



# Clinic for Special Children NEWSLETTER

VOLUME I NUMBER 34

\* LANCASTER COUNTY, PENNSYLVANIA \*

SPRING 2013

## 2013 Benefit Auctions

**September 14, Blair County, PA**

Morrison's Cove Produce, Rt. # 36 South of Roaring Spring, PA

**September 21, Lancaster County, PA**

Leola Produce Auction, Brethren Church Road, Leola, PA

September brings two benefit auctions for the Clinic for Special Children. The first is in **Blair County, PA, September 14th** at Morrison's Cove Produce Auction on 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.

### PLEASE JOIN US

The last and final auction of the year is in **Lancaster County on September 21st** 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 and Dr. Strauss are scheduled at 11:30am with special items and quilt and furniture sales immediately following remarks. This year there will also be a silent auction block for many items including gift certificates for farm, home and mid-wifery services.

Among the special items to be auctioned this year are a special maple tree branch sculpture and individual maple leaves that are beautiful works of art hand forged by a local Amish owned iron works company (see article about the "Memory Tree"). A Replica 1909 P. E. Shirk traction gear powered by New Holland hit and miss engine with working cycle bar mower engraved with CSC logo and date on top of the attached wagon bed is another item crafted especially for this year's auction. Quilts include the Postage Stamp, Autumn Splendor, Wedding Ring, Grandma's Bits and Pieces, Scrap Star, Log Cabin, Trip Around the World and many other patterns. A new Amish carriage, Meadow Brook and pony carts, household furniture, a 3D painting of a roadside market by Lorraine Reiff, farm supplies, outdoor furniture, swing sets, sheds, plants and many other items will be on four auction blocks. Many people come just to enjoy the food. Chicken and pork barbecue, donuts made on site, soft pretzels, subs, baked goods, salad bar and freshly made ice cream are among the delicious offerings.



**The three auctions held this summer were all well attended with good weather and very successful in raising needed support for the Clinic.**

### June 1, Union County, PA

Families in **Union County, PA** organized the second benefit auction for the Clinic on June 1st. at the Buffalo Valley Produce Auction in Mifflinburg. At least 73 quilts, sporting goods including kayaks and bikes, furniture, sewing equipment, low protein pizzas and many other delicious treats were sold at the auction. Specialty items included engraved wooden whistle locomotives, mini 1 pint ice cream freezers engraved and a mini conestoga model stagecoach. We are very grateful to the Hoover, Martin, Lapp, Horning, Weaver, Zimmerman, Nolt, Stoltzfus and many other families for their time and effort to organize this very successful auction to benefit the Clinic for Special Children. This support is very much appreciated.

### June 22, Shippensburg, PA

The annual benefit auction for the Clinic in **Shippensburg, PA** was held on June 22. Thousands of donuts made that morning at the sale sold out by early afternoon. Bidding on a new locally made carriage brought a good price.

Handmade toys, quilts, furniture, landscaping plants and a wide choice of food were available for buyers. The Shippensburg Benefit Auction will be held every year on the 4th Saturday of June instead of the third Saturday of July. Thank you to the Oberholtzers, Zimmermans, Leinbachs, and many other families in the Shippensburg region for this wonderful support.



## July 13, Shiloh, Ohio

On July 13th the Morton's travelled to **Shiloh, Ohio** to thank families in Ohio for their support of the Clinic for Special Children. This auction also supports the DDC in Middlefield, OH. Handmade quilts, furniture, crafts, farm supplies, garden items, and of course delicious food all contributed to a very successful sale that grows every year. Thank you to the Newswangers, Sauders, Burkholders, Martins and many other families who helped with this auction. This support is very much appreciated.



