



NEWSLETTER

Clinic for Special Children

CELEBRATING 25 YEARS

NUMBER 36

* LANCASTER COUNTY, PENNSYLVANIA *

SEPTEMBER 2014

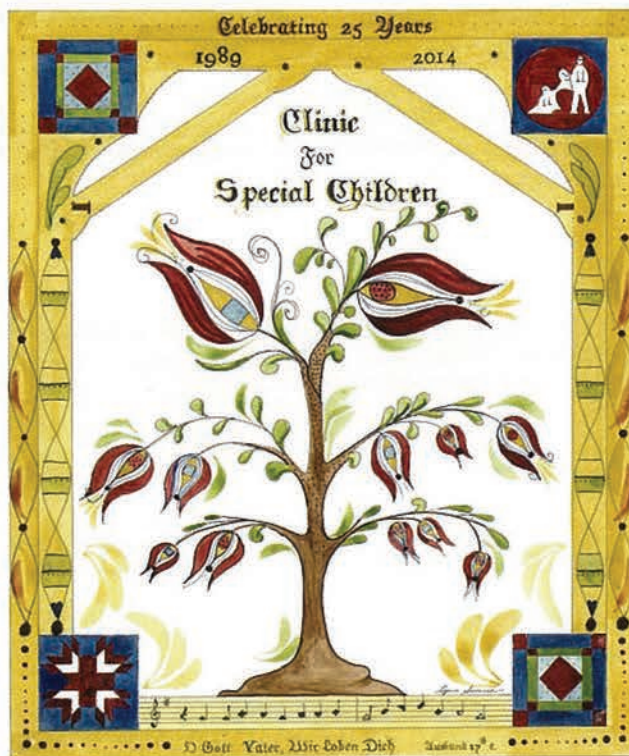
FROM A CORNFIELD

On a recent summer day the CSC staff gathered around lunch to listen, exchange scientific information and share stories. From our location in the middle of an Amish corn field - some years it's alfalfa - we talked about progress in treating rare genetic disorders. Visiting the Clinic this summer to participate in these discussions were a pediatric specialist from China who treats MSUD, GAI, Crigler-Najjar, a pediatrician from Brazil, NIH Genetics Fellows from Paraguay, Brazil, Israel, Saudi Arabia, Poland, China, Netherlands and USA, all of whom are working on improved diagnosis and treatment for rare genetic disorders. All came to the Clinic for Special Children to hear of our progress. Twenty-five years ago many thought the Clinic would be isolated and singular in our efforts to treat complex genetic disorders from this rural location. We built the Clinic where we thought it was needed - near the children who needed it. That example has traveled far, much farther than we imagined. We are grateful to so many who make this Clinic possible - this year, for twenty five years - and we hope, for many years to come. CSM

Commemorative Fraktur

A commemorative fraktur, a traditional form of Pennsylvania German folk art, was created by local fraktur artist, Lynn Sommer, to celebrate the Clinic's 25th Anniversary. The fraktur features symbols and music representing the Amish and Mennonite communities we serve as well as designs that are unique to the clinic. If you look closely you will find posts and beams, strands of DNA, the Clinic's old and new logos, quilts and a genogram hidden within the family tree.

Several signed prints of the fraktur will be available for bidding at the auction and sets of notecards can be purchased from the Clinic. All proceeds from the sale of the cards and print support the Clinic. We are very grateful to Lynn for her beautiful design and for her generous, thoughtful gift to the Clinic.



2014 Benefit Auctions

Two to Go.....

PLEASE JOIN US

September 13, Blair County, PA

September brings two benefit auctions. The first is in **Blair County, PA, on September 13th** at Morrison's Cove Produce Auction, Route #36, south of Roaring Spring. In addition to quilts, furniture, crafts, chicken barbecue and other delicious food items, this sale always has a beautiful array of mums to get us ready for fall.

September 20,
Lancaster County, PA

The last and final auction of the year is in **Lancaster County on September 20th** at the Leola Produce Auction, Brethren Church Road, Leola, PA. Breakfast is available starting at 7:00 am and the auction opens at Block #1 at 8:30 am. **Remarks by Dr. Morton, Dr. Strauss and Dr. Williams are scheduled at 11:00am with special items, quilts and furniture sales immediately following.** There will also be a silent auction block for many items including gift certificates for farm, home and midwifery services.

Among the special items to be auctioned this year are a special maple tree sculpture and individual maple leaves that are beautiful works of art hand-forged by a local

Amish iron works company and signed prints of the Clinic's commemorative fraktur. Quilts include the Postage Stamp, Wedding Ring, Log Cabin, Trip Around the World, antique and many other patterns. Carriages, furniture, farm supplies,

outdoor furniture, swing sets, sheds, plants and many other items will be sold on four auction blocks and of course, delicious food, food, and more food!!!

