

CLINIC FOR SPECIAL CHILDREN NEWSLETTER

VOLUME I NUMBER 13

* LANCASTER COUNTY, PENNSYLVANIA *

SUMMER 1997

ANNUAL BENEFIT AUCTION SATURDAY, SEPTEMBER 20, 1997



Summer months are busy at the Clinic. Fruit trees -apple, plum, cherry, peach, and pear -planted at our open house and dedication six years ago keep the wildlife very content. We've watched blue birds, indigo buntings, Baltimore orioles, yellow finches visit. Butterflies fill their bushes planted at all corners of the building and dance with children as they approach. The corn is high enough to hide in and we wonder how many children think of that possibility, particularly on immunization day. We are asked if work at the Clinic is lighter in the summer. At least once each week during these months we have greeted a new family to the Clinic with a child who has a complex disorder. Some are infants who require immediate attention. Others are transported here from other states, and occasionally other countries. The seeds of our work and of your support continue to grow.

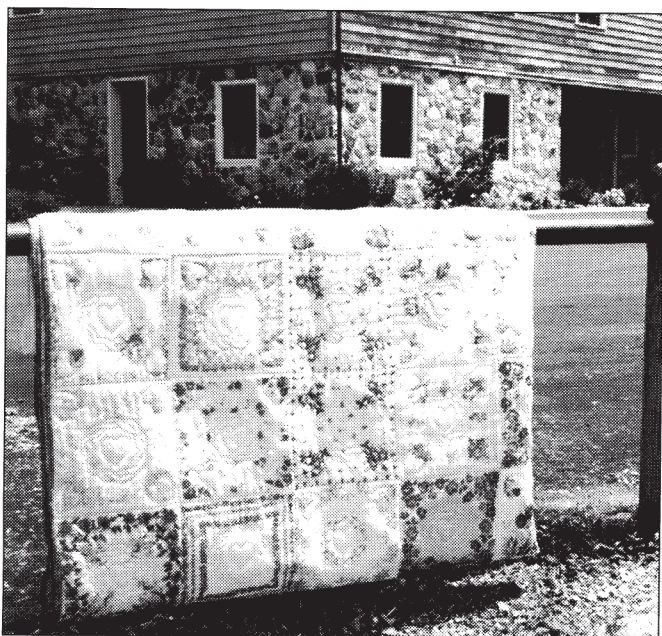
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Plans for the annual benefit auction are in progress. There is much discussion of how much chicken to cook, how many subs to make, pies and pretzels to bake, and of the items donated thus far. Among beautiful quilts of many patterns is one made from colorful printed cotton handkerchiefs given over the years to two sisters who are patients at the Clinic. The girls and their family decided to use them for a quilt to benefit the clinic. It is very unique, very special quilt. A newly released limited edition print, "Osceola Mill" by Richard Bollinger will be donated. The 42" x 29" framed print is numbered and signed by the artist, and will likely be one of the few left for purchase by the time of the sale. The old Osceola Mill is a Lancaster landmark. There will be at least one new oak bedroom set, lawn furniture,

many other woodwork items, and another playhouse with log cabin-like siding. The playhouse is 8ft. x 8ft. with a porch and dormer window. A very handsome hackney driving pony with new harness and wooden cart is also ready to go. Keaton's Pottery in Perry County, PA, will donate a large gallon-sized piece of stoneware custom produced and inscribed "Clinic for Special Children 1997". This gift was ordered by a friend of the clinic, but when the potter inquired about the clinic and the purpose of the auction, he decided to donate it himself. The original donor however, will prepare "a large surprise package from the Country Card Shop" which a reliable source in our office says will be a real treat for a lucky bidder. Each day brings new items for the auction, another quilt thoughtfully made and new stories of a generous spirit.

The auction will begin a half hour earlier this year at 8:30 a.m. The quilts will be auctioned starting at 11:00 a.m. with a break around noon for a few comments from Dr. Morton. The Leola Produce Auction facility was expanded over the winter to provide much more space under roof. There will also be improvements in the sound system. Information about delivery services for large items purchased will be available at the desk this year. If you have items you wish to donate, please contact the clinic or call one of the following for information: (717)-626-4863 ; (717) 354-5415 ; (717) 656-9694 ; or (717) 733-2645.

SATURDAY, SEPTEMBER 20TH, 8:30 A.M.
Leola Produce Auction, Brethren Church Road, Leola, PA



Handkerchief Quilt

There are several other events planned with support for the Clinic in mind.

