

CLINIC FOR SPECIAL CHILDREN NEWSLETTER

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* LANCASTER COUNTY, PENNSYLVANIA *

DECEMBER 2008

~ GREETINGS ~

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

At the Lancaster auction, Dr. Morton shared a story about a boy and his family, their struggle to pay hospital bills, and how a meaningful simple gift lead to even greater generosity. We share this story of Giving which inspired many at the auction in September:

THE GIFT OF HENRY:

*from Auction Day Notes: September 20, 2008
Holmes Morton, M.D.*

Henry gave me a simple bird-house. It was made of scraps of wood, a patch of metal roofing, nails, and in his free time after a day of hard farm work. There are about 16 small new nails, the other nails along the roof are old, reused. The peg for the bird to stand on is a hand-made square nail made by a blacksmith probably more than 100 years ago. The cost to make this house is less than 10 cents, but I ask you "What is its value?"

The house is made of weathered wood, sheltered by a curved corrugated metal roof, and is sturdy. It will last through many generations of wrens or gold-finches or bluebirds. From each family that nests here will come many more birds. Imagine an endless unfolding of small birds whose lives began and were sheltered by this simple, safe place that Henry made. "What is the value of song birds in the fields and woods near your home?"

"Here," Henry said, "This is for your Auction."

It was not many years ago that almost half of the children with his disease died long before the age of 17, and many of those that did survive could not work on a farm, as he does, or make a bird-house. We should be thankful just for his ability to make the house. We should always remember, such is the purpose of our work as doctors. Not just money, not just research or publications, not how many visits per year to a doctor or hospital, the final purpose of our work is the quiet continuation of the ordinary work and events in the life of a person like Henry.

This bird-house is also like the house Henry grew up in. When I first knew the family of Jesse, at the time Henry was born, they lived in an old and small log and board structure that was on the property when Jesse bought the farm. Part of the work of Jesse and his brothers is to tear down old barns and houses and salvage logs and lumber that are reused, often in fine new homes along the Main Line west of Philadelphia. From such salvaged materials Jesse and his brothers built a sturdy, warm and dry house for a family of 13. Their house, just like Henry's bird-house, was made from material saved and refashioned into a home



that will last for many generations. All of us, who live in world where so much is thrown away, wasted, undervalued - could learn something from the example of Jesse, Henry and his family.

The bird house is a gift from Henry himself to help others. He knows that is part of his place in his family and in this Community. This auction, the quilts and furniture and food and auctioneers all the hard work of this day come from people who share this sense of Community purpose. Each item sold here today is a gift and each has its story of how it came to be here. Henry has learned this - feels this. The birdhouse takes its value from this purpose too.

The day Henry gave this house I had gone out to the home to arrange a meeting with the CEO of Lancaster General Hospital, who wanted to meet with the family in their home and work out a way to help them with their medical bills. We had this meeting. Having gone to the home, seen the children we care for, and heard Jesse's story, he understood their need. He helped solve their problem.

After we had settled the bill for Lancaster General Hospital, Jesse remarked that he still had a bill at the Clinic of almost \$9000. I said, "We'll

talk about the bill at the Clinic after we see what Henry's bird-house brings at the Auction." I heard Lena, Henry's younger sister, snicker about that bird-house. She didn't know how valuable, how important, Henry's gift was. Lena and Henry are here today. I thought it would be good for them to learn what a gift can bring....

There is a story I enjoy about an auctioneer who tried to sell an old fiddle. At first there was no interest, no offers were made. A Master of the instrument stepped forward and played the violin. From the weathered and worn violin came the beautiful old music of Bach. Everyone then knew its value, and it sold for a high price. I have told you about the Meaning of Henry's Gift. And, it is a good bird-house too.

NOTE: The bird-house was sold for \$6,000 to an Amishman, a young man who has a good business, and a child we care for at the Clinic. Henry, Lena, and all of us learned something about how some ordinary thing became Meaningful, and about Giving, and about how fortunate we all are to live in a Community such as this. dhm 9/21/2008

Henry gave me a replica of the bird-house a few weeks after the Auction. I asked him, "What's my bill?" He said, "I figured I would give you that one. I am still making \$3000 for each house. I reckoned that's still pretty good money." dhm

.....And there was nothing left for the BIRDS

Records were set at the 4 annual auctions held in July and September. All was sold by the end of the day. From beautiful quilts to mums, hand crafted turkey callers, engraved music boxes, intricate marble rollers, a Persian rug, locally made furniture, a beautiful young Morgan horse, manure spreader and a bird house,.....there was something for everyone at any of the four auctions this year. There was also literally tons of food. Here is a sampling from the auction in Lancaster which set a record in food sales this year. Not much was left by mid afternoon at any of the food stands.