Special Item for Lancaster County Auction

## THE MEMORY TREE

The unique maple branch sculpture and leaves created for the auction this year by a local iron works company is a preview of a 1/2 scale model maple tree sculpture being forged as a special project in anticipation of the Clinic's 25th Anniversary next year. The **Memory Tree Project** is inspired by the Japanese Maple tree planted in front of the Clinic building when it opened in 1991. The tree was planted by the Morton's in memory of children with glutaric aciduria, maple syrup disease and other treatable genetic disorders who had died before the Clinic was established. The Japanese maple was chosen because it was the favorite tree of one of the mothers of children who are remembered.

With the Clinic's upcoming 25th Anniversary The **Memory Tree Project** seeks to honor the vision of Holmes and Caroline

Morton and their fervent belief that children with rare, inherited disorders deserve local, accessible, state of the art medical care. This fundamental belief continues to guide the Clinic's mission and has led to major scientific advances for children everywhere with these disorders. The



Clinic has grown to exemplify preventative medicine and the extraordinary economic benefits for the communities we serve.

In 2014 the forged **Memory Tree** and planned garden at the Clinic will honor all special children - past, present and future.

## Genomic Medicine & the Plain Populations of North America Conference

The Clinic for Special Children sponsored a conference in July to review diagnosis and management of genetic diseases in Plain populations in North America. The two day conference which will become an annual event addressed the following topics:

- ❖ An overview of genetic disorders prevalent in Plain populations in various regions,
- ❖ Reviewed newborn screening approaches and compared follow-up programs,
- ❖ Discussion of population specific methods available for genetic testing,
- ❖ Information on current research projects on specific disorders and
- ❖ Need for collaborative efforts among clinics serving Amish, Mennonite and Hutterite communities.

The conference, held at Franklin & Marshall College, was supported in part by a grant to F & M from the Howard Hughes Medical Institute through the Undergraduate Science Education Program.

The Clinic for Special Children, the Das Deutsch Center for Special Needs Children in Geauga County Ohio, the Community Health Center in Topeka Indiana, and The New Leaf Clinic in Holmes County Ohio are all community-supported non-profit health-care centers designed as 'Medical Homes' for patients with complex health care needs. Each clinic offers a range of services based on the needs of the local community. Parent education, family support groups, nutritional advice, immunizations, occupational & physical therapies, dental care, access to medications and equipment for those with special needs. Doctors and staff at these Clinics use knowledge about genetic risks within the Plain Populations to provide high-risk carrier testing and improve the care of newborns at high-risk for genetic illness. Services in Canada for Plain populations were also discussed by Victoria Siu, MD, from Southwestern Ontario and FORGE Canada. In addition to representatives from the clinics, speakers included Donald Kraybill, Young Center at Elizabethtown College, Edwin Naylor, PhD., Alan Shuldiner, MD, PhD, Amish Research Center, Aravinda Chakravarti, PhD, Johns Hopkins, Rob Jinks, PhD, Berwood Yost, Ellie Rice, all from F&M and Dr. Robert O'Reilly, Nemours A I duPont.

## CLINIC OUTREACH

Central Pennsylvania Clinic: Dr. Holmes Morton and his brother, Paul Morton, continue their efforts to work with a local board to establish a new Central PA Clinic for Special Needs (CPAC) to serve children and adults in Belleville, PA. A benefit dinner was organized in McAllisterville in June and plans are in progress for a benefit auction next spring to help raise support for the proposed new clinic.



The NEW LEAF CLINIC serving children with special needs in the Holmes County, Ohio region held an open house in July. Dr. Olivia Wenger, a pediatrician with Children's Hospital of Akron, serves as the Medical Director for the new clinic.



Holmes and Caroline Morton attended the event to celebrate with Dr. Wenger and found this familiar quote on the wall:

"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."

**Indiana:** The Community Health Center in Topeka Indiana is ready to provide services. Dr. Zineb Ammous the Medical Director of the new clinic spent two weeks at the Clinic for Special Children and also at the DDC in Ohio in preparation for her role at the Community Health Center.

**Wisconsin:** Progress to form a community genetics clinic in Western Wisconsin was discussed at the recent Genomics Conference by Dr. Christine Seroogy, Dr. Greg Rice and Sandy Van Calcar, all from the University of Wisconsin, Department of Pediatrics, and by Dr. Jim DeLine from LaFarge, Wisconsin.

