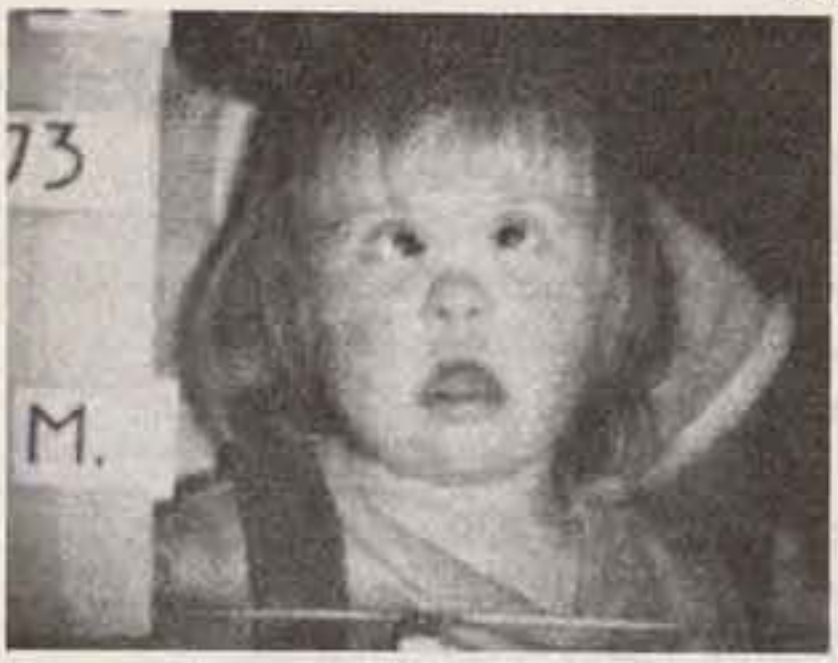
My name is Rachel. The name means "patient in suffering". I am trying to be patient, but it is difficult when I see so many being hurt by the suffering they see in a situation which sometimes seems hopeless. I know there is hope, but I am so frustrated at being unable to express myself in words and make people believe and understand me. So I have asked my mom to write this story for me with the hope of shedding some light on the subject.

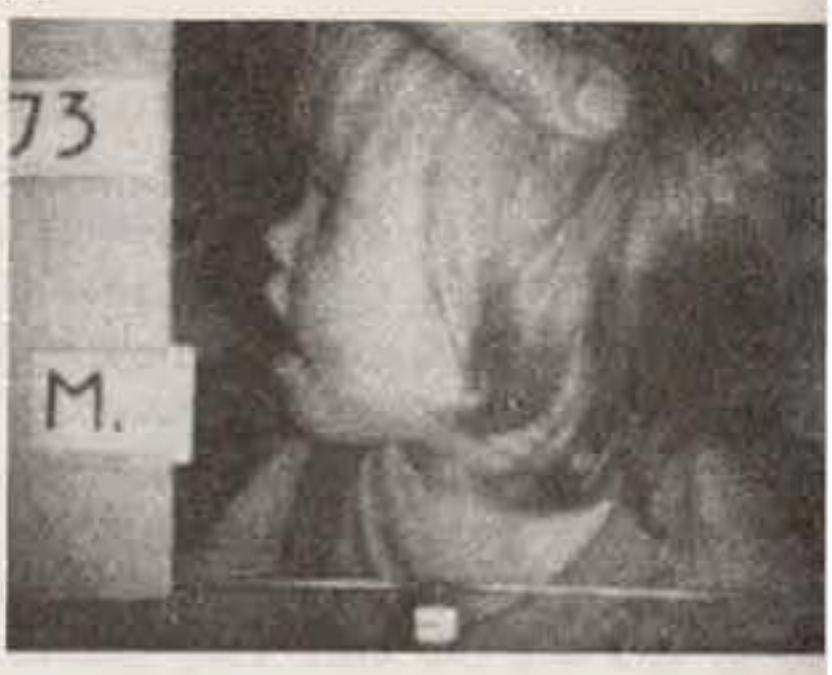
The condition I was born with is called Downs Syndrome or "mongolism". The doctors who attended me after my birth explained to my mom and dad that they had the option of institutionalizing me, and should not feel guilty in doing so, or that they could take me home and "love" me; but that there was not much else that could be done. Later, another doctor tried to talk my mom into giving me up because he said I would ruin the whole family. But, I was born into a family where I was loved and accepted, and where I had parents who never gave up hoping, even when the doctors said there was no hope.

My health problems during my first year were quite severe and the doctors concurred that my physical and mental condition was even more severe than average for a Downs child. At six months of age, I contracted a condition known as hypsarythmia (a disrythmia of the brain wave, causing siezures). Apparently, in many cases, it results in severe mental retardation or death. Fortunately we found a pediatrician who was well-informed, and not afraid to try something new. The medication used was found to work in a few cases under just the right circumstances. It worked for me, and the siezures were gone within four days of treatment, never to return again. This all happened before the "U" Series.

Another problem I had was respiratory disorders, including asthmatic bronchial pneumonia at the age of nine months. I worsened when I entered the hospital and while there, one lung collapsed. After about ten days, I was released and mom finished nursing me back to health at home.

BEFORE





AFTER

After all this, plus severe constipation, teething, sleeplessness, and the 'no hope' attitude of the doctors who had attended me, my parents were ready for some hope from somewhere. It came from a parents meeting where they heard that some parents had found hope in the "U" Series formulated by Dr. Henry Turkel of Detroit, Michigan. Together, my folks decided they had nothing to lose, and that it was worth trying - although it was somewhat expensive and the traveling was going to be a real hassle. If other parents were excited about it, they felt they owed it to their family to try it.

After giving it the six-month trial they had decided upon, they knew they could never take me of it until I was discharged by Dr. Turkel. My coloring changed (no more big purple circles around my eyes - no more purple hands and feet). Gradually my skin became more soft and supple; less chapped and dry. My respiratory condition improved my hyperactivity improved gradually, and my big fat tummy resided completely. When mom experimentally took me off the series for a couple of weeks (after about 2 ½ years) my skin became purple and blotchy again and I was less alert and attentive. After being back on it for a week, I again improved.

