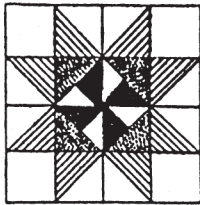


CLINIC FOR SPECIAL CHILDREN NEWSLETTER

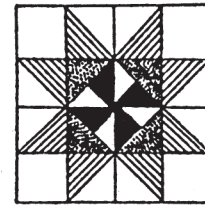
VOLUME I NUMBER 7

* LANCASTER COUNTY, PENNSYLVANIA *

SUMMER, 1994



AUCTION TIME ! SEPTEMBER 17TH, 1994



Summer brings the excitement of fresh plans for the next auction and full schedules at the Clinic. All welcome after a harsh winter with roof slates slipping with melting ice, unpredictable days dictated by weather and emergencies and numerous house calls due to a snowbound Clinic. We owe our neighbor and his team of mules much credit for opening the Clinic lane where at least two plow trucks had failed. Winter also brought the death of Danny Lapp, one of the first Clinic patients. We all miss Danny, but now work with hope as his baby brother who has the same disorder grows and remains healthy. Danny taught us much about glutaric aciduria and we are thankful.

AUCTION PLANS FOR SEPTEMBER 17TH

A dedicated group of parents is at work to plan the 4th Annual Benefit Auction to help support the Clinic for Special Children. Mothers, grandmothers, greatgrandmothers, aunts and neighbors of the Clinic's patients gathered recently for several quiltings. A number of quilts are complete, for others the needles are still gliding. We hear in addition to the barbequed chicken, subs, pies, soft pretzels and other food prepared for past auctions, sticky buns will be freshly baked at the sale this year. Last year's auction raised over \$105,000, one-third of the amount of our annual budget. The auction funds help to keep our patient fees at affordable levels for all families with or without insurance. The event also brings together special children, their families and friends to celebrate the joy these children bring to all of us.

We hope this year will be equally as fun and productive if not more so. Paul Horst will again be the auctioneer in charge with help from other local acutioneers. Their talents contribute much to the sale and we appreciate their time and effort. We need donations of items for the sale : **quilts, crafts, dolls, antiques, wooden toys, furniture, art work, farm supplies, and baked goods.** Please call one of the committee members at (717) 354-5415; or 626-4863; or 656-9694; or 733-2645 for information about donations of items for the sale.

MSUD CARRIER TESTING

Testing to detect carrier status for the gene for the classical form of Maple Syrup Urine Disease is now available at the Clinic for Special Children. The testing program was organized by Lisa Kratz, PhD. and Dr. Richard Kelley of the Kennedy Institute in Baltimore, MD. Dr. Kratz travels to the Clinic once or twice a month to collect and process blood specimens for the test. Results are reported confidentially within two weeks and the charge is \$50.00 per sample.

For couples who are close relatives of MSUD children, determination of their carrier status will either eliminate the anxiety of uncertainty if their baby will inherit the disorder or will serve to alert them for immediate screening 12 hours after the birth of a baby at risk for MSUD. Although many states including Pennsylvania have MSUD in their newborn screens, often these results are not available for several days. The Clinic performs diagnostic testing for MSUD in high risk infants (parents are known carriers) as soon after birth as possible (12 hrs.) and the results are immediately available. For the infants diagnosed within 12 to 24 hours of age, special formula is given immediately, amino acids are monitored frequently and none have required hospitalization during the newborn period.

In addition to MSUD, carrier testing is also available for Medium Chain Acyl Dehydrogenase Deficiency (MCADD). MCADD is an inherited metabolic disorder of fatty acid metabolism that is episodic and masquerades as Reye syndrome, cyclic vomiting and sudden infant death syndrome. A number of Mennonite children have been found to have this potentially serious but treatable disorder. (More about MCADD in the next article.) Please call the Clinic at (717) 687-9407 for more information about the carrier testing or for an appointment.

MCADD

In June Dr. Morton was asked to give remarks at the Scientific Symposium to celebrate the 125th Anniversary of Children's Hospital in Boston. The following is an excerpt from his

presentation of a series of essays titled "Through My Window". It describes his work related to MCADD, medium chain acyl dehydrogenase deficiency, a disorder that is easily treated if diagnosed, but can be lethal if not recognized.

