

# CLINIC FOR SPECIAL CHILDREN NEWSLETTER

VOLUME I NUMBER 5

\* LANCASTER COUNTY, PENNSYLVANIA \*

SUMMER, 1993

## SEPTEMBER AUCTION PLANS

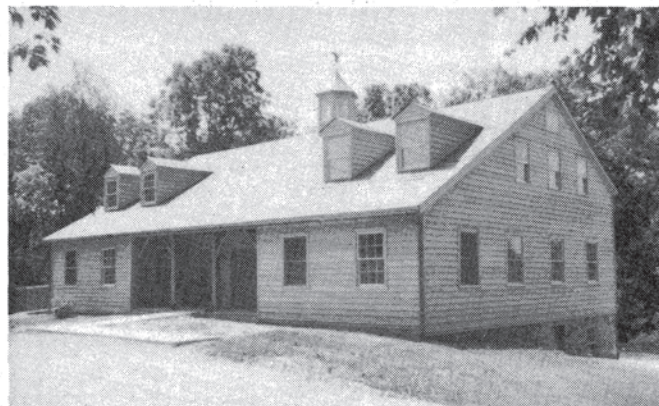
Mothers are quilting, chicken barbecue formula is being tested, tasted, and further refined (it was already superb!), favorite recipes for baked goods are found, crafts are in production, the date is set.

**Saturday, September 18, 1993**

The Auction Committee of parents is now in full swing for the third Annual Benefit Auction to help support the Clinic. For the past two years parents have organized a September auction to raise funds to supplement the Clinic's income. Auction proceeds help the Clinic meet its cost of operation and help keep clinical service fees at reasonable rates so that all families who need the Clinic's services can afford them. Auction funds also off-set the cost of newborn testing programs for early detection of children at risk and support research to improve care of children with inherited disorders. The Clinic is operated as a non-profit diagnostic and medical service for children in the Lancaster County region who suffer from inherited disorders such as Maple Syrup Urine Disease and Glutaric Aciduria. The Clinic does not receive any financial assistance from the state or federal government. We hope funds from this year's auction will also enable the Clinic to be in a better financial position to hire a much needed second full-time physician to work with Dr. Morton.

The Auction Committee is seeking donations of items for the sale. Quilts; hand made toys, dolls, furniture, crafts; lawn, garden, and farm equipment and supplies; and baked goods are among many items that will be appreciated. Auctioneering will be performed by Paul Horst and other local auctioneers. Anyone interested in donating items to be sold at the auction can contact committee members at the following numbers: (717) 354-5415 or (717) 626-4863.

WE HOPE TO SEE YOU THERE !



## SPECIAL CLINIC DAY FOR CHILDREN WITH NEUROMUSCULAR DISEASES

Doctors from Johns Hopkins and Kennedy Institute, in Baltimore, Maryland, and from Children's Hospital of Philadelphia participated in a special clinic day for patients with neuromuscular diseases and movement disorders. Dr. Richard Kelley of the Clinic and Kennedy Institute and Dr. Holmes Morton organized the session. Patients with known disorders such as Amish nemaline myopathy, which has been under study at the Clinic for the past year, and type I glutaric aciduria were included as well as patients with unknown diseases in the process of diagnosis. One of the goals of the session was to evaluate interventions which could improve movement disorder, to assess the success of intervention tried over the past year, and to identify other means to help children live their daily lives with greater ease.

In addition to exams, meetings were held with parents for questions and discussion about their children. The day ended with an informal conference among the physicians to review and share their observations. We thank the following physicians who gave of their time and expertise to benefit the Clinic's children: Dr. Michael Johnston and Dr. David Kube, Kennedy Institute; Dr. Thomas Crawford, Dr. Orest Hurko, Dr. Joseph Maher, Johns Hopkins; Dr. Lynn Price, Lancaster, and Dr. John Sladky of Children's Hospital of Philadelphia.





Thank you to the parents who also agreed to participate in this special clinic day. We hope there will be much to gain for the benefit of the children over the next few months. Participating doctors came away with many new ideas for diagnosis and treatment which they are pursuing.

#### MSUD COURSE TO BE OFFERED

The Clinic for Special Children now cares for more than 30 children with classical MSUD which is approximately one fourth of all children with the disorder in the US. Although the Clinic was founded to be a local medical service for children in Lancaster County, we are increasingly involved in the care of children in western Pennsylvania, Kentucky, Ohio, and New York.. The Clinic's approach to management of MSUD emphasizes the importance of primary care by a physician who is knowledgeable about outpatient management of metabolic derangements caused by otherwise minor childhood illnesses and injuries and who has basic laboratory skills and equipment to assess a neonate and older child with MSUD. Because information about the treatment of MSUD is difficult for primary care givers to obtain, the Clinic will offer a two day training course about comprehensive management of MSUD. The course will include instruction in laboratory methods such as branched chain quantitation by paper, thin layer, & HPLC chromatography, and 2-ketoacid quantitation by gas chromatography/mass spectrometry and the DNPH reaction. The Clinical aspect of our course will use case studies to review management of the neonate with MSUD, long term nutritional management, primary care on sick days, indications for hospitalization, and the initial emergency management of the severely intoxicated patient. The course will be designed for primary care givers of children with MSUD but will also be open to fellows in genetics and metabolic diseases, and physicians in referral centers who have been designated to follow-up neonates with MSUD but who have limited experience with the disorder. Further information can be obtained by writing or calling the Clinic (717) 687-9407.