Now I am 7 years old, slim, long-legged and (pardon my modesty) quite beautiful - so they tell me. I haven't been to the doctor for a cold or infection or flu or anything for over a year and a half.

I'm enclosing some pictures. The first set (front and side view) were taken just before I started the treatment. The second set was taken after eight months of treatment. Notice how much of my puffiness resided even at this point. The last picture is my school picture taken this year - aren't I gorgeous?

U.S. FOR D.S. 12-1-78
P.O. BOX 64465
LOS ANGELES, CALIF. 90064

TO WHOM IT MAY CONCERN.

ALEX WAS BORN ON OCTOBER 18, 1970 IN THE CITY OF BELLFLOWER, CALIF. HE IS THE FOURTH ONE IN THE FAMILY. WE WERE ALL HAPPY HAVING A SMALL CHILD. OUR FAMILY DOCTOR HAD ALWAYS TOLD US THAT OUR SON WAS FINE AND HEALTHY AS ANY OTHER CHILD WAS. HE NEVER TOLD US OF THE PROBLEM OUR SON HAD. HE PROBABLY DID THIS SO IT WOULD NOT WORRY US. AT THE AGE OF 6 MONTHS WE NOTICED THAT HE HAD SOME KIND OF PROBLEM AND THAT STARTED WORRYING US. WE WENT BACK TO OUR FAMILY DOCTOR AND GAVE HIM OUR REASONS, BUT HE SAID ALEX WAS FINE. WE WENT TO ANOTHER DOCTOR AND HE TOLD US ALEX'S PROBLEM. WE COULD NOT ACCEPT THE PROBLEM THAT OUR SON WAS NOT NORMAL AND MADE US VERY SAD. WE TOOK ALEX TO MANY DOCTORS, BUT THEY SAID THERE COULD BE DONE NOTHING FOR HIM. WHEN ALEX WAS FIVE YEARS OLD WE FOUND OUT ABOUT A DOCTOR, BY THE NAME OF "HENRY TURKEL". THROUGH THE "PREVENTION MAGAZINE". IMMEDIATELY I WROTE TO HIM AND HE ANSWERED BACK VERY QUICKLY.

WE HAD SEVERAL CONVERSATIONS OVER THE PHONE, AND THEN HE GAVE US AN APPOINTMENT. IN MAY 1975 I TOOK ALEX TO DETROIT, MICH. DR. HENRY TURKEL EXAMINED ALEX AND PUT HIM ON A ONE YEAR TREATMENT. AFTER A COUPLE OF MONTHS WE NOTICED SEVERAL CHANGES THAT OCCURED IN ALEX, SUCH AS HE WOULD GET THE FLU A LOT LESS AND HIS NOSE DID NOT RUN ANYMORE. AS THE MONTH HAVE COME BY WE'VE NOTICED THAT ALEX IS A LOT MORE HENLTHIER AND IS MORE ACTIVE, ALEX HAS BEEN ON THE TREAMENT FOR 3 YEARS AND THE DOCTOR SAYS HE ONLY NEEDS IN IT THE MOST ONE MORE YEAR. OUR RELATIVES AND NEIGHBORS HAVE NOTICED THAT ALEX IS GETTING A LOT MORE BETTER. WE HAVE VERY MUCH FAITH IN GOD AND IN MODERN MEDICINE, WE HOPE ALEX WILL BECOME BETTER THE ONLY PROBLEMS WE HAVE HAD ARE TAKING ALEX TO DETROIT, MICH. HOTELS, LONG DISTANCE CALLS, THE LAST THING IS THAT THE MEDICINE IS VERY EXPENSIVE AND PAYING THE DOCTOR MONTHLY, ALL THESE THINGS OUR INSURANCE WILL NOT PAY. I THANK GOD BECHUSE I LIVE IN THE MOST WONDERFUL COUNTRY IN THE WORLD, BUT CAN NOT UNDERSTAND WHY THE GOVERNMENT

DOES NOT ACCEPT DR TURKEL'S TREATMENT, SO THAT EVERYONE IN THE UNITED STATES CAN BENEFIT FROM IT. IT IS INCREDIBLE THOUGHT THAT DR. TURKEL'S TREATMENT IS ACCEPTED IN JAPAN.
I HOPE THAT MY LETTER WILL REACH THE CONGRESS OF THE U.S.A. AND THE REST OF THE WORLD.
SO I CAN GIVE MY TESTIMONY OF DR. TURKEL'S TREATMENT FOR DOWN'S SYNDROME CHILDREN. I HOPE GOD WILL OPEN THE EYES OF THE CONGRESS, SO THEY CAN APPROVE THE TREATMENT "U-SEMIES" BY DR. HENRY TURKEL. SO IT CAN BE USED TO CURE EVERY ONE IN THE U.S.A. AND ALSO THE REST OF THE WORLD WHO IS IN NEED OF IT.

THANK YOU!
ALEX'S FATHER.
ALEJO [illegible]

Dec. 7, 1978

Dear Arline Burman,

I just got your letter in the mail today so I couldn't possibly meet the Dec. 1st deadline. Please change my address on your records because we've moved. Route 4, Box 18-B Cullman, Ala. 35055

My son, Jacob, is only 7 months old so I am fairly new to this organization. I wish I could correspond with some other young mothers. I'm still adjusting and I sure would like any literature you could provide me with. I would like to correspond with any mothers who might have some suggestions and advice for me. I and really interested in your new book with children's pictures and parents stories. My son has been taking the "D Series since he was 4 months old. Many doctors have told me that Jacob is a "mild case" or borderline" (if there is such a thing) so I'm not sure if he's made alot of progress (I mean I don't really know what to expect). I hope you understand what I mean. I am trying to say I don't know what he would have done if he hadn't