Ten years ago, when I was a second year resident here (Children's Hospital of Boston), I was paged by a nurse who said that Dr. Katz had admitted a 2 year old boy to the intensive care unit with a diagnosis of Reye syndrome. The nurses in the intensive care unit knew of my interest in the disorder. Through work with Dr. Fred Lovejoy I became interested in the mechanism of intoxication in Reye syndrome. I wanted to understand the biochemical basis of the illness and learn how to control and reverse the abnormal metabolic state. After the association between salicylate, varicella, and Reye was recognized, we saw few cases of true Reye syndrome and became more aware of the biochemical disorders that were commonly mistaken for Reye syndrome. When paged that night I was roaming the hospital as night float. I needed something interesting to keep me awake. A metabolic disorder misdiagnosed as Reye syndrome and an argument with Dr. Katz was perfect. I immediately went to the ICU, reviewed the chart, examined the child, and wrote a rare legible note stating that this was not Reye syndrome but was medium chain acyl dehydrogenase deficiency. I was right. Dr. Katz lost our wager, but, still owes me the Chinese dinner. After some minor changes in therapy Eric rapidly recovered and has not been ill again. I get a Christmas card from the family each year to report his continued good health and repeat their thanks.

I remain especially interested in biochemical disorders that cause episodic illnesses and masquerade as Reye syndrome, cerebral palsy, sudden infant death syndrome, cyclic vomiting, and culture negative sepsis. The natural history of these disorders reveals that they are treatable. Affected patients may be asymptomatic for months or years between episodes of illness. We need only to learn what adaptations allow tolerance of the biochemical defect during periods of stability and what factors trigger acute biochemical intoxication. Then, often with relatively simple principles of care, we can prevent serious illness, limit hospitalizations, and improve outcome. No gene repair required, just an understanding of the metabolic adaptations to fasts and illnesses, applied biochemistry, an educated parent & patient, and ready access to care during the common illnesses that provoke crisis.

Two years ago I found the first case of medium chain acyl dehydrogenase deficiency (MCADD) in the Mennonite population of Lancaster County. She is 16 years of age and was seen intermittently for many years at a regional medical center for idiopathic cyclic vomiting. Her older sister died suddenly at 6 months of age, her case was signed out after autopsy as Reye syndrome. The next three cases of MCADD I saw in Lancaster were all asymptomatic neonates sent to me by Dr. Naylor at Magee Women's Hospital in Pittsburgh through his innovative supplementary screening program. The third infant Dr. Naylor referred to me shows the importance of screening for MCADD. When first seen the infant was 10 days old and had no signs of an underlying disorder. His sibling, just 18 months before, had died at age 2 months, 12 hours after her first DPT and just 3 months before Dr. Naylor added

the test for MCADD to his routine screens of neonates born at Lancaster General Hospital. Her death was at the time attributed to sudden infant death syndrome but was in fact metabolic death provoked by immunization and an overnight fast in an infant with a disorder of fatty acid oxidation. Dr. Naylor confirmed the deficiency in this infant by retrieving her filter paper specimen from storage. A fatty liver was described in the original autopsy findings but was not recognized as a sign of metabolic illness. In the first 55,000 neonates screened by Dr. Naylor from the general population of Pennsylvania, 12 cases of MCADD were found, for a prevalence of 1/5000 which is twice to three times more common than PKU. At the Clinic we can diagnose and monitor MCADD through urine and blood analysis by gas chromatography / mass spectrometry and provide comprehensive follow-up care and carrier testing.



Dr. Morton with friends at the Clinic

MSUD PHYSICIAN'S CONFERENCE

The Clinic for Special Children will sponsor a conference for physicians involved in research and care of children with Maple Syrup Urine Disease. The conference will be held in October or November at the Clinic to provide an update of recent advances in care of neonates and to review and investigate problems encountered by older children with MSUD. The Clinic manages the care of over thirty children with classical MSUD and through this work has improved the protocols of care for infants. Clinical studies of nutritional problems and critical care in older children are also topics of continued investigation at the Clinic.

The Clinic is in the process of developing a comprehensive handbook for physicians and parents of children with maple syrup urine disease which will provide a much needed resource to improve care not only for patients who use the Clinic but also for MSUD children in other areas of the country.

