



# CLINIC FOR SPECIAL CHILDREN NEWSLETTER

VOLUME I NUMBER 6

\* LANCASTER COUNTY, PENNSYLVANIA \*

DECEMBER, 1993

*GREETINGS TO ALL  
WITH OUR WISH THAT IN CARING FOR OTHERS  
UNDERSTANDING AND HOPE WILL GROW  
IN ALL OF US  
AND ENRICH OUR LIVES*



Life at the Clinic for Special Children over the past six months has given us moments of gratification with healthy children, events to celebrate and affirm our purpose, but also times of frustration and sorrow. We will share some of the triumphs in this newsletter. It is hard to convey the difficult challenges of caring for children with unknown disorders, with disorders others consider untreatable where we challenge that assumption and see potential, often working on an uncharted course to keep a disease at bay. The Clinic lost three very special children over the last several months each to a different ultimately fatal genetic disorder. These children taught us much about their disease, about living and dying at a very young age. Katherine, Suzanne, and Larry will always be in our hearts and they will continue to challenge our minds to understand the diseases that made their lives all too brief. We thank them and their families for what they continue to give us.



## 1993 BENEFIT AUCTION A GREAT SUCCESS

Rain did not dampen the spirits of those who attended the 1993 Benefit Auction for the Clinic for Special Children. In fact rain may have helped bring the best ever results with a net total of \$105,359 raised to help fund the Clinic's medical services and research on genetic disorders. Dr. Holmes Morton, the Clinic's director, clinic staff and Board members wish to thank all who participated and all who donated items for the sale, those who baked, cooked, quilted, collected, and spent many hours to make this year's sale such a success. Among items sold were over 80 full

size quilts and as many wall and crib size quilts, antique dolls, handmade toys, furniture, collector Winross trucks, household goods, farm tools and supplies and a pony with cart. Food stands kept everyone happy and well fed with strawberry pies, soft pretzels, baked goods and subs. Maybe it was the rain, but this year's chicken was fantastic.

Funds from the auction are essential to the Clinic's operation. The moral support and encouragement expressed by so many in the community are also deeply appreciated by Dr. and Mrs. Morton, the clinic staff and families of special children. There are often long, difficult days for everyone involved in caring for children with unusual complex medical problems, but there is also much joy and opportunity to grow together as a caring community. Thank you to all who participated to make the work of the Clinic possible. Special thanks to the members of the Auction Committee who for the third year gave tirelessly of their time and energy to make the auction such a success: Mr. and Mrs. Leonard Hurst, Mr. and Mrs. Enos Hoover, Mr. and Mrs. Harvey Hoover, Mr. and Mrs. John Fisher, Mr. and Mrs. Steve Huyard, Mr. and Mrs. John Stoltzfus, Mr. and Mrs. Steve Beiler, Mr. and Mrs. Jacob Zook, Jr., Mr. and Mrs. Daniel Stoltzfus, Mr. and Mrs. Ernest Zimmerman, Mr. and Mrs. Ralph Atkinson, and Miss Rebecca Huyard. The auctioneers who volunteered and the men who barbecued all that chicken in the rain deserve special appreciation and thanks.

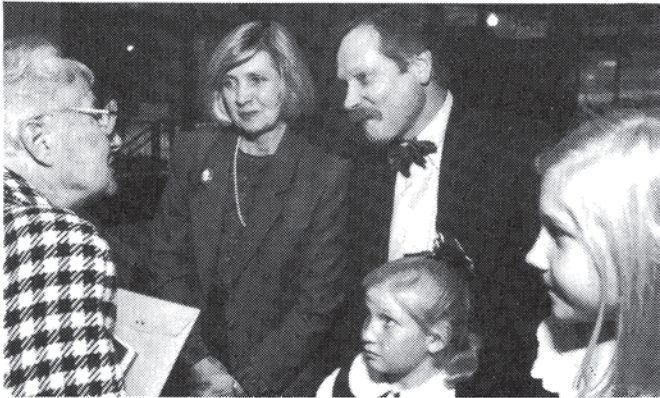
The non-profit Clinic depends on contributions to supplement its income from patient fees. This support helps cover the cost of maintaining its unusual laboratory equipment and diagnostic services, and provides support for clinical research to improve care and prognosis for children born with disorders such as maple syrup urine disease and glutaric aciduria, both potentially lethal disorders of protein metabolism. With its unusual setting in the middle of an Amish farm, the Clinic, under the direction of Dr. Holmes Morton, has become one of the primary centers in the US for diagnosis, clinical research, and care of children with these metabolic disorders. It is the only facility of its type that combines pediatric primary care with highly specialized laboratory services to provide a coordinated approach in caring for children with metabolic disorders. Contributions through the Auction every year help to keep fees at reasonable levels so that all families who need the Clinic's services including the testing for all Amish infants, can better afford them.