BENEFIT AUCTION IN MARTINSBURG AREA

Several Old Order Mennonite families in the Blair and Bedford Counties region of Pennsylvania will sponsor a local benefit auction on September 6th to raise funds to support the clinic and also to help fund next year's Maple Syrup Urine Disease Symposium to be held in Lancaster in June 1998. The auction will be held at the Morrison's Cove Produce Auction located on Route 36 north of Woodbury, PA. Information about the auction can be obtained by calling one of the following: (814) 793- 2423, (814) 793-3926, (814)793-3010.

ROCHESTER NY FUND RAISER

For the 5th year friends and family of a Clinic patient in Rochester, NY, will hold a pig roast fund raiser to benefit the Clinic and its research on MSUD. The event will be held on October 4, 1997 in Rochester. For more details, call (315) 986-1505.

NOTE: Based on requests and discussions with families of patients who have maple syrup urine disease (MSUD), at the Clinic we will from now on refer to the disorder as maple syrup disease or MSD.

1998 MSD SYMPOSIUM TO BE HELD IN PA

The Maple Syrup Disease Family Support Group will have their next meeting in Lancaster County in June of 1998. The group sponsors an international symposium every two years and parents of MSD children in this region of Pennsylvania are hosts for this meeting.

DEVELOPMENT OF MSD MANUAL

In conjunction with the support group symposium, the Clinic for Special Children will sponsor a series of seminars for physicians and those involved in research in the diagnosis and treatment of MSD. These seminars will be coordinated with the symposium agenda and will serve to better define the standards of comprehensive care for patients with MSD. The development of a manual that addresses all aspects of care and is a useful resource for physicians, health care providers, and parents is the goal of the meetings.

Eight or more professionals involved with treatment of MSD will be asked to serve on a review committee for the manual and participate in the seminars and symposium. Families in attendance will have opportunities to review and comment on the manual draft as part of the symposium. The manual will present an approach to care based on the experience with the disorder over the last few years at the Clinic for Special Children. It will incorporate the valuable lessons learned by many specialists over the years. The need for such a reference tool is evident in the increasing requests received by the clinic to review case histories, evaluate and guide the care of MSD patients not only in the U.S. but also in other countries. These requests have come from both parents and physicians. We also realize it is important to offer guidelines that have been refined and reviewed by many recognized as experts in the treatment of MSD so that there is a broad base of consensus as to what constitutes essential standards of care. The manual will be organized into 3 parts:

Part 1 will include information about genetics, biochemistry, and the natural history of maple syrup disease as well as a history of research and treatment of the disorder among the Mennonite people of Lancaster County, PA. Neonatal screening program information will also be compiled.

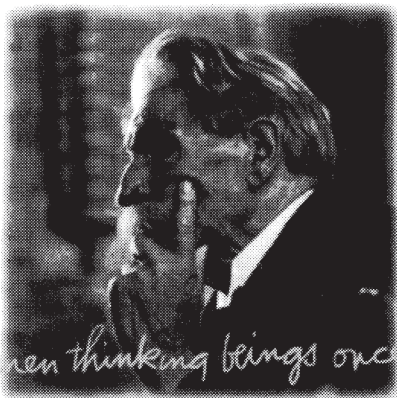
Part 2 will present a systematic approach to the long term care of patients with MSD and will provide detailed care plans and sources of information relevant from the newborn phase of care to adult care. Laboratory methods will be outlined and methods for home monitoring will be discussed.

Part 3 will discuss research and controversies in treatment. Use of dialysis, management / prevention of cerebral edema, use of supplements in diet, neonatal screening are a few of the topics. We will be busy during the next few months, but we feel it is an important effort to contribute to the care of children with MSD.

"CELEBRATION OF LIFE" **TO HONOR ALBERT SCHWEITZER**

On September 13th and 14th, the **Pennsylvania Academy of Music** in Lancaster will inaugurate an annual series that will commemorate the life and work of individuals who have contributed much to others and for whom music enriched their lives. This year's event will honor Albert Schweitzer with a series of concerts and lectures. Dr. Schweitzer was a medical missionary who founded a hospital in Africa and received the Nobel Peace Prize. Before he devoted his life to medicine he was a theologian, musician, organist and scholar of Bach's music. His writing and expression of "Reverance for Life" continue to inspire many: physicians, musicians, theologians, humanists, those concerned about the environment.