We hope this conference will be useful to all physicians who have responsibility of managing the care of an MSUD child.

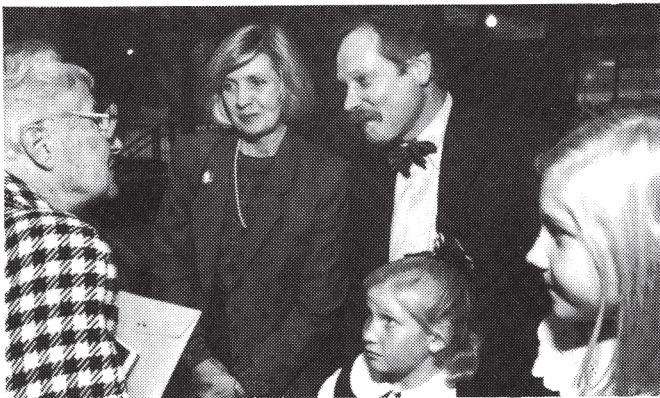
CYSTINURIA PROJECT

Dr. Morton and Dr. Butch Wieland, a family practice resident from Lancaster General Hospital visiting the Clinic for the month of July, started a new project to look at a metabolic defect called cystinuria that appears to be carried in several

**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.

Mennonite families in Lancaster County. Cystinuria is an inherited familial disorder that results in the formation of cystine stones in the kidney and bladder. The disorder is adult in on-set and between 3% and 59% of patients with cystinuria present with a urinary tract stone at the average age of 22 1/2 years. As the stones migrate from the kidney into the bladder, they can cause obstruction, inflammation, and infection. Other complications include high blood pressure and kidney failure. Several treatments are available to reduce formation of new stones and aid in dissolution of existing stones. Dr. Morton and Dr. Wieland are using the Clinic laboratory to monitor therapy and develop treatment protocols for use by local practitioners.

For more information about this disorder, especially for Mennonites in the Lancaster region who have experienced these symptoms, please contact the Clinic at (717) 687-9407.

FARM SAFETY

"Farm Safety 4 Just Kids" is a voluntary group organized nationally by a mother from an Iowa farm who lost her child in a farm accident. The group seeks to identify dangers for children who live and work on farms and develop safety information for families to help prevent injuries and deaths. Farm accidents claim approximately 300 children's lives in the U.S. each year and injure at least another 5000. Many of these accidents could have been **prevented** with fairly simple measures. The Lancaster County chapter of Farm Safety 4 Just Kids is newly organized and is asking for volunteers to help think about safety measures that are appropriate to the farm equipment used on Amish and Mennonite farms in Lancaster County. The Clinic is interested in this project to promote prevention of injury for local farm families and Debbie Kennedy is our representative. The local group also includes Dr. Al Price, Roseville Pediatrics and Dr. Butch Wieland, a senior family practice resident at Lancaster General who spent July working at the Clinic.

A farm safety information booth will be set up at the benefit auction again this year. Please contact Debbie at the Clinic (717) 687-9407 or call 569-6481 for more information or ideas about local farm safety. Families who can share experiences of previous farm accidents might help another family avoid a tragedy. Children deserve every protection, please help.

IMMUNIZATION ALERT

The Clinic's immunization service under the direction of Debbie Kennedy, continues to grow with more and more families bringing their children to the Clinic for "baby shots". We want to remind adults that it is important to have a tetanus booster every ten years. The recent tragic case in Lancaster County of tetanus infection in a teenage boy should serve as a reminder to all to have a current tetanus injection (within 10 years), especially those who live and work on a farm or do shop work. Vaccines given at the Clinic are provided by Lancaster General Hospital. A \$5 fee is charged per visit for administering the injections and a brief check-up.