**DR. MORTON WINS  
ALBERT SCHWEITZER PRIZE  
FOR HUMANITARIANISM FOR 1993**

Dr. Holmes Morton, founder of the Clinic for Special Children, is the recipient of the 1993 Albert Schweitzer Prize for Humanitarianism. Given in Baltimore, MD on October 27th by The Johns Hopkins University on behalf of the Alexander von Humboldt Foundation, the prize recognizes Dr. Morton for his dedicated and effective work at the Clinic for Special Children. Previous recipients include former President Jimmy Carter, Marian Wright Edelman, Norman Cousins, and former Surgeon General Dr. C. Everett Koop. The Prize includes an award of \$10,000 to Dr. Morton which he will donate to the Clinic.

The work recognized by the Schweitzer Prize is made possible through the support of many who helped raise the Clinic from frustration and hope since the need became public through the Wall Street Journal in the fall of 1989. In a sense the prize also belongs to many of you who have made the work at the clinic possible and to many of the families who come here. In his acceptance speech, Dr. Morton spoke of why children within the Amish and Mennonite cultures born with genetic disorders who have complex medical problems are thought of as Special Children, how they are accepted as a gift rather than as a burden, and why these children inspire his work. Many who heard his speech in Baltimore asked for a copy. We decided to print his remarks in this newsletter as one way to share his thoughts about his work and say thank you to all who have made it possible.



*Mrs. Rhena Schweitzer Miller talks with the Mortons about her father at the award ceremony in Baltimore.*

The Schweitzer Prize Acceptance, October 27, 1993  
Holmes Morton MD

I am honored and happy to have the work at the Clinic for Special Children recognized by the Schweitzer Prize. I thank Randy Testa who nominated me and the members of the committee who awarded the Prize.

There are several people who in an immediate way share this Prize with me. My wife Caroline and I together decided to establish the Clinic. Without her ideas, her hard work, and her understanding, the Clinic would not be. Richard Kelley was my mentor. He taught me much of what I know about genetic diseases and much credit for the scientific work done at the Clinic goes to Rick. Without his help and friendship the Clinic would not be. Enos & Anna Mae Hoover, Amos & Susie Miller, Rebecca Huyard, and others in the Huyard family understood the need for a clinic for special children long before the idea was widely accepted within the Amish and Mennonite communities. Without their prayers and their work the Clinic would not be. I also must thank again a writer named Frank Allen, whose words helped the dreams of all of us become real.

The Prize is also a tribute to my teachers. A few of them are here today. I was never an easy person to teach. I doubted, questioned, and argued my way through an unusual education. My interests in people and art, medicine and science, which are the sustenance of my work each day were fostered by a few teachers of literature, writers, scientists, and doctors. I remember them as gifted teachers and thoughtful people.

After the letter came from Dr. Richardson about this award, I began to read about Albert Schweitzer. The Prize has caused me to think about the work and words of a great person. That alone was a valued gift. Dr. Schweitzer's example always now will be in my thoughts about our work at the Clinic.

By age 30 Albert Schweitzer had advanced degrees in music and theology. He was recognized in Europe as an authority on the music of Bach, his theological books were widely read, and he taught at the University in Strasbourg. Yet he then turned away from a life as an academic. At age 30 he decided to learn medicine and surgery and go to Africa as a missionary doctor. He studied for eight years to obtain his Medical degree. When he was 38 he and his wife went to a remote region of western Africa to start a clinic. His first operating room was fashioned from a chicken coop and his patients stayed in thatched huts with dirt floors. He repaired hernias and broken limbs, treated diseases of malnutrition, and, in a time when medicine had little to offer, he cared for those who would die of malaria, sleeping sickness, tuberculosis, leprosy, and malignancy. His difficult work at Lambaréne continued for more than 50 years until his death at age 90. His writings make me think that his work was sustained by his ideas and his ideas were ever renewed and enriched by his work. I would say that is why his work endured.

