



CLINIC FOR SPECIAL CHILDREN

NEWSLETTER

VOLUME I NUMBER 24

* LANCASTER COUNTY, PENNSYLVANIA *

DECEMBER 2006

*We hope the spirit of this season will bring joy
and the gift of peace to each of you*

In the last few months we were incredibly saddened but also uplifted and renewed through the community we have the privilege to serve. We welcomed the amazing support and turn out for our annual benefit auctions. Good news came our way that will help further the work and mission of the Clinic. We also experienced great loss. We grieved with families in the death of their special child from disease we have yet to conquer. In October we shared the shock and tragic loss of children in our community and offered help in the difficult process of recovery. The strength of this community to endure loss, to forgive, to bring support and build hope is an inspiration, a lesson, a gift to all of us.

WORDS OF THANKS

"Prayers are said, prayers are answered in many ways", and lessons from grief were the guiding themes in the remarks given by Dr. Holmes Morton and Dr. Kevin Strauss to express thanks at the auction in Lancaster in September. The following are excerpts from their remarks:

Remarks from Dr. Strauss ~

The auction is a special day. It is a day to celebrate important progress made over the past year. So I ask, what makes this progress happen? What is the source of this work?

I think that it is, more than our successes, our failures. For every child helped by our efforts, there is another that suffers. For every child that lives a longer and healthier life through our work, there is one that died too young, and for whom we could offer no treatment and no hope. The parents that care for such children understand, perhaps better than most of us, what the clinic means to families, and why its future is so

important for the community.

This year I had the opportunity to hear one such parent talk at a gathering of Plain families in Canada. The couple lost two young girls to a disease caused LYK5 deficiency. We discovered the genetic cause of the condition this year, and quickly identified 16 affected children. The mutation in the LYK5 gene results in a severe malformation of the brain, and 40% of children with the disorder die at a young age.

As a Mennonite man, the father was asked to speak to other Plain families about his experience caring for his two daughters with the disease. I was moved by what he read, and would like to share parts of it with you now. The words were taken from a passage called "The Gift of Grief", by an anonymous author:

*"Death and disease take away.
That's all there is to it.*

But grief gives back. By experiencing it, we are not simply eroded by pain. Rather, we become more compassionate, more aware, more able to help others, more able to help ourselves.

Grief is powerful. It does more than enable us to change; it demands it.

The way we change is up to us. It is possible to be forever bowed by grief. It is possible to be so afraid that we become frozen, stuck in sorrow and resentment, unable to

move on.

But it is also possible to be enlarged, to find new direction, and allow the memory of the beloved to live within us, not as a reminder of our misery, but as a source of strength, love, and inspiration.

By acting on our grief, we can eventually find within ourselves a place of peace and purposefulness."

These words express to me what the clinic is all about. I want to say a special thank you to all of the children who cannot be here. They are in our minds, in our hearts, and in our prayers. And they, more than anyone, show us the way ahead.



Remarks from Dr. Morton ~

I am often asked what I think about when I stand before this crowd. I remember an evening in August 1989, 17 years ago. I was driving from Baltimore to our home in Saint Davids. I stopped along the highway to think about what to do. By then I knew there would not be grant money from National Institutes of Health or Johns Hopkins to support my studies of glutaric aciduria. By then I knew my research fellowship at the Kennedy Institute would soon end, and there would be no job from there. By then too I was supporting our family entirely by working nights and weekends in the newborn intensive care units of Bryn Mawr and Harrisburg Hospitals, which was difficult work and would not help the Amish families with glutaric aciduria. I had on that day decided to come to Lancaster to work as a pediatrician, but I had no idea how to start a practice, set up the laboratory I would need, or build a Clinic. My former teachers in Boston at Harvard Medical School and Children's Hospital told me the move to Lancaster county would end a promising career in academic medicine. My wife, Richard Kelley, and my father were supportive, but were understandably worried. A few Amish and Mennonite families knew about the idea of Caroline and me to start the Clinic, but they were understandably skeptical that such a Clinic could be supported by them, and were doubtful that the other members of the Plain communities would help. On that rainy day in August, the Clinic for Special Children, as we know it today, seemed an unlikely dream.

I cannot say how long I sat by the road that day, or what new ideas I may have found. I remember at one point there were tears of frustration and disappointment in my eyes. I said to myself out loud, "If this ever works out, I hope you will always remember this day. I hope you remember how difficult this time really was." Every year for 16 years, as I have looked out over this crowd, I do remember that time.

Prayers are said, prayers are answered in many ways.

Each quilt, each piece of furniture, the pictures, the music boxes, the work of those who help with this auction in so many ways - each has a story. I always imagine the conversations, the memories, and at times the sadness, at times the thankfulness, that inspires the work of this day.