On-Line Quilt Auction

We are trying something new this year! We will have a limited quilt auction on-line -for those who may not be able to attend the auction. Three full/queen size traditional hand sewn Amish quilts and five wall hangings will be up for bids. These quilts



are offered in addition to the quilts donated for the auction and will be available for bidding on -line for two weeks ending the day of the auction, September 20th. Please visit our web site to view the quilts and link into the on-line quilt auction.

www.clinicforspecialchildren.org

MEASURES OF SUPPORT

We are so very grateful for the generous support we received through the three previous benefit auctions held this year.

Families in **Union County, PA** sponsored the third benefit auction for the Clinic on June 7th at the Buffalo Valley Produce Auction in Mifflinburg. We are very grateful to the Hoover, Martin, Lapp, Horning, Weaver, Zimmerman, Nolt and Stoltzfus families and many others for their time and effort to organize this event to benefit the Clinic for Special Children. This support is very much appreciated.

In **Shippensburg, PA** on June 27th, thousands of donuts made that morning were sold along with handmade toys, quilts, furniture, landscaping plants and a new carriage. Thank you to the Oberholtzers, Zimmermans, Leinbachs, and many other families in the Shippensburg region for this wonderful support.

The **Shiloh Ohio** auction on July 12th supports both the Clinic for Special Children and the DDC in Middlefield, OH. Handmade quilts, furniture, crafts, farm supplies, garden items, and of course, more delicious food was found at the Blooming Grove Produce Auction. Thank you to the Newswangers, Sauders, Burkholders, Martins and many other families who help with this auction.



Matching Challenge! For our 25th Year, a local family foundation is offering a donor matching challenge gift of \$25,000.

**PLEASE HELP US MEET THIS CHALLENGE BY
DECEMBER 1ST.**

THE MEMORY TREE

A Special Tree for the Benefit Auction



The maple tree sculpture will be featured for bidding at the Clinic's Lancaster Benefit Auction on September 20th.

The 3/4 scale sculpture is a unique work of amazing artistry and can be displayed indoors or outside. A duplicate of the tree was created and

donated to the Clinic for the new garden area.

The **Memory Tree** sculpture (seen below next to the original) was inspired by the Japanese Maple tree planted in front of the Clinic in 1991 by the Mortons. The Japanese maple was chosen as it was the favorite tree of one of the mothers of the special children who are remembered.



Check out the video about the Tree on our web site!

Translational Genomic Medicine in Plain Populations of North America Conference #2

The second conference on Genomic Medicine & the Plain Populations of North America was held on August 15 and 16 at Case Western Reserve University in Cleveland, OH, coordinated by the Das Deutsch Center in Middlefield, Ohio. Children's Hospital of Pittsburgh, UPMC, Center for Rare Disease Therapy also helped sponsor the conference. Representatives of clinics that serve plain populations in Ohio, Pennsylvania, Indiana, Wisconsin and Ontario, Canada exchanged information on diagnosis and management of genetic diseases and shared recent research updates on Chicken Breast Disease, Pyruvate Kinase Deficiency, Inherited Cardiomyopathy, GM3 Synthase Deficiency, HARS, Troyer Syndrome, SCID, Propionic Acidemia, Liver Transplantation and new directions for metabolic and molecular screening.

Coming Up:

September 18: CNTNAP2 (also referred to as CASPER 2) Family Research Day at CSC.

OUTREACH & RESEARCH

CSC hosted a clinical review session for Medical Genetics Fellows from the National Institutes of Health. **Dr. Carlos Ferreira**, originally from Paraguay and an NIH biochemical genetics fellow, shared the experience of his month long rotation at the Clinic in a stunningly succinct and insightful presentation. We hope he will return! Currently **Dr. Leah Fleming**, another NIH Fellow, is spending a month at CSC. We look forward to continuing our mutually beneficial relationship with the NIH Fellowship program.

This summer the Clinic was fortunate to welcome **Dr. Kin-Hung "Kim" Poon**, Senior Medical Officer for the Department of Pediatrics & Adolescent Medicine at Tuen Mun Hospital in Hong Kong. Dr. Poon cares for patients in Hong Kong with Maple Syrup Urine disease, Crigler-Najjar, and other metabolic disorders and was interested in learning more about the CSC's treatment protocols.

Dr. Karina Donis from Brazil, joined us for three weeks as she prepares to work on her doctorate in biochemical genetics in her region of Southern Brazil.

Avery Fellowship

The Clinic is pleased to announce that **Aarti Rao** began her year as the Clinic's 2014-2015 Avery Fellow. Aarti graduated from Swarthmore College in May with a Bachelor's of Arts in Sociology, Anthropology, and Biology. In her honors program at Swarthmore, Aarti conducted public health research in rural villages of Rajasthan, a desert region in northern India. Aarti plans on expanding her work in public health at CSC.

