

# CLINIC FOR SPECIAL CHILDREN NEWSLETTER

VOLUME I NUMBER 26

\* LANCASTER COUNTY, PENNSYLVANIA \*

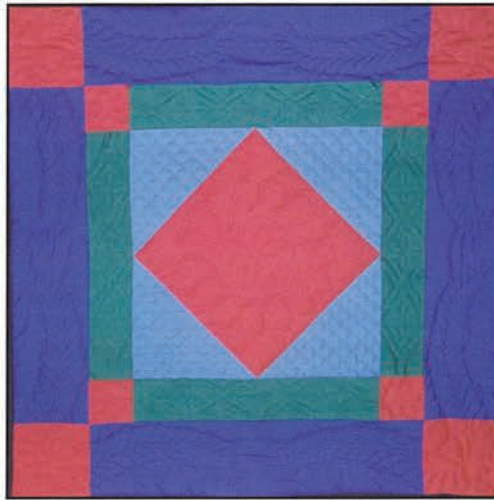
DECEMBER 2007

~ GREETINGS ~

WITH OUR WISH THAT ALL WILL SHARE THE SPIRIT OF JOY,  
REJOICE IN THE GIFT OF HOPE  
AND GROW IN UNDERSTANDING THROUGH CARING FOR OTHERS

## WITH THANKS TO ALL

We are very grateful for the support received from this year's benefit auctions. Together, all four events brought a record level of funding for the clinic's annual operating budget. Families in **Shiloh, Ohio** again sponsored an auction to benefit the clinic in July. This was the fourth auction in that region, and we are very grateful for the support growing from this community. Lots of ice cream was sold on a hot day in July to a record crowd in **Shippensburg, PA**. In addition to 51 quilts, tops and wall hangings, a new wagon and furniture, this auction always has many garden items and beautiful plants donated for sale. This was the 11th year for the auction at Morrison's Cove in **Blair County**. In addition to many beautiful quilts, furniture, great chicken barbecue and soft pretzels, plants and especially mums for fall bring in bidders from the central Pennsylvania region.



As always, the last auction of the year for the Clinic was on the third Saturday of September in **Lancaster County** at the Leola Produce Auction. This was the 17th year for the auction, planned by essentially the same group of volunteers who planned the very first auction for the clinic in 1991. We are very thankful for their faithful and enthusiastic support.....and for their attention to all the details that make the auction so successful year after year.

Who was there this year and what did we have to eat? There were 1542 buyer's numbers signed out with many duplicate cards provided for family members to use one buyer number. Nineteen auctioneers and eleven clerks volunteered. Approximately 3,936 items, all donated, were sold at seven simultaneous auction blocks, four inside and three outside between 8:30 am and 5:45 pm when the gavel sounded after the last item was sold. Quilts are always a feature of the sale and this year there was a record of 97 large quilts and as many smaller, wall hanging sizes. Most of the large quilts were made especially for the Clinic's auction by friends and family members of children who receive services at the clinic. Other featured items included many pieces of hand made furniture, original art work, a unique marble roller, a new Amish carriage, a pony with harness and wagon, a hand carved

wooden chest, garden furniture and sheds. It is hard to believe, but the following food items were all sold out by mid afternoon:

**3,000 pounds of Barbecued Chicken**  
**2200 Pork Sandwiches from 8 Roasted Pigs**  
**20,000 Donuts -made and sold out by mid afternoon**  
**570 Omlets made from 120 dozen eggs by 10am**  
**570 Complete Breakfasts**  
**1,000 lbs. of ice to convert a canoe to a Salad bar**  
**350 16" Pizzas**  
**3100 Subs**  
**4000 Soft Pretzels**  
**1700 Whoopie Pies in 10 variations**  
**1300 Fried Pies in 9 flavors**  
**230 Strawberry Pies and 355 Fresh Fruit Cups**  
**7200 Servings of Ice Cream and 550 Milk Shakes**

**Lemonade, ham & cheese sandwiches, french fries, homemade potato chips, soup and a huge variety of baked goods also fed the crowd.**

Thank you to all who volunteered; to all who donated sale items and food; to all who came; to all who bid; to all who enjoyed the food. Most importantly, we thank the children who inspire all of us to keep the Clinic growing and thriving as a source for their comfort and care.

## CLINIC BENEFIT AUCTION DATES FOR 2008

**July 12, Shiloh, Ohio**  
**July 19, Shippensburg, PA**  
**September 13, Blair County, PA**  
**September 20, Lancaster County, PA**

## SUPPORT COMES FROM OTHERS

We thank a Lancaster area family foundation for their matching challenge gift of \$50,000. We must match that amount by the end of December and we are half way there! PLEASE HELP US MEET THE MATCH!