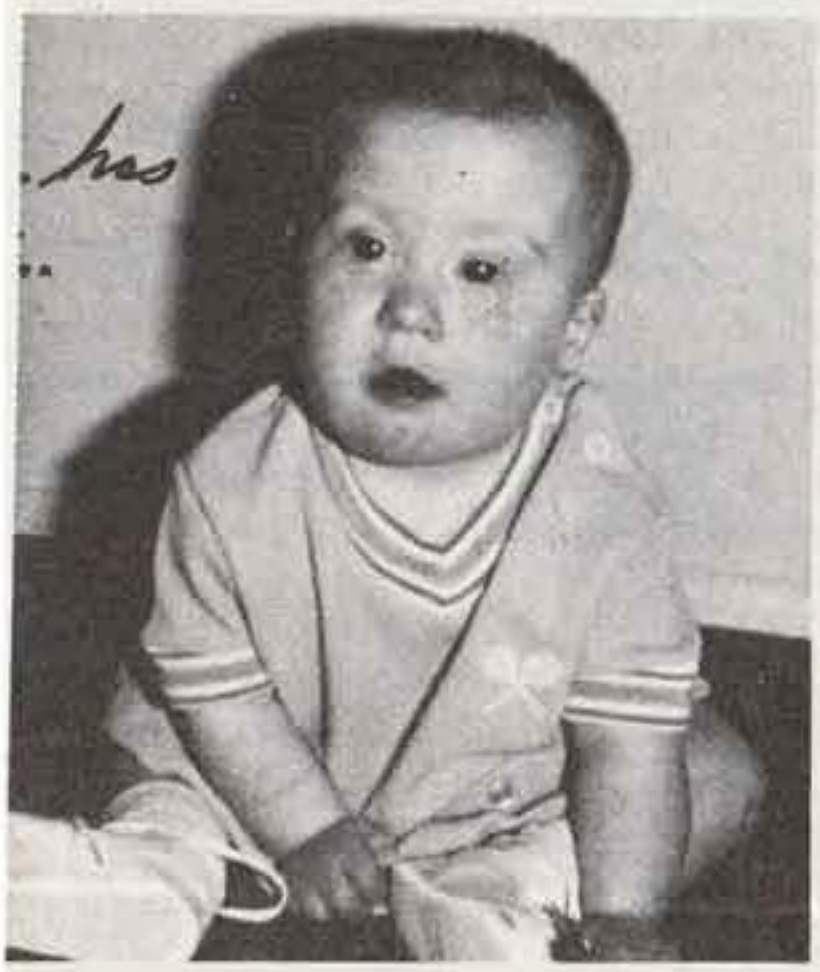
been taking the "V Series". I really feel like he looks good and is making good progress. I would like to discuss him with some other mothers. If you can help me please give me their address. I will be looking forward to hearing from you. Thanks for the lovely Christmas card.

Debbie Shear
Rt. 4 Box 18-B
Cullman, Ala. 35055

10-15-79

Carlene was 7 months old when we started her on Dr. Tunkel's treatment. We consider ourselves very fortunate to have learned about Dr. Tunkel when our daughter was so young. After two weeks of her receiving the treatment our family noticed Carlene was much more alert to what was going on around her. Also her eye to eye contact improved tremendously as she had very little previously. We are very pleased with Carlene's development since she comprehends all that is said to her and can follow directions very well. Carlene has just turned 6 years of age.

Jean Thuby



MR. HAROLD L SILVERMAN
1970 WINDOVER RD
PASADENA, CA 91107

<

HAPPY NEW YEAR

Sept. 26, 1984

Dear Dr. Turkel:

I have just received the program for the symposium and believe me it is a fantastic and wonderful program---I stop and think how wonderful it would have been if we had it fifteen years ago---it sure would have saved me a lot of trial and error. The important thing however is that progress is being made to help the Down's children.

Brad (Thank God) is in the graduating class at Pasadena High School and taking all regular classes and will graduate with his class as a student like all the rest of the students. I have to look forward to his future years---I have quite a few options that I will start to pursue and hope to come up with some right answers.

Now that you are coming out to California will it be possible for Brad, my lovely wife and yours truly to get together possibly for Dinner some evening during your stay---it would be no problem for us to drive down to the Disneyland Hotel and break bread together.

Looking forward to a positive response. Give my love to your lovely wife and I sure hope we can all get together and chat.

Humbly yours,

Harold Silverman

AND MANY, MANY MORE HAPPY NEW YEARS TO YOU AND YOURS IN THE FUTURE

North Beach Drive
Fox point, WI. 53217
March 21, 1980

Dr. Henry Turkel
19145 West Nine Mile Road
Southfield, Michigan 48075

Dear Dr. Turkel:

It is important to me that the information in this letter be a part of the medical records you hold regarding our son Gino, born with Down's syndrome, June 10, 1971.

The following statements are true and without exaggeration regarding physical and mental progress Gino has experienced, and we have witnessed, since beginning the "U-Series" treatment at the age of two years, 8 months, on February 10, 1974.

**** Gino had a constant yellow-green mucus discharge from the left nostril from the age of 16 months. It could not be alleviated after many weeks of treatment by an Otolaryngologist. February 10, 1974 you sprayed your prescriptive nasal mist in Gino's nostrils, and we continued doing same three times a day for three weeks. At the same time Gino was ingesting the complete "U-Series". Since the latter part of February, 1974 Gino has had no involuntary discharge from the nostrils and never an infectious discharge when clearing the nasal passages by blowing his nose as part of his personal hygiene routine.

**** Gino had severe constipation beginning at birth. Each bowel movement of hard black nuggets tore tissue in the rectum which caused much bleeding. The pediatrician said it was a problem of Down's syndrome and Gino would have to live with it. Thirty (30) days after being on the "U-Series" Gino was having normal bowel movements with no discomfort, and eliminating regularly every two days. He continues to have normal stools and regularity.

**** Gino, at one year, was diagnosed by Arche Pequet, M.D. as having a heart murmur. Dr. A.T. Buscaglia diagnoseda heart murmur. February 10, 1974 you, Dr. Turkel, diagnosed a heart murmur. Mr. Maglio and I were allowed to listen with the stethescope and confirmed we heard a "swishing sound". August 12, 1974, six months later, and six months of the "U-Series" treatment, you heard no heart murmur. Mr. Maglio and I confirmed we could not detect the "swishing" sound we heard previously. Dr. Kenneth Johnson, in examining Gino November 1974, found no heart murmur. The readings of Gino's heart continue to be positive.