Dr. Kevin Strauss travelled to **Brazil** last October to meet with a consortium of parents, physicians, laboratory scientists and government representatives involved in establishing a non-profit clinic for children in rural Brazil, **Casa Para Crianças Especiais**, inspired by the Clinic for Special Children.

**Marina de Franca Basto Silva**, a medical student in Brazil, heard Dr. Strauss speak at the symposium and applied to study for five weeks at CSC to learn laboratory methods and observe clinical approaches to care for metabolic diseases. In her words: *"I realized that the Clinic for Special Children is the best place to learn about these conditions due to the combination you make of humanity and technology. I read and understood about the difficulties you had in the past and realized that unfortunately we are still living this reality here. Brazilian children with these diseases usually are not diagnosed early enough to prevent damage or death or the diagnosis is not associated with appropriate management. It is clear for me that the Clinic is the place to learn and study about inborn errors of metabolism."*

## MATCHING CHALLENGE 2013

Once again a local family foundation has generously offered to **match up to \$25,000** for donations received by the Clinic before **December 1, 2013**. We are very grateful for this thoughtful challenge to help increase needed support for the Clinic.

## THE SEARCH IS SUCCESSFUL!!

We are **VERY HAPPY** to announce the following:

**Katie Beth Williams, MD**, will join the Clinic for Special Children staff as a **Pediatrician in November**. Dr. Williams is completing her residency in Pediatrics at the University of Wisconsin. We look forward to welcoming Dr. Williams, her husband, Matt, and their two young sons when they move to Strasburg in the Fall.

(More about Dr. Williams in the next Newsletter!)

**Millie Young, RN**, will join the Clinic staff in September. Many families already know Millie and her excellent nursing skills and compassionate way of caring as she served on the pediatric floor at Lancaster General Hospital. We look forward to welcoming Millie in late September.

We are not as happy to announce that **Miriam "Mim" Echter-nach** retired in June from her position at the Clinic as Assistant Office Manager. Mim managed patient billing and accounts, kept the rest of us headed in the right direction on most days and shared her amazing talent for doing what needs to be done around the office before anyone else realizes what needed to be done! She also speaks Deutsch and could ease the anxiety of many little children with a few well chosen words. She is looking forward to spending more time with her granddaughters and tending to many other projects. She is missed by all of us at the Clinic and we are very thankful for her time, energy and commitment to the Clinic since 1999.

**As in other years summer is a busy time with a number of college, pre-med or medical students involved in on-going research projects on various topics.**

## AVERY FELLOWSHIP

The Clinic for Special Children created a fellowship to honor the legacy of Dr. Mary Ellen Avery, formerly Physician -in-Chief at Children's Hospital, Boston, and one of Dr. Morton's most highly respected teachers. This year's **Avery Fellow** is **Abigail Benkert**, recent graduate of F & M. Her research focus will be the 3BHD deficiency.

## F&M 2013 EYLER FELLOW

Recent Franklin & Marshall College graduate, **Joshua Wesalo** is this year's **Eyler Fellow**. Josh will continue his work at the Clinic on GM3 research that he began at F&M.

**Shawn Becker**, F&M '12, is participating in a six week clinical rotation at CSC as part of his training in the Physician Assistant Graduate Program at Lock Haven University of Pennsylvania.

**Elizabeth Gura-Gavin**, Brookline, MA, was assigned an independent writing project based at CSC this summer.





Clinic for Special Children  
P.O. Box 128  
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The Clinic for Special Children's web site was recently redesigned with a new look and a more interactive, informative format. Check in with us from time to time for news updates, auction event information, conferences and progress reports.

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

#### MISSION

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

**Clinic for Special Children**  
**P.O. Box 128, Strasburg, PA 17579**  
**(717)687-9407**

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 1-800-752-0999. Registration does not imply endorsement

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