In **Springfield, New Jersey**, the Hammer Family sponsored another Fun Day for area families to generate support and awareness of the Clinic. Thank you to all the Hammers and their friends and family.



### Clinic Receives Grant from Sertoma

The Strasburg Area Sertoma Club assisted the Clinic in the development of our Genetics of Hearing Loss Program and Testing Services for infants and children in the Plain Community. Funds raised by local club members through various projects were matched with a Community Service Matching Grant from Sertoma International. The total raised, \$7,500, will purchase a clinical audiometer with inserts and speakers to help equip the new hearing studies lab at the Clinic. We are very grateful to members of Strasburg Area Sertoma Club for their hard work and commitment to assist the Clinic with this project. The Sertoma Clubs' mission has a focus on assistance to people with communicative disorders, including hearing loss.

We hope to raise the additional funds needed as soon as possible to purchase the remaining pieces of equipment for the hearing lab. Dr. Morton donated \$10,000 from his MacArthur Fellowship to this project.

### NEWS NOTES

We are pleased to announce a new member of the Clinic's Board of Directors, **John A. Fry, President of Franklin & Marshall College**. President Fry's vision of the Clinic's partnership with Franklin & Marshall and with Lancaster General Hospital to promote greater research and educational resources to benefit our community will help guide the Clinic's future. We welcome President Fry as we seek to develop the mission of the Clinic.

With deep appreciation and great regret we say farewell to staff member **Roy Martin**, part time lab technician for the past two years. Roy plans to spend more time with his family's business. He will be missed by all of us at the Clinic and we thank him for his fine work.

### A Place for Teaching and Learning

In the Clinic's mission and five year plan we outlined several goals to fulfill the Clinic's role as a place to encourage teaching and learning in fields related to medicine. For years we hosted medical students for various pediatric training rotations and we will continue to offer that experience. We also seek to provide worthwhile, stimulating learning experiences for college students interested in disciplines leading to the study of medicine. Through our partnership with F & M we have the opportunity to work with many bright students who will some day contribute to others through medicine and science.

Currently we are hosting Eric Sherman, son of Don and Donna Sherman of Ephrata, a junior at Ephrata High School. Eric is working with Dr. Puffenberger on several projects including a mapping study that identifies a new form of Glutaric Aciduria referred to as type 3.

It is very unusual for us to host a high school student, however Eric already has an accomplished history. He won the junior division of the Lancaster County Science Fair two years in a row, won the senior high division the past two years and placed 2nd in microbiology in 2006 and 3rd in molecular biology in 2007 at the International Science Fair. We are pleased to offer inspiration and encouragement to Eric.

*In the last few months the Clinic was the source of reflection at several special events from Lancaster to Boston.*

### Dedication of the Barshinger Life Science & Philosophy Building at F & M

Dr. Morton was the keynote speaker for the dedication of the new Ann & Richard Barshinger Life Sciences & Philosophy Building at Franklin & Marshall College on October 26, 2007. The state of the art facility brings under one roof several disciplines in life sciences and humanities to encourage interdisciplinary approaches. To highlight the value of multidisciplinary study, Dr. Morton played his cello as a complement to his remarks on science and education.

### Trinity College Lecture and Concert

The first in a series of "Clinic for Special Children MacArthur Lectures and Concerts" was sponsored by Trinity College in Hartford, Connecticut on November 11, 2007. The beautiful Trinity College Chapel was the setting for the concert featuring world renowned cellist, Matt Haimovitz with opening pieces played by Paul Morton on classical guitar. The concert was followed by a reception and lecture by Dr. Morton reflecting on his education and work at the Clinic.

The purpose of the event was to acknowledge growth of the Clinic, thank many from the region who contributed to the Clinic and to raise additional funds for the Clinic's Research and Education Endowment Fund. One of the many special guests at the event was Frank Allen, formerly with the Wall Street Journal, who wrote a front page story about the initial efforts to start the Clinic in 1989. Contributions from that story essentially funded the construction of the Clinic.

We thank Trinity College for honoring Dr. Morton with this event and for its support of the Clinic. Dr. Morton graduated from Trinity College in 1979.