**** Gino's skin was very dry. The skin on his arms and legs was like sandpaper. After being on the "U-Series" for five (5) months we were very aware of the soft velvety feeling of the skin on Gino's entire body. The soft flawless condition of his skin and beautiful complexion stimulates many comments of envy to this day. The boil-like eruptions on his buttocks disappeared at this same time, never to appear again in these six (6) years of the "U-Series" treatment.

**** Gino's legs and arms, particularly, had a very mottled appearance, reddish-purple in color since birth. Obviously extremely poor circulation. His arms and legs were always cold to the touch. He wore knee-high stockings in the summer months to keep his legs warm. He wore sweaters the year around to keep his arms warm. Within nine (9) months after starting the "U-Series" the mottling decreased. Now only slightly apparent on his thighs. The arms and legs, for the past five years have been of constant normal body temperature.

**** Gino had severe respiratory problems. A vaporizer ran continuously in his bedroom and he slept with the head of his mattress elevated plus two adult pillows to make it possible for him to breath while sleeping. The labored breathing could be heard two rooms away. Three (3) weeks of the "U-Series"and he was then sleeping flat and breathing normal.

**** Gino had a very "puffy" appearance from head to toe. His face so full he appeared to have no neck. Puffy arms and hands. The hips and legs did not have the pronounced "puffiness" as did the rest of his body. The abdomen was extremely full. Within six (6) months to nine (9) months of the "U-Series" his body was slender and well proportioned. The fingers became slim and elongated to present a very graceful hand. He then displayed a slim, well defined neck.

**** The bridge of the nose from birth, until the age of approximately four years, did not exist. It was a flat area. When fitted for glasses at the age of five years the optical technician was amazed that he could readily fit Gino with an eye glass frame without special application for fit over the bridge of the nose. Indeed, the bridge of the nose had developed since being on the "U-Series". The nose structure remains normal, continues to develop with the appropriateness of growth.

Dr. Henry Turkel March 21, 1980

**** Gino's bone-age at 2 years, 8 months was that of a seven month infant. At three and one-half years, and ten (10) months of the "U-Series" his bone age was that of an eighteen (18) month old child. An eleven (11) month gain in bone-age development in ten (10) months treatment of the "U-Series". Gino continues to grow in height 2 3/4 inches to 3 inches each year since the age of three years. Previous to the "U-Series", 1/2 to 3/4 inches per year was maximum.

Let me assure you, tender loving care does not bring on these physical improvements. The truth of the matter is, the first three years of Gino's life he had constant adult attention . One can in all honesty say twenty-four hours a day. Due to his many problems it was necessary for a constant vigilance. The problems including a coma-like seizure which lasted for five hours at the age of one year, 9 months; another six months later which lasted two hours. The third "seizure" of the same nature occurred at the age of two years, nine months and was forty-five minutes in duration. Having been on the "U-Series" treatment since that time Gino has had no reoccurrence of these spells.

Three months after being on the "U-Series" Gino was able to entertain himself and required so little attention that family members were able to indulge in a more normal way of life. Gino required <u>less</u> tender loving care after the age of three years, after the treatment of the "U-Series" had been initiated.

Mentally Gino made tremendous strides within four (4) months of the "U-Series" treatment. From 15 months to 3 years Gino had a fair attention span and at times seemed to listen well but, seldom produced meaningful actions. At 2½ years he was just a loveable, soft little marshmallow laying on our shoulder, molding to the curves of our body. His muscle tone left much to be desired.

At 2½ years of age Gino had no likes or dislikes. He showed no response to music, no interest in television. He never indicated he was hungry. He did not cry, he did not laugh. He needed to be shown <u>each</u> <u>time</u> how to hold a rattle or small toy. At the age of 3 years, and having been on the "U-Series" for four (4) months he became responsive, expressive, curious, aggressive, demanding. He became a little boy. He solved many of his own little problems. He comprehended direction and discipline. He developed rythm to music by clapping his hands, pounding his feet on the floor and "singing" to music. At 3½ years he imitated finger play to songs "Inky-Dinky Spider", "The Wheels on the Bus" and others. He could recite the alphabet through the letter "K" and recognize the printed letters out of sequence. He could count to 15 and recognize printed numbers in that range. He could pick our <u>his</u> <u>name</u> printed on a

sheet with other names on it. Mechanically he could turn any type of electrical wall switch on or off. He could work a key in a lock.

If one cares to look at the number I.Q., Gino's I.Q. obtained from testing with the Peabody Test is 73. Determined by a member of an educational multi-disciplinary team on Feb.29,1980. A long cry from 1974 when one could not be obtained because of Gino's inability to perform.

At the age of 2½ years Gino was dropped from a one-to-one speech program because he was unable to produce or imitate the sounds of "ba-ba-ba" or "ma-ma-ma". The simplest form of human speech. After seven (7) months of the "U-Series", at the age of 3 years, 3 months he shocked the speech clinician by his abilities at that time to imitate sounds and identify verbally; bus, car, ball, Dad, apple, Mom and top. Words he was not able to verbalize, or a situation that required more than one word, he developed a fantastic ability to use body language or gestures to make himself understood. For the past two years he has used complete sentences. Now with an extensive vocabulary and good articulation he has no trouble being understood. Using such sentences as "May I borrow your pencil?", "Let's play games, instead.", "Is tomorrow a school day?". He is able to verbally sequence happenings. Gino is reading primer books, printing, spelling and doing simple math as of this date.

He independently showers and dresses himself, including buttoning and zippers. He selects his own clothing for school, making sure colors coordinate. He has impeccable manners. Enjoys eating in restaurants and orders his own food. He has good reasoning and good logic.