Will our work at the Clinic last as his did? I too was 38 when I went to Lancaster County to work with the special children. If I am blessed with as many years as Albert Schweitzer then I have 47 more years to work at the Clinic. The Clinic for Special Children is in a timber frame building with a roof of barn-slate. Such buildings have lasted hundreds of years. We are found at the end of a long lane in the middle of an Amish farm and there are hitching posts in the parking lot. Dr. Schweitzer would have understood why the Clinic is there - it is where it is needed. The natural histories of diseases we treat make preventative care and ready access to special care essential. He also would have understood that it is important that the Clinic was built and is supported by people whose children need the care that the Clinic provides. Our work and lectures have started to change medical practice in Lancaster County. Midwives, nurses, and doctors who staff the local hospitals and other clinics in the region are better informed about genetic disorders. They know that some disorders, which are elsewhere rare, are common in Lancaster County and should be recognized by a general practitioner. More important, they have learned that some of these conditions can be effectively treated and they know we are available to help. These are encouraging signs that the Clinic will last. Nonetheless, I believe that ultimately our work will be sustained by the children we help. I want to tell you more about the special children.

Albert Schweitzer's writings about his reverence for all life have led me to think about an aspect of our work that is often overshadowed by scientific efforts, here and elsewhere, to describe and prevent genetic disorders. As I care for children with complex, sometimes lethal, inherited disorders, I am impressed by the hopes and worth of these children. The Plain People call them God's Special Children.



Amish friends, the Amos Millers, spent Saturday afternoon at our home a few weeks ago. Amos asked me about a small telescope on our back porch. I explained that my children and I used it to look at mountains and craters of the moon and the rings of Saturn. Amos didn't know that men had walked on the moon 13 times but seemed neither surprised nor impressed by the fact. He asked, "Have you thought much about why the stars are there? Do you think God made the moon and stars just to look at? What is the moon for?"

Amos Millers had five special children. Amos & Susie asked many times Why does God give us these children? What are special children for? The answer offered by modern genetics is not a sufficient answer for them. Scientific medicine does not even allow such questions. But these questions are asked, and can be answered, by the Plain families who have special children.

For us to understand the significance of such questions we must acknowledge that the world view of the Plain people is different from that of most of us and that these communities of the Amish and Mennonite people are not simple and antiquated cultures. To quote John Hostetler:

*The Amish people are neither relics of a bygone era nor a people misplaced in time. They have reached conclusions different from most moderns about how to live in today's world. Their past is alive in their present. They are a different form of modernity. (Amish Society 1983)*

Within cultures that endure for hundreds of years, as these have, beliefs, faith, events, stories, work, histories, the stars, and the elderly and children do have purposes. I believe that if we are to provide adequate care for special children of the Plain people then we must appreciate the place of these children in their families and communities. You will better understand what I mean if I take you on a house call. To do that I will read part of a letter I wrote last year to Jim Hopkins, who is here tonight and who 25 years ago taught me to read fine books.

I recently thought of you on a November night as I walked out of an Amish farmhouse into cold rain and darkness and paused to think about the dead boy and the gathering of people in the room behind me.

The father sent word that the boy died and I went to the home to sign the death certificate. Carriages and wagons of friends and family were parked along the lane. From where I first stopped I watched black figures move ahead of horses to the barn and then to the house. Through dark windows I could see light from an open door at the center of the house. As I stepped into the kitchen a figure in the lighted room motioned and said "Morton we are here."

From the doorway I saw that the harsh white light from a lantern above the bed made the hands and face of the dead boy cold blue-white. Bright silver light flashed from new coins placed over his eyes. But then I saw that the lantern light was softened in colors of the quilt gathered around him and the light was golden on his hair and on the hair of the children who played quietly on the end of his bed. The now soft light washed over the faces of those seated shoulder to shoulder around the room who one by one shook my hand. Several said, "I have heard Dr. Morton's name often and now I am glad to meet you."

"When did he die John?" "Oh, not so long ago. Maybe he is still warm." Then the father took the boy's hand and turned it in his with the gentleness used to hold a baby bird. The

father's hand was large and thick from heavy work. The skin over the palm and fingers was stained and cracked and looked like the bark of an oak. The boy's hand was so small. "No," he said, "he is cold now." Then he placed the lifeless hand in mine.

I sat on the chair by the bed for more than an hour. The boy's mother said just two days ago his grandfather carried him out to the barn to watch the milking and he pulled the tail of a cat and laughed. And yesterday as she read to him he pointed to pictures and softly made the sounds of animals as pages were turned. But today he was awake only a little while. At first his breathing was harder then weaker and, toward evening, just faded. He didn't seem to suffer. He had found peace.

I talked about how difficult it is to care for children who have illnesses that are not understood and cannot yet be treated. I said that as a doctor and scientist when each new therapy fails I must somehow renew my efforts to learn more. Then the boy's grandfather spoke. As he spoke he smiled and looked first at me then the children on the bed. He said, "we will be glad if you can learn to help these children but such children will always be with us. They are God's gifts. They are important to all of us. Special children teach a family to love. They teach a family how to help others and how to accept the help of others."