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" Through My Window"

from a series of essays by Dr. Holmes Morton

As I work with the mass spectrometer in my laboratory at the Clinic, I often pause to look through the window near my desk. Last summer blue birds, gold finches, and a pair of nesting orioles often caught my eye. One evening in the fall after the corn was harvested, I watched six deer, a red fox, and a skunk forage through the field all at one time. On the first warm day of Spring the window was open and I heard the calls of wild geese and stopped to watch their high northward flight. I have also watched the sun rise over the field in all seasons after long worried nights at work because of a sick child. I especially like to watch Jake or his son-in-law work in the field with a team of mules. Jake and Sam plow, plant, and harvest with four small red mules. You may think, such a contrast, the work of a doctor, analytical chemistry, biochemistry, efforts to understand how an inherited disorder injures the brain of an infant, all within 100 feet of an Amishman's fieldwork with mules. Such contrast, you say. Yes, I say, but these people and their way of life have much to teach us.

I have come to respect the labor in the field. Jake worked his land for 30 years and last year his young son-in-law took over the farm. The field helped Jake and Naomi feed 12 children and gave them all, taught them all, meaningful work. The work there also fed many generations of livestock and, at the same time, fed many generations of wildlife. The field was cleared more than 100 years ago. The Amish people have worked the fertile land around the Clinic for 300 years with the same simple, low cost, labor intensive, high yield methods of farming. Last Spring when I walked through the freshly plowed field I found a flint arrowhead and was reminded that before Amishmen the woodland was harvested in another way by another people. History and timelessness come through my window like Spring air and sunlight, like the calls of wild geese, to remind me that my work here too takes its place in time.

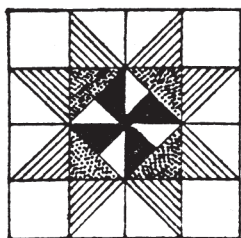
When Jake's mules turn at the end of a row, he often looks to see if I am at my window and waves. We can each respect the work of the other. He knows I measure the usefulness of my work against the usefulness of his. He knows that I measure the success of my work, not in terms of lectures, publications, grants, or income, but in terms he understands. He has grandchildren with the disease that I study and we hope that they can live to work in the field.

The Clinic for Special Children is a non-profit diagnostic and primary pediatric medical service for children with inherited metabolic disorders in Lancaster County, Pennsylvania. The clinic serves Old Order Amish, Mennonite and other families who suffer from a high incidence of genetic diseases such as glutaric aciduria and maple syrup urine disease. Clinic services include infant testing programs for early diagnosis, primary medical care to prevent devastating effects of metabolic diseases, clinical research to improve treatment, and services to support the needs of parents. The Clinic is funded through a combination of fees for services, benefit auction proceeds and private contributions. The Clinic does not seek or accept federal or state support and is tax exempt under IRS 501 (c)(3), ID # 23-2555373.

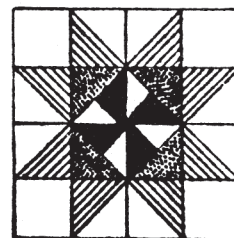
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THE CLINIC FOR SPECIAL CHILDREN, INC.
P.O. BOX 128
STRASBURG, PENNSYLVANIA 17579



4th Annual
Benefit Auction
to support



THE CLINIC FOR SPECIAL CHILDREN

Quilts Handmade Toys Furniture Crafts Baked Goods Chicken Barbeque

Donations Appreciated

September 17, 1994

All Day from 9:00 A.M.

Location: Leola Produce Auction, Brethren Church Road, Leola, PA

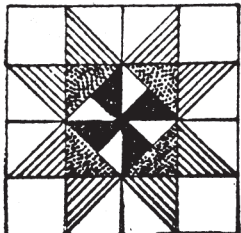
Directions: From PA Turnpike, exit 21 Rt. #222 south, exit to Rt. #772 south east, left on Peace Rd., 2nd right.

From Lancaster: Rt. #23 east, turn left (north) on Brethren Church Rd. past Leola.

From Rt. 30 east: right to Rt. #772 (Newport Rd.) north west to Rt. #23, right on #23 (New Holland Pike), left on Brethren Church Rd. Auction is approximately 1 mile.

Come enjoy the fun, fellowship, and lend support !

If you wish to make a donation for the sale, please call one of the following for information:
(717)-626-4863 ; (717) 354-5415 ; (717) 656-9694 ; or (717) 733-2645



The Clinic for Special Children is a registered charitable organization. In accordance with Pennsylvania law, we are required to advise you that a copy of our official registration and financial information may be obtained from the PA Dept. of State by calling toll free 1-800-732-0999. Registration does not imply endorsement.