3,000 pounds (1 1/2 tons) of Barbecued Chicken
2,000 Pork Sandwiches from 8 Roasted Pigs
17,000 Donuts -plus as many donut holes
700 Omelets made from 144 dozen eggs by 10am
744 Pizzas
430 salads from salad bar
3275 Subs made and donated by Sheetz
1900 lbs of potatoes for french fries and homemade potato chips
4200 Soft Pretzels
4,000 Whoopie Pies in 11 variations
1500 Fried Pies in 8 flavors
209 Strawberry Pies
7200 Servings of Ice Cream and 650 Milk Shakes
Lemonade, 1,000 ham & cheese sandwiches,, soup and a huge variety of baked goods also fed the crowd.

The Clinic depends on the auctions for a significant portion of the cost of maintaining and staffing the clinic and providing services to children. Without this support, the cost for an office visit would be four times as much as it has been for the last 12 or more years at \$35.

Thank you to all who volunteered; who donated sale items and food; to all who came and bid generously; 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.

Next year will be the Clinic's 20th year - it is hard to believe but some of us have a few gray hairs to prove it! We hope to announce some special events in the coming months to mark this milestone. We also have many patients who are now grown up and healthy- which is our true celebration.

HELP US CELEBRATE

THE CLINIC'S 20TH ANNIVERSARY IN 2009



CLINIC BENEFIT AUCTION DATES 2009

July 11, Shiloh, Ohio

July 18, Shippensburg, PA

September 12, Blair County, PA

September 19, Lancaster County, PA

NEWS NOTES

WE MET OUR MATCH

We are pleased and thankful to announce that we met the matching gift challenge generously offered to the Clinic from a Lancaster area family foundation. Around 40 donors with gifts from \$25 to \$10,000 helped us meet the challenge to raise \$50,000 by December 1st.

We are grateful to all who contributed, especially to the family foundation who matched these gifts to give us much needed support.

The **Ultrasound machine** previously on loan to the Clinic is now back after being used elsewhere on a project for several months. We are hopeful, based on preliminary information, that the clinic will receive our own ultrasound equipment in the near future. Meanwhile, appointments can be made for children who need screening for polycystic kidney disease and heart problems, especially those with propionic acidemia and MCC disease.

With help from several donors, the **genetics of hearing lab** is almost ready for evaluations of children experiencing hearing loss. We need one additional piece of equipment to fully complete the lab for the complex hearing evaluations proposed. Funding for the equipment and lab included donations received in memory of Dr. Morton's mother, Mary, who passed away in July, 2008.

In October, Clinic staff traveled to central PA and met with families in that region who have children with **Pyruvate Kinase Disease** to assess the natural history of PK disease, especially in adults, where the risks of severe infections and iron overload are very high. We are doing further research to provide better care for children and adults who suffer complications from this disease.

RECENT LECTURES

On December 17th Dr. Morton gave the Director's Invitational Lecture at NIH on **A Pediatrician's Perspective on the Human Genome Project and Genomic Pediatrics**.

Kevin Strauss, M.D. and Erik Puffenberger, PhD. gave the second in a series of five **F&M MacArthur Lectures**, on November 5 at Franklin & Marshall College. The lecture elegantly illustrated the concept of **Bioinformatics** as it applies to human biology and medicine. Dr. Puffenberger and Dr. Strauss also presented a workshop on pediatric genomic medicine with grand rounds at York Hospital in York, PA.

Dr. Strauss was the guest speaker in November at the Johnson & Johnson Excellence in Science Symposium at the corporate center in NJ.

Drs. Morton, Strauss and Puffenberger all lectured in various courses at F&M in the Fall. Donna Robinson, CRNP, lectured at several nursing schools in the region.

A Place for Teaching and Learning

This fall **Nicholas Muenke** joined the Clinic as a student volunteer in the lab. Nicholas is a recent graduate of the University of Vermont and hopes to attend graduate school for a PhD. or M.D. He is working on various projects with Dr. Puffenberger in the genetics lab and with Dr. Morton on the mass spectrometer. Nicholas is the second recipient of the Morton scholarship award named in honor of Dr. Morton's parents, Mary and Paul



Morton and funded through Dr. Morton's MacArthur Award and a gift left to the Clinic by Dr. Morton's father.