We talked about the boy's sister who had lived a little longer and about other special children who had come and gone before. And of those ill like this boy who were living still but may not live through winter. We were thankful for the health of their new baby. Then we talked about the harvest just finished, the needed rain falling outside, the weddings of November, and signs that winter would be long. John said, "we are glad you came. Thanks for your help."

As I looked back into the house, I remembered the children at play on the death bed and what the grandfather said. His simple words would change the way those children, and I, would remember the life and death of the boy. I understood that the gathering in the room was not only a ceremony about death and life after death, but was the means by which the family would both endure and be strengthened by the loss of a child. That was the child's gift to his family and to all of us who knew him.

Special children are people who hope to suffer less and lead fulfilled lives through the help of others. Within their families and communities they are not merely the object of compassion and love but often are the very source. Special children shape the Amish and Mennonite cultures, and inspire work such as that at the Clinic in important and forceful ways. We should not underestimate the value of their lives, however brief or however difficult. We should not assume that the Plain cultures, or our own cultures, would be better without them.

These special children are not just interesting medical problems, subjects of grants and research. Nor should they be called burdens to their families and communities. They are children who need our help and, if we allow them to, they will teach us compassion. They are children who need our help, if we allow them to, they will teach us to love. If we come to know these children as we should, they will make us better scientists, better physicians, and thoughtful people. And, because of them, the Clinic for Special Children will likely endure. Our work, like Dr. Schweitzer's, will be sustained by our ideas and our ideas will be ever renewed and enriched by our work.



### MSUD CARRIER TESTING

Thanks to the response from our wish list, the Clinic received a PCR machine to perform blood tests to detect carrier status for maple syrup urine disease. The necessary laboratory supplies are now on order and the specific laboratory methods are almost completed. We expect to start carrier testing for MSUD by early spring. The cost will be based on actual costs of performing the test and are estimated to be less than \$100.

### CLINIC RECEIVES SUPPORT FROM NEW YORK COMMUNITY

One of the Clinic's youngest patients is a baby from the Rochester, New York, area who was born with maple syrup urine disease. Laura's family was referred to the Clinic after she was diagnosed with MSUD through newborn screening but specialized care and laboratory monitoring for her disorder were not available to the family in that region of New York. The family commutes five hours to the Clinic on a regular schedule for Laura's care and we work with her local pediatrician as needed to manage immediate care. She is thriving as a bright healthy baby, and is one of three children with MSUD we monitor from New York.

After hearing of the Clinic through the Colby's experience, friends in the Rochester area organized several fund raisers to help support the Clinic. A chicken wing cook off contest was held in August with the proceeds sent to the Clinic. Later in the fall, a pig roast was organized by friends. A total of \$6,024 was sent to the Clinic from these events. We wish to thank Bill and Joanne Colby, their family and friends for their generous, helpful support. It is very appreciated.

### VOLUNTEERS TO HELP

The Clinic is fortunate to have several dedicated people who help us on a routine basis. Elmer Stoltzfus spends his day off every week at the Clinic to help us with record keeping. Elmer is a book keeper for an Amish business and as a quadriplegic has a special interest and understanding of the Clinic's children and their families.

Lillie Rizack is a pediatric nurse at Hershey Medical Center in pediatric oncology. On her time off Lillie helps with the Clinic's immunization program.

Thankyou to Elmer and to Lillie for all your help.

### WISH LIST

In the last newsletter we listed several items we needed, but deferred purchase. The response was wonderful and we thank each of you who fulfilled our wish list of the following items:

IBM Selectric typewriter;

Dozen folding chairs;

FAX machine

Printer

PCR Machine for carrier identification for MSUD

Xray view box (4 unit)

There are two items still on the list :

Hewlett Packard EKG machine; and a Pulse Oximeter.

(If you need to contact the Clinic for more information, please call 717 687-9407.)

*The Clinic for Special Children is a non-profit diagnostic and primary medical service for children with inherited metabolic disorders in Lancaster County, Pennsylvania. The clinic serves Old Order Amish and Mennonite families who suffer from a high incidence of genetic diseases such as glutaric aciduria and maple syrup urine disease. Clinic services include an infant testing program for early diagnosis, primary medical care to prevent devastating effects of metabolic diseases during common childhood illnesses, clinical research to improve treatment, and services to support the needs of parents. The Clinic is funded through a combination of fees for services based on cost and private contributions. The Clinic does not seek or accept federal or state support.*

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