We were told at the time of Gino's birth he would never walk, never talk or ever leave his crib. His life span would be about four years because of the severe effect of the Down's syndrome. Watching the lack of development for the first 2½ years of Gino's life it was evident that prognosis was not in error. You could not know our dismay in the drastic improvement, our personal experience, in knowing the "U-Series" treatment had brought Gino quality of life. It seemed he had stored up so much and then it all came forth. Now it was possible for him to learn, he could express himself and he was in excellent health.

Health? Gino has not had one cold, temperature, flu-----not one sick day in the six years he has been on the "U-Series".

Dr. Henry Turkel March 21, 1980

We revel in Gino's independence. The first 3 years Gino needed care twenty-four hours a day. Watchful eyes and keen hearing constantly. Since the intervention of the "U-Series" Gino has required less attention and he is a productive and contributing member of our family. Tender loving care has good effect on all members of the human race. Tender loving care does not develop good circulatory function, develop the bridge of the nose, relieve severe digestive problems, develop curiosity, sinus cavities, strong growing bones. Tender loving care does not clear and nourish the brain so that it can be receptive and expressive.

The "U-Series" has made it possible for Gino to develop in a near normal way. You did <u>not</u> tell us the "U-Series" was a cure for Down's syndrome. You did tell us it was a treatment. Just as insulin in a treatment for diabetes. Only the good Lord knows where Gino would have been without your "U-Series" treatment. Perish the thought.

It is devasting to us, as a family, to think a whole generation of Down's syndome children, and other children with problems, have been denied the benefits of the "U-Series" treatment. Denied the right to have their quality of life enhanced by this treatment. Denied the right to good health, mental improvement which brings about easier learning, independence and social acceptance because of better coordination, less prominent physical characteristics, say nothing of the contribution to the family and an acceptable member of the community in which he lives. Yes, tax dollars saved because the individual can live at home and be productive.

Dr. Turkel, your development of the "U-Series",and sharing it with as many children as possible under very adverse government agency opposition is most commendable, to say the least. How does one explain away the hard headidness of the medical community-----those committed to healing the body? The health insurance companies that would rather pay $50,000.00 per year to institutionalize a Down's syndrome child, than grant payment of beneficial health care for $2,000.00 per year for a few years (anywhere from 2 to 6 years) so the individual could live at home, continue to improve in physical and mental growth? Yes, and in independent growth. How does one explain that there are national organizations that profess to be dedicated to the needs of the retarded citizen and, yet, refuse to put forth any effort to even research the logic and theory of the "U-Series" treatment? Why?

Dr. Henry Turkel March 21, 1980

I know you have put forth great energies and a gross amount of money in the past two decades attempting to make the "U-Series" treatment available to the population of the United States. You have endured tremendous harassment, which is unforgivable. We commend you for standing up to all of this for the sake of Gino and all the other "Ginos" that have benefit of your labors. You are a benevolent man.

God love you and keep you for those of us who care. With great personal regards and unwavering admiration, I remain,

Sincerely,

June E. Maglio

June E. Maglio (Mrs. Sam)

Subscribed and sworn to before

me this 24th day of March, 1980.

BRUCE BRIAN JACOBSON
My Commission is permanent
Milwaukee County, Wisconsin

A life of HOPE

Mother battles to give others hope

the

JUNE MAGLIO
story

FROM THE ethnic MILWAUKEE SERIES

AS PUBLISHED AND CREDITED TO

THE MILWAUKEE JOURNAL Wednesday, September 14, 1983

A life of HOPE

By Linda Steiner

Journal Ethnic Reporter

June Maglio doesn't raise her voice much. She's a soft-spoken woman who is dedicated to her family — and to the families of just about any disabled or retarded person she comes in contact with.

In her controlled, determined way, she gives of her time and energy until she accomplishes whatever it is she sets out to do.

Since 1981 she has been in charge of Festa Italiana's VIP Day, which honors thousands of disabled on the opening day of the festival, and she recently was appointed to the Milwaukee County Commission for the Handicapped and Disabled.

She has done volunteer work with the handicapped through the Jewish Vocational Service and started a group called HOPE — Helpline Offer to Parents of Exceptional Children.

Maglio learned how to get things done through her personal pain and suffering. And she has vowed never to let other parents go through what she experienced.

Now 56, she had her third child, Gino, at age 44. He was born with Down's syndrome.

"I didn't know there was anything other than my family and their needs for the first 25 years [of marriage]," Maglio said as she relaxed in the living room of her Fox Point home. "I ran around with a little cotton frock, kept the cookie jar full. ... That was my role and I was going to play it to the hilt.

"Gino changed everything."

Courtship remembered

Before him, Maglio, who refers to herself as a converted Italian, had lived a traditional life. She met her husband, Sam, a Commission Row merchant, in March 1947, and the couple were married the next January.

She laughs when remembering how Sam sent a friend "to check me out" at her office after having met her through business conversations over the telephone.

"Those Italians will do that kind of things, you know," she said.

She converted to Catholicism and enveloped herself in the Italian way of life — with a major focus on the church, home and family.

Although two doctors had told her she probably would not be able to have children, less than a half-year after her wedding she became pregnant. The couple's first child, a daughter, Marilyn, known as Spook, was born in March 1949. Her second child, a son, Sam Jr., came 11 years later,

in September 1960. Eleven years later, she found she was pregnant with Gino.

Despite her age, she was thrilled.

Troubled pregnancy

Maglio didn't even know she was pregnant until she had a miscarriage, a twin of Gino's. When she went to a doctor to be checked after the miscarriage, she was told she had a tumor, and she was scheduled for surgery. While in the operating room, a lab technician ran in and announced that the "tumor" was a fetus and that she was still pregnant.

A few days later, her doctor told her not to expect to carry the child to term, and two other doctors offered to perform an abortion because of her age. She refused, wanting very much to have the child.

"All these things pointed up to me that Gino was meant to be there," Maglio said, remembering how she felt when he was born.

Something was wrong

But almost immediately after Gino was delivered, things started to go wrong. First, her doctor told Maglio's husband not to tell his wife that "something was wrong with the baby." She was not allowed to see the child for almost two days and eventually went searching for him in the hospital. She couldn't find him.