### Dedication of the Jeffrey Modell Immunology Center at Harvard Medical School

Dr. Morton was invited to give the special address to celebrate the opening of the Jeffrey Modell Immunology Center at Harvard Medical School in November. The new center is designed to promote productive collaboration among students and researchers in immunology and related disciplines to contribute to greater understanding and treatment for immune disorders. The center was designed and built in partnership between Harvard Medical School and the Jeffrey Modell Foundation. The Foundation was established to promote research and improve treatment for children with immune system diseases. It was inspired by the life of Jeffrey Modell, a beloved son who lost his battle with immune system disease at the age of fifteen.

In the last year the Clinic was actively involved in seeking new methods for early diagnosis and treatment approaches for infants with severe immune disorders. This work developed in immediate response to the needs of one infant brought to the Clinic soon after birth in severe condition. As we described in our last Newsletter, the Clinic identified the gene mutation involved to confirm diagnosis, used molecular methods to identify a sibling as a bone marrow donor, collaborated with Children's Hospital in Philadelphia to arrange bone marrow transplant, and now follows the child on a regular basis to monitor her progress. We are very happy to report, she is a bright, happy, healthy, normal child who is beginning to walk! The work at the Clinic, the work that takes place in Boston, the efforts by the Jeffrey Modell Foundation, all were inspired by the life of a child.

Dr. Morton and Dr. Strauss both studied medicine at Harvard Medical School and trained at Children's Hospital in Boston. Dr. Nick Rider, also involved in immunology research and treatment at the Clinic, trained at Hershey Medical Center and will join our staff next summer. *With admiration and thanks to Vicki and Fred Modell for their dedication and tireless work to help children with immune diseases.*

### EDUCATIONAL WORKSHOPS

In recent months the Clinic sponsored two workshops for physicians in the Central Pennsylvania region.

**Pediatrics & Genomics in the Plain Communities.** This first CME course for physicians was held on October 17, 2007. Sponsored by a gift from Dr and Mrs. Tom Rea, the course will be offered again in 2008.



**Workshop on Inherited Disorders that may be mistaken for Abuse, Neglect, or Sudden Infant Death**, July 2007. This workshop formed the foundation for a course that will be offered next year for pathologists, pediatricians, geneticists, radiologists and other physicians who need to be informed about symptoms of certain inherited disorders.

**Grand Rounds: Dr. Strauss and Dr. Puffenberger** presented *Genomics in a Community* at **Children's Hospital of Philadelphia** on December 5, 2007.

## LOOKING AHEAD

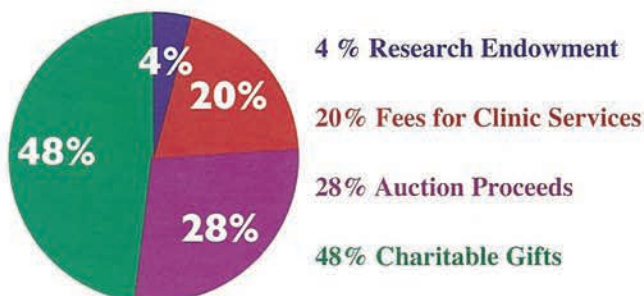
Rudene DiCarlo Memorial Lecture by Dr. Morton at Lucille Packard Children's Hospital, March 7 and CSC Benefit concert with cellist Matt Haimovitz and Paul Morton, classical guitar, Stanford, CA on March 6.

MacArthur Lecture by Dr. Morton and concert with cellist Matt Haimovitz and Paul Morton, classical guitar, Franklin & Marshall College, Lancaster, PA, Sunday, April 13.

CME course, Pediatrics & Genomics in the Plain Communities, at the Clinic, July 31-Aug. 1, 2008.

## OUR NEED FOR SUPPORT

We are fortunate to have support within the Amish and Mennonite Communities for our clinical work. The four Benefit Auctions of 2007, a yearly gift from these Communities, provides about 28% of the yearly budget. We hope this support will continue, but probably will not grow as fast as our costs to operate the Clinic. Our budget next year will increase by 25% to \$1.5 million as we add a third physician and develop more clinical studies in response to the needs of our patients.



Fees charged for clinical and lab work cover approximately 20% of our budget. We have not raised our fees for lab work or clinical visits in over 15 years. We have always felt that the cost of coming to the clinic for the care of a child should be affordable to all families.