Last year the Postage-Stamp quilt was bought by a family from Florida who in the winter of 2005 brought their child to the Lancaster General Hospital, severely ill from Maple Syrup Disease. They left the large medical centers of Florida and came to Lancaster County for help. Not just because of Dr. Strauss and me, but because a whole community of people over many years have worked to care for children with this difficult disease. We all know that the lessons were often difficult.

In the early years, 1966-1986, death and sadness were often the inspiration for the Mennonite community to look for new and better ways to care for these children. Before the Clinic was started in 1989, 40% of children born with Maple Syrup Disease died of brain edema before their 10th birthday. Among those who survived mental retardation, difficulty walking, and other disabilities were common problems. Today, that has changed. From 1989 until now there have been no deaths from cerebral edema, children learn to walk, ride bicycles, and go to school with their friends. But the transformation did not come easily.

The little girl from Florida survived because of the community of people that are here today. When I look at the Postage Stamp quilt, and I know that the same person has made this same quilt for this auction year after year. I know that in her husband's sister's family three children died of Maple Syrup Disease, and the one who survived was badly crippled before the Clinic started. I imagine that each piece of the quilt has a story, a remembrance. It is a quilt that was inspired both by sadness and by hope.

As you walk through this crowd and see the work that makes this auction possible, understand that all the work of this auction, the knowledge gained at the Clinic, which changes the lives of many children, here and elsewhere around the world, are Gifts from Special Children to us. Today we thank them in many different ways.

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2006 AUCTIONS

The annual benefit auctions held in July in Shippensburg, September in Blair County and in Lancaster County were all well attended and in total brought a record level of support for the Clinic's operational costs for the coming year. We thank all who helped with contributions and their time - we know there are many, and all who attended. The Clinic would not be here without this amazing community support. For sixteen years the Benefit Auctions have consistently contributed 30% of annual operating costs. This year we expect the Clinic's annual budget to reach \$1.3 million. We need to increase our support so that the cost to families who bring their children to the clinic will *not* increase. We have a good start this year and wish to express our

THANKS TO ALL.

Highlights from SHIPPENSBURG in July

A new two seat spring wagon, 37 quilts and wall hangings, a grandmother's clock, landscaping plants and many hand crafted items highlighted the sale this year. As you might expect on a hot July day, ice cream was a big seller along with chicken barbecue, home made donuts, soft pretzels and much more.

Highlights from BLAIR COUNTY in September

Mums decorated the platform where 26 quilts were auctioned with furniture, handmade items, sheds and garden supplies outside. After breakfast, chicken, fresh fruit, home made ice cream, soft pretzels, donuts, baked goods and so much more was available and all sold.

LANCASTER COUNTY ~ September 16th This year 1577 registered bidders bought items at six different auction blocks staffed by 24 volunteer auctioneers for a record sale. An estimated 7,000 attended this year. Of the 88 full size quilts, the top seller was the Postage Stamp quilt which brought a record of \$5,000. Furniture sold included 3 complete bedroom sets, 3 roll top desks and numerous other hand crafted pieces.

Featured items included a chest hand carved on site by a local artist, hand made and engraved music boxes and turkey callers. Dr. Kelley found his marbles in an exquisite dual track hand made marble roller now located in the Clinic for patient therapy and staff diversion! Outside, a new Amish carriage, a Spring Wagon, driving pony, many locally made sheds, garden items and playground equipment found their buyers. And, of course there was the food:

(Caution! Please don't try to add up the calories!)

3,000 pounds of Barbecued Chicken
2220 Pork Sandwiches from 8 Roasted Pigs
19,000 Donuts -made and sold out by mid afternoon
500 Omlets made from 120 dozen eggs by 10am
2100 Whoopie Pies in 10 variations
550 Salad Bar servings
1,000 lbs. of ice to convert a canoe to a Salad bar
552 16" Pizzas:
3200 Subs:
800 Ham & Cheese Sandwiches
4900 Soft Pretzels
1700 Fried Pies in 9 flavors
150 Strawberry and Peach Pies made
200 Gallons of Ice Cream
1275 Milkshakes
1920 16oz Lemonade or Rhubarb Drink

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4900 Soft Pretzels
1700 Fried Pies in 9 flavors
150 Strawberry and Peach Pies made
200 Gallons of Ice Cream
1275 Milkshakes
1920 16oz Lemonade or Rhubarb Drink

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

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

Board of Directors

D. Holmes Morton, M.D.
Caroline S. Morton
Richard I. Kelley, M.D., Ph.D.
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Jacob Zook

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