#### MORE THAN AN OUNCE OF PREVENTION

The Clinic's immunization program under the direction of Debbie Kennedy, nurse practitioner, is reaching an increasing number of Amish families and will be expanded soon to accommodate requests for appointments. Well child exams including height, weight, brief history, review of nutritional and dental needs are included with the immunizations. Records are maintained at the Clinic and reminders for follow-up series are sent. Currently only 5% of our

immunization patients are over due for the next series. In the next few months further emphasis on preventive care will incorporate information about farm safety for children developed by Lancaster County SAFE KIDS / Farm Safety 4 Just Kids which is chaired by Dr. Al Price. A Lancaster pediatrician, Dr. Price is seeking greater involvement from Amish and Mennonite farm families to help develop more appropriate safety information according to local farming methods and equipment. For more information, please contact either the Clinic or Dr. Price at (717) 569-6481. Farm safety awareness is an important preventive care measure.

#### GENETIC DISORDERS & SPECIAL CHILDREN

The work at the Clinic is not only relevant to the care of children with inherited disorders in the Amish and Mennonite communities of Lancaster. Genetic disorders are more common in the general population than most realize. In the United States approximately 3 in 100 babies are born with disorders that require medical attention and 25% of admissions to hospitals for children in the US are for treatment of genetic disorders.

We are often asked if the work at the Clinic will ultimately **prevent** the birth of children with genetic disorders in the Amish and Mennonite populations. This is a difficult question to answer. There are many influences at work in the Plain cultures that determine patterns of marriage and birth which are little changed by scientific information. One of the least appreciated of these influences is the positive effect of special children upon their families and communities.

In our work caring for children with complex, sometimes lethal, inherited disorders, we are impressed by the hopes and worth of these children. They may be seen as 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 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. They may force us to see the best of ourselves.

#### OUTREACH

Recent lectures by Dr. Morton include:  
Lancaster General Hospital/TempleUniversity Family Practice Review Course, Lancaster PA;

Annual Pediatric Review Course, Charleston, WV, March, 1993. Topic: *The Family Physician and Prevention of Life Threatening Illnesses in Children with Inherited Metabolic Disorders: The Common Cold and Death from Medium Chain Acyl-CoA Dehydrogenase Deficiency.*

The Rockefeller University Seminars in Clinical Research, NY, April, 1993. Topic: *Prevention and Management of Acute Encephalopathy in Children with MSUD and Glutaric Aciduria;*

LGH: Pediatric & Family Practice Rounds, April; Nason Hospital Continuing Education Lecture, Roaring Springs, PA. June, 1993. Topic: *The Importance of the Recognition and Management of Genetic Disorders by Primary Care Physicians.*

National Youth Science Camp, WV June 1993.

Elizabethtown College, Amish Society Conference, July, 1993 Topic: *The Clinic for Special Children*

### MORE HELP

The Clinic has had the benefit of two physicians working part time over the last few months along with the Clinic's full time physician and director, Dr. Holmes Morton. Dr. Richard I Kelley now spends one day a week on a regular basis at the Clinic. Dr. Kelley is a pediatrician, geneticist, and specialist in metabolic disorders and myopathies from the Kennedy Krieger Institute and Johns Hopkins in Baltimore.

Dr. Lynn Price, a specialist in pediatric neurology, Lancaster, frequently contributes her time and expertise to work with children who have neurological problems. We thank both Dr. Price and Dr. Kelley for their commitment and for carving time into their busy schedules to participate in the work and challenges of the Clinic.

### PASSAGES

The Clinic Board of Directors sadly accepted the resignation of Board member Pat Payne, CNM, who moved in June to practice nurse midwifery in Flagstaff, Arizona. She will be missed by all of us who appreciated her time, effort, advice, and wit.

The Clinic Board welcomes John Riehl as a new Board member. As a parent of three children who are handicapped by an unknown disorder and are cared for by the Clinic, and as a member of the Old Order Amish Church who was one of the founders of the Amish school for Special Children, John's advice and help will be appreciated.

### POT PIE BENEFIT

Hearty chicken pot pie hit the spot for many on a cold February day and gave a \$2500 boost for the Clinic. The Bird-in-Hand Fire Co. sponsored the benefit dinner featuring this local traditional dish. In our unbiased opinion it was the best pot pie we have had the privilege to enjoy. Proceeds from the dinner

were shared by the Fire Co. with the Clinic. We thank all the members of this volunteer fire company for their support of the Clinic, especially the organizers, Tim Hoerner and Reuben Stoltzfus for their time and effort. It is meaningful in many ways to have the support from so many in the community for the Clinic and the special children and their families we serve.

### WISH LIST

From time to time we are asked what the Clinic needs in equipment or supplies. There are items we need, but often defer purchase so that our funds can be used more directly to benefit the children and families we serve. Here are some items on our wish list that would be very helpful:

IBM Selectric typewriter;  
Dozen Folding chairs with padded seats;  
FAX machine;  
Apple Image Writer II or Laser printer;  
Hewlett Packard EKG machine;  
Pulse Oximeter  
Step Ladder.  
PCR Machine for carrier identification for MSUD and GA  
Xray view box (4 unit)

*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.*

### Clinic for Special Children Board of Directors

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John A. Hostetler, PhD Vice President  
Richard I. Kelley, MD, PhD Secretary  
Caroline S. Morton, EdM Treasurer  
Enos Hoover  
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D. Holmes Morton MD, Director  
Caroline S. Morton, Associate Director Admin.  
Rebecca Huyard, Office Manager  
Deborah Kennedy, Nurse Practitioner



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

3rd Annual  
**Benefit Auction**

to support



**THE CLINIC FOR SPECIAL CHILDREN**

*Quilts Handmade Toys Furniture Crafts Baked Goods Chicken Barbeque*

**September 18, 1993**

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 to Brethren Church Rd.

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 !*

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.