Dr. Holmes Morton, founder and director of the Clinic for Special Children is one of the speakers as a recipient of the Albert Schweitzer Prize for Humanitarianism. Other speakers are Dr. Harold Robles, founder and president of the Albert Schweitzer Institute for the Humanities, Dr. Robert Reece, of the Massachusetts Society for the Prevention of Cruelty to Children, and Paul Pritchard, former president of the National Parks and Conservation Association and first recipient of the Albert Schweitzer Prize. Featured musical performers include renowned flutist Eugenia Zuckerman and Michael Murray, recognized as this country's finest organist who will present a "Schweitzer Recital" of music by Bach. Other musical performers include the Academy's Newstead Trio and Children's Choir, John Darrenkamp, and the Auscultation Brass, who are all Lancaster County physicians with a love for music.



Dr. Albert Schweitzer

Information for the Saturday concert at the Fulton Opera House in Lancaster and for the Sunday afternoon organ recital at St James Episcopal Church can be obtained by calling (717) 399-9733. Proceeds from these events will benefit the Clinic for Special Children and the scholarship program for the PA Academy of Music. We thank the Academy and its supporters for the development of this inspiring event and for its thoughtful interest and support of the Clinic.

CSC CLINICAL STUDIES APPROACH

The Clinic receives numerous requests from students for the opportunity to study here. For the past few years several medical students and residents have arranged assignments for rotations as part of their clinical studies. Due to the nature and

complexity of our work we generally recommend that for the most meaningful experience those to be considered for study here are either in medical school or residency program in pediatrics, family practice, genetics or neurology. Dr. Morton is in the process of developing a course curriculum which will include comprehensive case review with a detailed written report; familiarity with diagnosis and management of infants and children who have maple syrup disease, glutaric aciduria type 1, medium chain (MCADD), and Crigler-Najjar disease; and acquaintance with on-going research related to conditions seen at the clinic. Students should become aware of methods of research used and in what ways research might improve care of those who have genetic disorders.

In September we will welcome Kevin Strauss, a fourth year medical student at Harvard University, as our first participant in the revised clinical studies course.

PROGRESS NOTES:

* A paper on the current approach to treatment of Glutaric Aciduria type1 has been submitted for publication by Dr. George Hoffmann based on the consensus derived from the GA1 meeting he sponsored in Marburg, Germany last fall. Dr. Morton is a contributing author and the experiences at the clinic influenced much of the content.

* The Mennonite form of the gene for type 6 Glycogen Storage Disease has been identified by Drs. Les Biesecker and Claire Francomano at NIH in collaboration with the Clinic for Special Children.

* Dr. Ira Fox, University of Nebraska, has tried a new form of gene therapy for Crigler-Najjar Disease with a liver cell transplant that shows some promise and is in further study.

* The Bile Salt abnormality described by Dr. Gerald Salen and diagnosed by Dr. Morton in a number of children in the Amish community over the last year is in fact different from Byler's Disease. This newly recognized disease is responsive to treatment with Ursodiol and fat soluble vitamin replacement therapy. It is more common than previously realized with at least 10 children diagnosed to date.

* The Clinic has had the chance to observe one of our MSD patients after liver transplant made necessary by vitamin A induced liver failure. Her amino acid levels in blood have remained stable and her neurological problems related to MSD have resolved. She is learning to eat a normal diet!

BALLOONS OVER THE CLINIC

In the last issue we reported on the need for an activity group for older youth no longer eligible for school programs, who are so severely handicapped they can not participate in any of the workshop programs. Most of these youth are mentally bright, but totally dependent on others. We are happy to report the "Special Hearts Circle" now meets on a regular basis with 9 participants, several staff and volunteers in the lower level of the Clinic. We welcome their presence and the inspiration they bring to us as we see balloons and bubbles rise from their circle past our windows. They remind us of our purpose here.

We welcome your gift of support !

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

7th Annual
Benefit Auction

to support

THE CLINIC FOR SPECIAL CHILDREN

Quilts Handmade Toys Furniture Crafts Baked Goods Chicken Barbeque

Donations Appreciated

September 20, 1997

All Day from 8:30 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, food, 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 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 is tax exempt under IRS 501 (c)(3), ID # 23-255373.

P.O. Box 128 Strasburg, PA 17579 (717) 687-9407

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