Nancy Presnick, recent F & M graduate, is the recipient of an Eyler Award for a summer research fellowship at the Clinic.

Becky Willert, also a graduate of F & M and our highly capable lab technician, concluded her work in CSC's lab to begin her studies in the Physicians Assistant Program at Drexel University. We wish Becky well in her graduate program and future career.

Recently Published: A study of Bipolar spectrum disorder in the Old Order Amish population.

Strauss KA, Markx S, Georgi B, Paul SM, Jinks RN, Hoshi T, McDonald A, First MB, Liu W, Benkert AR, Heaps AD, Tian Y, Chakravarti A, Bucan M, Puffenberger EG. *A population-based study of KCNH7 p.Arg394His and bipolar spectrum disorder*. *Human Molecular Genetics*. 2014. doi: 10.1093/hmg/ddu335.

Our Dedicated Staff

Front Row:

Becky Willert (Formerly, Lab Technician)
Donna Robinson, CRNP, Pediatric Nurse Practitioner
Holmes Morton, M.D., Founding Director, Senior Pediatrician
Caroline S. Morton, EdM., Founding Director
Christine Hendrickson, RNC, Nurse
Abby Benkert, Lab

Back Row:

Adam Heaps, Administrative Director, Laboratory Scientist
Erica Sue Eisenbise, Office Manager
Millie Young, RN, Nurse
Katie E. Williams, M.D., PhD. Pediatrician
Kevin A. Strauss, M.D., Medical Director
Erik Puffenberger, PhD., Lab Director
Yalonda Kosek, Medical Receptionist
Matthew Sware, Development Director

RESEARCH AND EDUCATION FUND CHALLENGE

WITH AN ANNIVERSARY GIFT FROM LGH

In honor of the Clinic's 25th year, **Lancaster General Health** is donating \$75,000 each year for the next two years to the Clinic's Research and Education Fund. The R & E Fund helps support CSC research to gain insight and improve treatment for patients with various genetic disorders. Recent efforts have included clinical research designed to improve scientific understanding and clinical management of MSUD, GA1, Chicken Breast Disease, Congenital Adrenal Hyperplasia (CAH), GM3 Synthase Deficiency, Propionic Acidemia (PA) and many other genetic conditions. The R & E Fund also supports the Clinic's educational programs that include the annual Avery Fellowship, student research projects and seminars for midwives, physicians and families that share recent improvements in treatment for different genetic disorders.

The generous gift from **LGH** serves as a catalyst to our efforts to match this gift with other donations for the R & E Fund. Our challenge is to raise \$1 million for the fund in the next two years. Please contact Matt Sware at the Clinic for more detailed information about this challenge.

We are very grateful to **Lancaster General Health** for this recent generous gift and thank them for their meaningful support for the Clinic for the past 25 years. As some may recall until our timber frame building was ready, LGH provided temporary office and lab space for the Clinic to begin providing services to Plain families. Our partnership has continued with grants for scientific equipment, support for research studies and services to assist families in need. We are so pleased LGH has joined us in celebrating 25 years with this very significant gift.

EXOME SEQUENCING COLLABORATION:

The Clinic is very pleased to announce a new three year agreement with **Regeneron Pharmaceuticals, Inc.** that will provide a source of DNA exome sequencing as part of CSC's molecular diagnostic process. Exome sequencing will hopefully generate data to inform treatment possibilities for rare genetic conditions.

New CSC Board Member:

The Clinic enthusiastically welcomes **Dr. Stephen Ratcliffe** as a new member on its Board of Directors. Dr. Ratcliffe is the Director of the Family Practice Residency Program at Lancaster General Hospital and brings his perspective, wisdom and experience in public health issues and the practical delivery of medical care.





Clinic for Special Children

535 Bunker Hill Road, PO Box 128, Strasburg, PA 17579 T 717.687.9407 F 717.687.9237



CELEBRATING **25** YEARS



Clinic for Special Children

"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, and if we allow them to, they will teach us love. If we come to know these children as we should, they will make us better scientists, better physicians, and thoughtful people."

D. Holmes Morton, Co-founder

Board of Directors

Herman Bontrager, Chairman

Enos Hoover

Leonard Hurst

Richard I. Kelley, M.D., Ph.D.

Mark Martin, Treasurer

Caroline S. Morton, Secretary

D. Holmes Morton, M.D.

Stephen Ratcliffe, M.D.

Jacob Zook

Kevin A. Strauss, M.D., Ex-Officio

MISSION

Provide comprehensive local medical care, integrate the science and the practice of medicine, and share knowledge to improve the health of children who suffer from genetic disorders.

CLINIC FOR SPECIAL CHILDREN

535 BUNKER HILL ROAD

PO BOX 128

STRASBURG, PENNSYLVANIA 17579

717 687-9407

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