Neither she nor her husband knew what Down's syndrome was and could get no information from anyone at the hospital. No literature was available there, either.

When Maglio finally was allowed to see her child, the nurse who brought him in dropped him on the bed and left the room in a hurry when Maglio asked her a question about his condition.

The pediatrician who saw the baby declared coldly that the child would never walk or talk, would be a terrible burden on the family and should be put in an institution immediately.

"My God, this isn't a monster, I thought, it's a darling baby!" Maglio said.

After three days in the hospital, she insisted on going home — with her child.

Mother, father agreed

"I'm not going to take this abuse, I thought," she said. "Thank goodness I was a mature mother. A 22- or 23-year-old would have just put him away.

"Sam and I talked about all this, and I said, 'I wonder why the good Lord sent Gino to us?' There had to be a reason. We found he opened a whole new life for us."

After months of coping with Gino's health needs, which were great, searching for literature on Down's, which was scarce, and trying to locate other Down's parents, whom she couldn't find, Maglio read a newspaper article on what she calls "a special school for special children."

At age 15 months, Gino was accepted into what is now called the St. Francis Children's Activity and Achievement Center, which turned out to be a beacon in the storm. For the first time since he was born, Gino was treated with professional care — and faith. And he was learning to do things.

Literature available

Through the center's auxiliary, Maglio started HOPE, which offers support services to other parents of infants with Down's. She has seen to it that literature on HOPE is available in almost every hospital in town.

Gino's severe health problems led the Maglios to a doctor in Detroit who treats Down's victims with a megavitamin therapy. After observing marked improvements in Gino's physical condition, Maglio got involved with a national group called US for DS, which is dedicated to the training of Down's syndrome patients and the promotion of the special treatment. She is now a national vice president.

Financial boost needed

For the last two years, Gino, who is now 12, has been enrolled in a residential school for the mentally retarded and developmentally disabled, St. Coletta, in Jefferson. Maglio is an ardent backer of St. Coletta and works tirelessly at just about everything she can do for the school.

Her efforts at Festa Italiana's VIP Day — which provides free festival admission, food and a lot of love for the disabled — are heralded throughout the city's Italian community and beyond. She, along with Italian Community Center officials, are hoping that financial assistance to keep VIP Day alive will be forthcoming.

Gino Maglio

"I got involved with this because of Gino," Maglio said. "And through it I have learned a lot. . . . If it would end, I would crawl into a hole and pull it shut after me."

And as for Gino? The child who couldn't be educated now walks, talks, reads, spells, is a real rascal and has become the kingpin of his close-knit Italian family. He was the ring bearer at his brother's wedding and is the godfather for his infant nephew.

He was not left out

As he was growing up, his sister and brother took him along whenever they could, Maglio said. His brother "never let him get away with anything." His sister has a career in special education, thanks to Gino.

"We're hoping when he graduates from high school [at St. Coletta], he will be able to come home and work for his brother [on Commission Row]," Maglio said.

"Like the other children, Gino needed discipline. He had chores around the home and got the same kind of parenting the other children did.

"It just takes a little longer, that's all.

"We *all* have the same needs. That's been my premise with raising Gino and what I hope I can project in the future. I just hope I have the strength and stamina

to stick with it and continue to develop new programs, new things to give the disabled the things the rest of us have."

Source of hope, data

Maglio puts in countless hours every week meeting and keeping in touch with other Down's parents, letting them know what kind of services, schools and recreational opportunities are available to them — and that somebody cares. She keeps tabs on TV programs and written information on Down's and alerts the parents.

She is sensitive to the fact that she is an older woman and that young parents may not relate to her. She tries very hard to match parents with others of similar ages and backgrounds.

"I can't have other parents wasting their time like I did," Maglio said, "struggling, looking for these things.

"This is my whole thrust in life. If I can make it that much easier for anybody going through this trauma," she said, showing about an inch between her thumb and forefinger, "then it is worth it."

She sat back on her sofa and smiled.

"You know, I'm not the same person I was 12 years ago. I'm bold and aggressive. I speak my piece and have a very open mind — thanks to Gino."

In June's world,

June Maglio

These letters are from the "LETTERS TO THE EDITOR" column.

every life is worth living

Linda Steiner's tribute to my dear friend June Maglio that recently appeared in The Journal evoked smiles, but a few tears also.

Although a fine article, it merely touched on the warmth and generosity of this special lady who was recently appointed to the Milwaukee County Commission for the Handicapped and Disabled.

While working with her at the St. Francis Children's Activity and Achievement Center and at Festa Italiana's VIP Day, I noticed she had a talent for making you feel that you were the most important person, doing the best job you could — when, in reality, she inspired you to do your best because she always did her best.

She never is too involved, and she will sit quietly and listen attentively to your problems. Most often she has a solution to them.

Her entire family reflects this love and care, as they care in return.

This does make her sound very close to sainthood, but she has been known to instigate mischievous fun on more than one occasion.

Thank you for giving credence to what we, her friends, have known about her for a long time. She has rightfully earned this recognition.

SHIRLEY MELICHER

Whitefish Bay

What this mixed-up world needs more of are people like June Maglio.

To read the story about her in The Journal was like discovering gold in a coal mine. So much news in the newspapers and on television is "black."

But Linda Steiner's beautiful article shown like the sun by contrast. June and her son Gino are jewels.

Thanks, June, for caring for "the least" among men and women and for showing that *every* life is worth living.

Thanks, Linda, for your sensitive portrayal of a beautiful lady.

JEANNE ZAHALKA

Oshkosh

CONCLUSION

Mental retardation carries high costs. Twenty-five percent of the population has an I.Q. below 90, three percent below 70. Birth defects and genetic diseases affect 1/12 of all newborns and cause more than 60,000 deaths annually.[200] Down syndrome affects 1/1000. Institutionalization, loss of earning power, and other costs run at least $50 billion a year.