Since 2001 we have added about 100 new patients per year, in part, because the list of disorders that we can diagnose and treat increases. Also, we are able to offer more routine care for children with primary immune disorders, congenital heart problems, seizures and mental retardation. In the past many of these children did not get appropriate medical care or they traveled to regional medical centers for subspecialty consultation but had no local care providers. The Clinic now serves children with a range of more than 105 different genetic disorders. As our patient population increases with new disorders, our existing patient populations with biochemical genetic problems like MSUD, GAI, MCADD also increase in number and, because of successful care, these patients are now in a broader age range from infants to middle age adults who continue to rely on the Clinic for their care. Many of the newly recognized diseases require clinical studies and research both at the Clinic and in collaboration with other special-

ists to determine the best treatment approaches. The cost of most of these clinical studies is not charged to the patient's family, but is met through contributions to the Clinic and through income from the Endowment Fund. We realize that it may become necessary to increase Clinic visit & laboratory fees, but we hope not. We also hope that support for the Clinic as a local medical service makes good economic sense for business leaders within the Plain Communities.

The long-term security of the Clinic will come from building our Research and Education Endowment Fund which currently contains \$1.8 million. A percentage of the growth of this fund is used to help meet the costs of clinical studies and education each year. This year the Fund will provide \$65,000 in income, or approximately 4% of the total budget. The goal of the Endowment Fund is to reach \$5 million within the next three years and \$10 million in five years. We estimate this is the size of the Fund needed to meet the growing costs of clinical studies and services and insure the long term future of the Clinic.

The remainder of our annual budget, about 48%, comes from hundreds of donations from individuals, gifts from trusts, and foundations. We are looking for realistic grant opportunities that fit our needs. The scientific work being done here is important, and some of our clinical and educational projects will continue to be supported by Franklin & Marshall College, Lancaster General Hospital Foundation and other foundations and trusts. But, as our budget grows, the need to seek and find more support from contributions grows.

We believe the Clinic is a hopeful and inspiring place for children, parents, physicians, biologists, students, and we hope for all people who have the resources to be helpful to others through Philanthropy.

### Please consider a gift to the Clinic for Special Children.

Our needs include:

- General support for patient services
- Genetics of Hearing Services and Equipment Fund
- Support for Education and Clinical Studies
- Gifts for the Clinic's Endowment Fund

We received a Christmas card from the family of one of our patients with the following message:

*A hundred years from now it will not matter what my bank account was or the size of my house. But the world may be better because I made a difference in the life of a child.*

### Please help us make a difference! THANK YOU

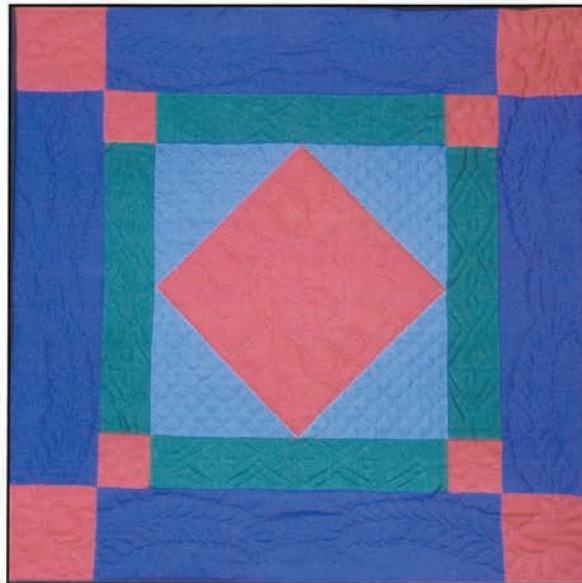


Dawn at the Clinic

photo by Tim Sauder



Clinic for Special Children  
P.O. Box 128  
Strasburg, Pennsylvania 17579



### MISSION

The Clinic for Special Children was established in 1989 is a non-profit medical service for Amish and Mennonite children with genetic disorders. The Clinic serves children by translating advances in genetics into timely diagnoses, and accessible, comprehensive medical care, and by developing better understanding of heritable diseases.

### CLINIC FOR SPECIAL CHILDREN

535 BUNKER HILL ROAD

PO BOX 128

STRASBURG, PENNSYLVANIA 17579

717 687-9407

[www.clinicforspecialchildren.org](http://www.clinicforspecialchildren.org)

The Clinic for Special Children is a non-profit 501(c)(3) tax exempt organization and a registered charitable organization in Pennsylvania. Tax ID# 23-2555373

PA law requires us to advise 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

### Staff

Holmes Morton, M.D., Director  
Caroline S. Morton, EdM., Executive Director  
Kevin A. Strauss, M.D., Pediatrician  
Erik Puffenberger, PhD., Lab Director  
Donna Robinson, CRNP  
Christine Hendrickson, RNC  
Roy Martin, Lab  
Rebecca Smoker, Office  
Miriam Echternach, Office  
Richard Kelley, M.D., PhD., Consultant

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