Eric Sherman, an award winning senior at Ephrata High School, continues to work on projects with Dr. Puffenberger. Eric's research on Glutaric Aciduria type 3 was chosen for a poster presentation at the annual meeting of the American Society of Human Genetics held in Philadelphia in November.

Lauren Saunders, a student at Dickinson College, is working on a research project related to iron metabolism in Pyruvate Kinase deficiency during the December-January winter break

Krysta Brown, F&M College, is working on research projects at the Clinic studying the genetic network involved in iron transport to determine if abnormal iron absorption or excretion contributes to the risk of iron toxicity in patients with Pyruvate Kinase deficiency.



LOOKING AHEAD

CME Courses at the Clinic for 2009:

The next CME session sponsored by the Clinic for Special Children will be held on January 15, 2009. The course, *"Approaches for Translational Research"* is designed for physicians in practice, medical students or residents and focuses on developing innovative strategies for solving some of the more difficult clinical problems encountered by

pediatricians. Each topic will consist of a brief overview followed by an opportunity for interactive discussion and creative thinking about practical ways tools of molecular and cellular biology can solve problems directly relevant to patient care.

Please contact the Clinic at (717) 687-9407 for more information or to register for the course.

A CME course specifically designed for midwives is planned for early 2009. This course will provide an update about expanded newborn screening, including rapid molecular testing now available using cord blood samples for selected disorders and instructions in the administration of vitamin K.

Another CME course for physicians is planned for late summer.

BONE MARROW DONOR DRIVE

In June we will sponsor a bone marrow donor drive. This project will be of particular interest for families from Amish and Mennonite backgrounds who have relatives with severe combined immune deficiency disorders. Please contact the Clinic to express interest in participating.

2008 IN REVIEW

In 2008 the Clinic for Special Children included 1,030 infants, children and some young adults in our active patient files.

The Clinic provided care for children with over 105 different genetic disorders that encompass diseases of all organ systems with 47% of these disorders affecting brain development or function.

The Clinic has the capability to diagnose 75 different hereditary conditions using state of the art molecular laboratory techniques. Many of these conditions represent "new" genetic syndromes and were identified by the Clinic's physicians and molecular biologist/population geneticist.

The Clinic for Special Children is often hard to describe. It has many dimensions in its approach to medicine, in caring for patients, in identifying and giving focus to research topics, in providing educational

experiences for promising future doctors and scientists, and in the unique ways we find our support.

On Describing the Clinic for Special Children.....

The Clinic is a paradigm of community genetics, designed to serve particular people living in a specific place and time, but it also represents a model of health care with deep biological relevance. Through investigation of rare genetic disorders, Dr. Morton and his colleagues have uncovered common molecular mechanisms of disease. Through early genetic diagnosis and systematic follow-up care, they have prevented death or disability, in hundreds of children and saved the Plain communities an estimated \$200 million in direct and indirect medical costs. The juxtaposition of state-of-the-art biomedical research and the best possible patient care within a single clinical setting exemplifies a seamless approach to medical care, a rarity given today's increasingly compartmentalized approach to health care delivery.

The Old Order communities measure the value of knowledge not in grant awards, publications, or academic promotions, but in stark human terms: alleviation of pain, prevention of suffering, social justice and fair economics. The Plain people understand that to translate knowledge into better community health, one must first commit to caring for individuals.

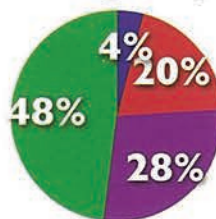
by Dr. Kevin Strauss, CSC, and Ryan Sauder, F&M



Dr. Morton and one of the youngest patients ~examining each other

WE NEED YOUR SUPPORT

We have trimmed our budget for 2009 as much as we can. Our basic costs to operate the Clinic this year are estimated at \$1,450,000. Although the annual benefit auctions provide significant support, we still need to raise approximately half of funds needed each year through charitable gifts and grants.



4 % Research Endowment
20% Fees for Clinic Services
28% Auction Proceeds
48% Charitable Gifts

Please consider a gift to the Clinic for Special Children.

THANK YOU

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

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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

Hope is the thing
with feathers that perches in the soul
and sings the tune without words
and never stops - at all.

Emily Dickinson

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