Illiteracy handicaps one third of adult Americans,[201] including some with treatable medical disabilities. Failure to treat leads to:

1. **Deprivation of the patient's right to treatment and improved health**
2. **High cost of medical care**
3. **High cost of special education**
4. **Crime**
   Victims of crime
   Police and prison expenses
5. **Welfare**

In Georgia (Atlanta ARC, 1973), "the mentally retarded offender population is estimated to comprise close to 39 percent of the prison population (I.Q.'s below 79)" If only ten percent of adult illiteracy and borderline retardation is caused by an underlying medical condition, reduced need for medical, welfare, or criminal justice services, including detention, can save $80 billion annually.

Dementia is now the predicted conclusion to the life of the Down syndrome person. Of the thousands of patients treated with the "U"

[200]Trenton, S.L.: Michigan's Genetic Services Program one of Three in the Country. Mich. Med. (July) 1982.

[201]Kozol, J.: Illiterate America. Anchor Press. Doubleday. 1985.

Series, many have reached middle age. Not one treated before puberty has developed Alzheimer's disease, although present theory assumes that all Down syndrome patients develop it during their third or fourth decade of life.

The vast misunderstanding about the role of primary and secondary accumulations, as explained in this book, has held back progress in the field. When I first demonstrated the "removal of accumulations" resulting from excessive gene products, the FDA denied that there were accumulations. The FDA, in fact, stated that to treat Down syndrome it would be necessary to remove the chromosome. As recently as 1975, a physician at the University Medical Center in Iowa City stated that "any medication which comes after the prezygomatic [sic] error has occurred is too late and can essentially not change the condition."[202]

This expert consultant was not talking about cure but about change, amelioration. It is ridiculous to state that any medication that comes after the prezygotic stage, namely before conception, is too late. What about thyroid for congenital hypothyroidism or insulin for diabetes? This expert opinion prevented the continued improvement of my patient; because of it, the Department of Social Services denied payment for treatment that, for the full four years, costs less than a month in the hospital.

> In 1961, I explained that
> Improvements which followed the ingestion of medication could be made to regress by withholding the medication and reappear upon resumption of medication. The ability to manipulate the condition of regression and improvement in the patient established the efficacy of medication. Thus, the

[202]Pers. Corr. Smith, E.M., Oct. 28, 1975.

body of each patient provides its own control.[203]

What constituted a mystery to scientists at academic centers was evident to orthomolecular scientists like Doctors Hoffer and Pauling, or practicing physicians like Dr. Robert Doman, who actually treated Down syndrome patients.

Experts at universities and the FDA denied the existence of accumulations until gene mapping and other new techniques conclusively demonstrated their presence. They now concur with the aspect of the "U" Series rationale that discusses gene-product accumulations. Despite post-mortem evidence, the FDA continues to deny the presence of waste-product accumulations, or that they affect the patient. Some experts deny that any genetic disorder can be ameliorated after conception!

The medical establishment's long delay in accepting the orthomolecular or "U" Series rationale for treatment of metabolic disorders in general as well as of mental retardation in particular is serious. Even an allergic reaction is not limited to hay fever or hives. Allergies or other metabolic disturbances can cause all kinds of erratic amd bizarre behavior, ranging from social withdrawal to pyromania. Yet, orthomolecular therapy of genetic diseases has only arrived at a stage reached 30 years ago by drug therapy for mental illness.

Thirty years ago, Freudian analysis was firmly entrenched. In 1953, the NIH established a $40 million research project to study the tranquilizers. The NIH appointed committees not to evaluate but to to belittle them.[204]

While traditional therapists were ridicul-

[203]Turkel, H.: Medical Treatment of Mongolism. In: Proceedings of the Second International Congress on Mental Retardation, 1961. p. 411.

[204]TIME 69:51; 1957.

ing the medical treatment of mental illness, I pointed out that it represented a proper approach - biochemical treatment of a metabolic disorder:

> The recent discoveries of Heath, Selye, Macht, Theorell, Pauling, and others, as well as the results obtained from the new tranquilizing drugs, indicating that mental illness is a symptom of physical or chemical disorder, point the way to a new approach. . .[205]

The introduction of tranquilizers eventually altered basic theories about mental illness. However, I soon joined the group of scientists who believed that a more logical therapeutic modality incorporated vitamins and minerals; after all, the "U" Series was one of the first regimens to treat serious disorders by means of the synergistic, systematic, and scientific use of medications, enzymes, vitamins and minerals.

I have treated patients with many different diseases: diabetes (Type II), ataxia telangiectasia, Tay-Sachs and other storage diseases, emphysema, and idiopathic mental retardation, as well as Down syndrome. Some patients have been helped more than others, but most have benefited sufficiently to demonstrate the value of reducing metabolic accumulations, the underlying theory of "U" Series therapy.

For patients with single-gene defects (as opposed to chromosomal excesses), removal of accumulations may not be enough. But then, again, neither is administration of the proper enzyme, if it is available. The massive accumulations have made it impossible to treat Tay-Sachs or other storage diseases by introduction of the enzyme into the patient's tissues. Combined

[205]Turkel, H.: Freud. JAMA 163:580 (Feb. 16) 1957.

use of the enzyme and the "U" Series has not been tried (despite the millions of dollars that the NIH have spent on the basic research).

Added to the harm done to untreated persons and their families because of medicine's blind spot regarding nutritional therapy (except for the obvious deficiency or dependency states), is the damage to the community. The problem of genetic diseases affects everyone, and no one is exempt from the possibility of having a family member with an inborn error of metabolism or chromosomal defect. At least 1/3 of hospital admissions (and 1/3 of human disease) are related to genetic disorders. Although older women are having fewer Down syndrome children, the overall incidence remains the same.[206]

Progress in basic genetic research is too slow for today's patients. They cannot wait. The sooner available treatment is approved, the sooner patients improve. As the children of the first pioneering parents improve, researchers and practicing physicians will combine their experience to build on today's knowledge and produce superior products. As long as we are at a standstill, no progress will be made.

Thirty years ago, the computer with the same capabilities as the one that sits on this desktop filled a whole room. Computers have changed, but bureaucrats have not. Consequently, the conquest of genetic diseases, predicted 25 - 30 years ago, has not come to pass.

