

# Clinic for Special Children

## NEWSLETTER

VOLUME I NUMBER 38

\* LANCASTER COUNTY, PENNSYLVANIA \*

SUMMER 2015

It is Time! The Quilts and the Clocks tell us it is Time for the Clinic's 25th Annual Benefit Auction to take place. We hope the "Nautical Star" quilt inspires all to join us at the Leola Produce Auction on Saturday, September 19th. Please Join Us!

\*\*\*\*\*

### *2015 Benefit Auctions*

#### **TWO TO GO:**

September 19, Leola, Lancaster County, PA

The 25th Annual Benefit Auction for Clinic for Special Children will be held at the the Leola Produce Auction on September 19th.

Quilts, furniture, hand-made toys, wood crafts, carriages, ponies and landscaping plants will be available for buyers. A wide choice of food including chicken barbecue, pulled pork, freshly made pies, donuts, whoopee pies in many flavors, ice cream and many other delicious treats will be featured. Breakfast is available starting at 7:00 am and the auction opens for bidders at 8:30 am. Remarks by Dr. Morton, Dr. Strauss and Dr. Williams are scheduled around 11:00am with special items, quilts and furniture sales immediately following their remarks.

Quilts ready for the auction include Nautical Star, (pictured above), Mariner's Compass, Postage Stamp, Diamond Jubilee, Wedding Ring, Flame Star, Stepping Stone, Lone Star, Diamond Back Log Cabin, Trip Around the World, Log Cabin, plus many more including wall hangings, comforters and pillows.

A new Amish carriage, a spring wagon with three seats, made of fiberglass and equipped with LED lights, pony carts and ponies will be there for the bidding.

Furniture to be auctioned includes a grand father clock, cherry bedroom suite, 5 piece oak bedroom suite, swivel glider rocker, sofa bed, a Bernina 330 sewing machine, pine furniture, red cedar log bed, deacons benches, and many other pieces.



Outdoors there will be swing sets, chain link dog kennel, picnic tables, PVC hot bed, Martin bird houses, lawn furniture, mini-barns, and various size storage sheds. Leola Produce Auction is at 135 Brethren Church Road, Leola, PA 17540.

September 12th,  
Blair County, PA

The Blair County Auction will be held on September 12th at Morrison's Cove Produce Auction, Rt. #36 South of Roaring Spring, PA. This auction, always on the second Saturday of September, supports CSC and the new Central Penn-

sylvania Clinic for Special Needs (CPAC) in Belleville.

Always a source of beautiful mums and other nursery items, handmade quilts and locally made furniture, this auction also features delicious chicken barbecue, soft pretzels and freshly churned ice cream, including low protein ice cream and other treats for those with MSUD to enjoy! For donations of items or information, please contact Paul Ray at 814-224-5442.

## THE CLOCKS ARE TICKING.....



Among special items for this year's auction are two hand-crafted clocks designed and made by a local master craftsman who generously donated them. Both clocks were entirely made by hand, not laser cut, and have many special unique features. They are truly works of art and will be treasures for the highest bidders.

The railroad clock is made of red oak, maple and walnut. The red oak wood is recycled from cabinet doors and the mahogany and maple are from manufacturing scraps that would have otherwise ended up in a landfill. The locomotives on each side have LED headlights which

are activated along with the locomotive horn by a pushbutton. Another pushbutton activates the flashing red crossing lights. The train horn does not sound on the hour. The bottom features a group of spikes with a "golden spike" in the middle.

The other clock is a cathedral style clock made of red oak and walnut. Again, the red oak is recycled and the walnut is from manufacturing scraps. It features 3 music boxes in the base (tunes- "How Great Thou Art", "Silent Night" and "Amazing Grace"), night lights in the second and third levels, and a top quality quartz triple chime movement with night shutoff and volume control. These clocks are each one of a kind and hand made by a well known master craftsman.



## IT'S A SPECIAL HIT AND MISS....

This Hit and Miss scale model replica of a New Holland Saw was made especially for the auction in Leola by the father of a special child cared for by Dr. Strauss and the CSC team. During his time with us, this child taught us all so much.



We are grateful to his family and to his dad for this very amazing contribution for the auction.

## 2015 Benefit Auctions

### THREE GONE ~ AND VERY SUCCESSFUL!!!

The auctions held earlier this summer on June 6, at Buffalo Valley Produce in Union County, PA; on June 27, in Shippensburg, PA; and on July 11, in Shiloh, OH, were all well attended and raised significant support for the Clinic for Special Children.

Beautiful handmade quilts, heirloom handcrafted wooden toys and furniture, new carriages, handsome horses, sporting goods, garden items and many watermelons attracted bidders who also enjoyed all the delicious food prepared at all of the events. As with all of the Clinic's benefit auctions, many of the items were made and donated by mothers, grandmothers, fathers, grandfathers, other relatives and friends of children who come to the clinic. They are stitched, carved, honed and made with loving care which makes every item even more special for those who give and we hope, for those who bid and take them home.