IT IS NOW TIME FOR CONGRESS TO INVESTIGATE THIS SITUATION: TO LEARN WHY PATIENTS IN OTHER COUNTRIES CAN USE THE "U" SERIES AND AMERICANS CANNOT!

[206]Murdoch, J.D., Ogstrom, S.A. J. Ment. Defic. Res. 28:177-187; 1984.

acrocentric: a chromosome with the centromere near one end.

amino acids: the building blocks of proteins.

aminoacidurias: diseases in which there is abnormal urinary excretion of amino acids (81-82, 84-86; also PKU, 139-141, 164).

amniocentesis: aspiration of amniotic fluid surrounding the fetus to test for genetic diseases.

anorexia nervosa: a disorder characterized by a false body image, abnormal eating patterns, extreme weight loss, amenorrhea (126, 127).

ataxia telangiectasia: an autosomal recessive disease; failure of muscular coordination, dilation of vessels; recurrent pulmonary infections and immunologic defects; occasional mental retardation (99-106, 396).

autosomes: the 22 pairs of chromosomes excluding X and Y.

borderline intelligence: between retardation and average IQ; individuals with an IQ between 70-90; slow learners.

candida albicans: a yeast associated by some researchers with a variety of abnormal psychological states (126, 127).

carrier: a person who has one normal and one abnormal gene for a recessive disease.

cataract: clouding of the lens (36-43, 287).

centromere: the constriction of the chromosome at which the chromatids are joined.

chromatids: spiral filaments joined at the centromere which make up a chromosome; they separate in cell division, each going to a different pole of the dividing cell and each becoming a chromosome of one daughter cell.

chromosome: structure in the nucleus that carries the genes; the normal count is 46.

chronological age: based on the birthdate.

commitment: placement of a person into treatment or residential custody; institutionalization.

community residence: group home care, as opposed to large residential facilities.

congenital: present at birth.

diabetes mellitus: Insulin-Dependent (Type I): associated with early onset, certain antigens and antibodies, low twin concordance. Non-Insulin-Dependent (Type II) associated with later onset, high twin concordance, variable insulin levels, and atherosclerosis (4, 38, 98, 164, 394, 396).

DNA: deoxyribonucleic acid; carries the genetic code.

dominant: a trait expressed by an individual with at least one gene for that trait; if present in a parent, it affects one half of the offspring.

Down syndrome: formerly mongolism, Down's syndrome; associated with 3 copies of chromosome 21 (trisomy 21); delayed development, physically and mentally.

emphysema: loss of elasticity of lungs (125, 126, 396).

enzyme: a protein that catalyzes a specific chemical reaction.

feedback inhibition: inhibition of reactions by their end products.

fibroblast: a cell grown in culture for genetic studies (117, 146, 215).

gamete: the sperm or ovum (egg); contains half the chromosome number (haploid number) following meiosis (e.g, 23 chromosomes in sperm or ovum).

gene: part of a chromosome with a detectable function in heredity; cistron.

genetic code: the code that relates nucleotide sequences to amino acid sequences. Each nucleotide triplet codes for a particular amino acid.

genotype: the genetic constitution of a person.

Hunter syndrome: a sex-linked disorder of mucopolysaccharide metabolism (122-124).

Hurler syndrome: autosomal recessive disorder of mucopolysaccharide metabolism (108-110).

inborn error of metabolism: a genetic block in metabolic pathways.

IQ: intelligence quotient or deviation IQ (73, 94, 194, 196, 198); a number (standard score) that expresses the relative level of intelligence of a person determined by comparing an individual with the performance of others on an assessment scale such as the Stanford-Binet(4, 17, 73, 74, 76), Wechsler scale for children (75, 76) or adults (290), Peabody, Vineland (18, 83, 197, 257-262, 290, 291), or Cattell (40, 74, 76).

karyotype: the chromosome set; photographs of the chromosomes arranged in order.

learning disabled: a child with learning difficulties, especially in language or math.

mainstreaming: integration of disabled children into regular classrooms.

meiosis: a type of cell division that produces the sperm or egg; in meiosis I, the number of chromosomes is reduced from 46 to 23.

mental age equivalent: the chronological age for which the achievement is average, regardless of the person's own chronological age.

mental retardation (classification):
mild mental retardation: IQ range 50 or 55 to approximately 70; considered educable.
moderate mental retardation: IQ range 35 or 40 to 50 or 55; considered trainable.
severe mental retardation: IQ from 20 or 25 to 35 or 40; require supervision.
profound mental retardation; IQ below 20 or 25; require close supervision or total care.

mitosis: formation of two cells with the same chromosomal composition as the parent cell through cell division.

mosaic: a person with at least two different cell lines, like 46 and 47 with trisomy 21 (166-168, 177-178).

nondisjunction: failure of the chromosomes to separate during cell division; can lead to trisomy (165-169).

orthomolecular: providing the optimal biochemical environment for normal function,

especially by use of substances normally present, such as vitamins (1, 2, 96, 126-129, 145, 203, 398); genetotropic (36, 202).

percentile: denotes percentage of population below the individual in that trait; 50th percentile is average (16, 49, 119).

phenotype: the total physical and biochemical nature of a person as determined by heredity and environment.

recessive: a trait that appears only when both genes are present; theoretically, 1/4 of offspring inherit the genetic factor and are affected.

reduction division: the first meiotic division, in which the chromosome number is reduced from 46 to 23 in the gamete.

Sanfilippo syndrome: a recessive disorder of mucopolysaccharide metabolism (110-122).

sex chromosomes: XX in females; XY in males.

Tay-Sachs disease: a rare recessive lipidosis characterized by very early onset, paralysis, dementia, cherry red retal spots, blindness, death by age 3 or 4 (106-108, 396, 397).

translocation: one chromosome becomes attached to another (169, 176).

trisomy: three copies of one chromosome (165, 168, 176, 177).

X-linkage: X-(or sex-) linked disorders, though recessive or dominant in females, are always expressed in males, who have one X chromosome.

zygote: the cell formed by the fertilization of the egg by the sperm.