*We are very grateful to the families and many other volunteers for their time and effort to organize each of these auctions to benefit the Clinic for Special Children. We thank all who generously donated their talents and workmanship for so many special items. This support is very much appreciated. It sustains the Clinic and inspires the staff to continue our work.*

**THANK YOU TO ALL!**

Looking ahead to 2016 ~~~~~

The date for the Clinic's Annual Benefit Auction in Leola will change from the Third Saturday in September to the Third Saturday in June !!!!!  
June 18, 2016

### REMEMBER OUR MATCHING GIFT CHALLENGE!

*Please help us meet the challenge of \$25,000 in matching gifts before December 1st.*

**THANK YOU!**

### STAFF NEWS

The Clinic welcomed **Carolyn Robinson** to our staff in July. Carolyn is a recent graduate of Franklin & Marshall College with a major in biology. She manages daily clinical diagnostic testing and performs amino acid analysis in the lab. We are happy to have her join our staff.







## JULY CONFERENCE

Pictured above are many of the participants in the **Translational Medicine in Plain Populations Conference #3** held on July 9-10, 2015 at Franklin & Marshall College, Lancaster, PA. Over 100 attended the conference hosted by the **Clinic for Special Children and Franklin & Marshall College**. Sponsors for the conference included **Center for Rare Disease Therapy at Children's Hospital of Pittsburgh of UPMC; Lancaster General Health and Nemours Children's Health System**. Staff representatives from clinics serving Amish and Mennonite populations in Ohio, Indiana, Wisconsin and Pennsylvania were joined by researchers, physicians, students, and interested community leaders who are thinking about the need for new clinics in Kentucky and other locations. Clinical services, research progress and organizational challenges were all topics of a full agenda.

## NEMOURS AND CSC PARTNERSHIP FLOURISHES

*Adam Heaps*

Since 2011, CSC has been working with Nemours A.I. duPont Children's Hospital in Wilmington, Delaware to provide affordable and accessible subspecialty care to CSC patients. Currently Nemours provides audiology (hearing), otolaryngology (ears, nose, and throat), ophthalmology (eyes), nephrology (kidney), orthopedic (bone) surgery, wheelchair fittings, and pulmonology (lungs) services on a regular basis at CSC. In addition to providing clinical services, the Nemours team has been integral in helping to better understand the disorders facing our patients.

The collaboration has resulted in better clinical care for CSC patients, increased coordination of advanced care, and exciting research opportunities. Starting August 1<sup>st</sup>, 2015 CSC and Nemours entered a collaboration designed to strengthen the partnership between the two institutions. Over the next 5 years, staff members of both institutions will be meeting on a regular basis to coordinate the research and clinical efforts between both organizations. One of the major goals is for CSC to help Nemours provide increased clinical and laboratory services to Amish communities in Delaware. We hope this collaboration will enhance the clinical, research, and education programs at both institutions.

## LOOK AND LISTEN

CSC's audiology exam room is now bright and cheerful thanks to the youth group at **St. James Episcopal Church** in Lancaster. The group under the leadership of **Katie Lutz** designed and painted the mural (pictured below) as their gift to the Clinic. **Many thanks to all!**



## RESEARCH AND FAMILY DAYS

The Clinic recently sponsored a workshop for families who have daughters with a newly identified genetic mutation known as DDX3X. The mutation only occurs in females and causes mild to severe intellectual disability and developmental delays. Some girls experience seizures and autistic like behavior and some also have poor muscle tone.

Discovery of the mutation was reported in an article published in the August issue of the American Journal of Human Genetics. Authors include **Dr. Kevin Strauss, CSC Medical Director and Karlla Brigatti, CSC Genetic Counselor**. CSC staff worked with **GeneDX** to identify one patient with the mutation who was referred to the Clinic. The mutation identification was linked to around ten others with similar characteristics who also had DDX3X. Researchers estimate that 1% to 3% of girls with undiagnosed intellectual disabilities and developmental delays may have the newly described mutation. For CSC it is unique in that none of the families who have daughters with DDX3X are from the Plain Communities.

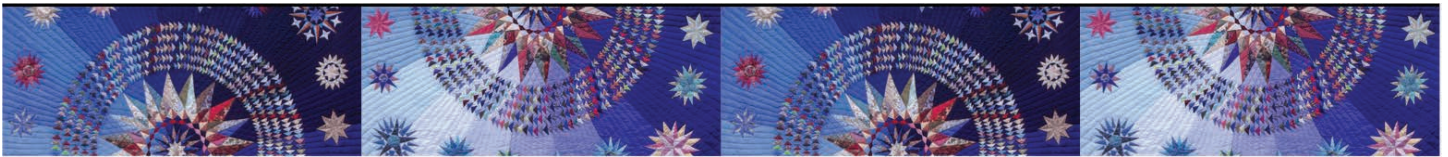


Photo by Dan Marschka, LNP

For families who have cared for daughters for many years without knowing a diagnosis or never meeting other families who share similar challenges, the family meeting held at the Clinic was a significant event. The meeting will hopefully lead to other connections, more answers where there had been only questions and new efforts in areas of research on DDX3X.

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

NONPROFIT ORG.  
U.S. POSTAGE  
**PAID**  
LANCASTER, PA  
PERMIT NO. 1746



2015  
Benefit Auctions  
TWO TO GO:

September 12,  
Blair County, PA

September 19,  
Leola, Lancaster County, PA



CLINIC FOR SPECIAL  
CHILDREN

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.*

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