

CLINIC FOR SPECIAL CHILDREN NEWSLETTER

VOLUME I NUMBER 18

* LANCASTER COUNTY, PENNSYLVANIA *

Summer 2001



AUCTION DATES

SHIPPENSBURG- JULY 21, 2001

BLAIR COUNTY - SEPTEMBER 1, 2001

LANCASTER COUNTY- SEPTEMBER 15, 2001



GROWING SEASON

The Clinic's roots are firm. We are in our growing season, a time to contemplate the yield of years of planning and work, to see seeds thoughtfully sown finally sprout and grow. There is a sense of excitement and renewed energy at the clinic this summer as plans come to fruition. The building addition is completed and beautiful and gives us space we need. Our quest is fulfilled for another physician to join us in the clinic's work and sense of mission. We realize much was accomplished over the last ten years that has built a foundation for much more work to be done to help children with complicated genetic diseases. The clinic brings hope to many families. The support we received to reach this season was extraordinary and has inspired us. As we strive to meet the needs and challenges that call each day, as we present to others lessons taught by special children, as we research genes, diseases, and new treatments, as we teach others and most of all as we care for children who need our help, we will continue to need yours. We express our thanks and ask for your continued interest and support.

THE CLINIC WELCOMES DR. KEVIN STRAUSS

Kevin A. Strauss, M.D. was officially welcomed to the clinic staff in July as a pediatrician and fellow in biochemical genetics. Dr. Strauss actually began his work with the clinic as a senior medical student during a monthly rotation that extended to several months. He and Dr. Morton have collaborated since then on several research projects investigating neurological effects, neuro anatomy, and biochemistry of several metabolic disorders including maple syrup disease and glutaric aciduria. Dr. Strauss's contribution to the care of special children is already profoundly helpful. We are very excited he has chosen the clinic as the place to pursue his work and very thankful to find a truly extraordinary physician to join Dr. Morton and staff in meeting all the challenges work at the clinic presents. Not only will

challenges be met, new ones created, but the "bar" will undoubtedly be raised for all in what is understood about how biochemical disorders affect children and in management of their care. Dr. Strauss also brings his considerable talent and skill as a classically trained artist to his work.

Originally from Allentown, PA, Dr. Strauss graduated from Colgate University, Harvard Medical School and recently completed his residency in pediatrics at Children's Hospital in Boston where he was selected by medical students to receive the Medical Student Teaching Award, selected by fellow pediatric residents for the House Staff Teaching Award, and recipient of the Michael Osbond Memorial Award for excellence in clinical research and patient care. Dr. Strauss and his wife, Ann, have three children, Gabriel, 4, Joshua, 2, and Elli, 6months.

Words from Kevin Strauss, M.D.....

BUTTERFLIES
Notes on Decision Making
Kevin Strauss, M.D.

*Though didst not know, who tottered, wandering on high,
That fate had made thee for the pleasure of the wind,
With those great careless wings,
Nor yet did I.*

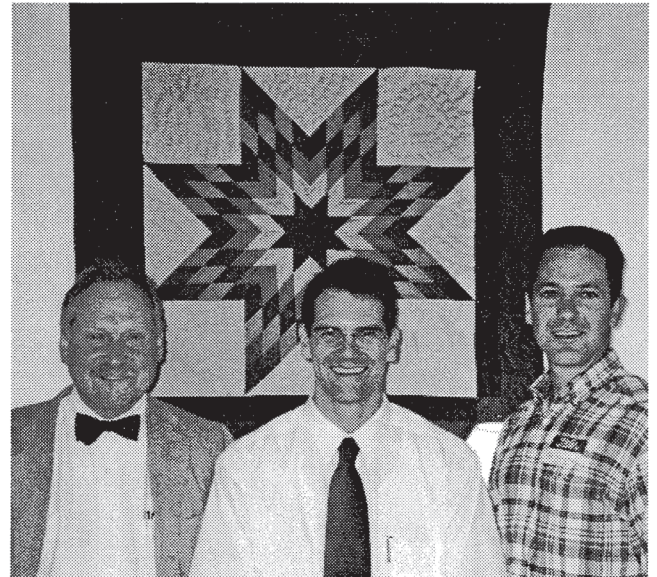
*And there were other things:
It seemed God let thee flutter from His gentle clasp,
Then fearful He had let thee win
Too far beyond him to be gathered in,
Snatched thee, o'ereager, with ungentle grasp.*
from *My Butterfly*, Robert Frost

Something catches my eye as I sit under the great vaulted timbers of a new office. In the orchard below, violet flowers frame a group of small white butterflies, moving in a cluster. I watch them intently and think about Caroline's question to me: "Why did you choose to come to the Clinic?" A simple choice, I thought, yet how shall I explain it . . .

Fascination with the wonders of living creatures compelled me as a boy to turn over every rock and leaf, and now directs my eyes toward the cluster of butterflies. As a boy, I would have watched them contentedly, curious, unaware of suffering. Now as a pediatrician, and as a father, I still watch them, but differently.

Everything in nature has something marvelous to teach us, about our universe and ourselves, and so I keep watching and learning. The children and families who seek our care teach us something unique. They teach us that the human impact of disease cannot be captured in the name of a gene, protein, or chemical substrate. They teach us humility; that our progress, while tangible, is inadequate. They teach us that in the materials of nature--in the intricacies of cells and organisms--lies *hope*. Finally, they teach us something important about knowledge itself. Knowledge alone does not represent the greatest achievement of science. More important is the *understanding* that grows from it, and our wisdom in its application.

Watching butterflies in their afternoon dance, I think of the word *propriety*. When I met Dr. Morton for the first time in the spring of 1993 we talked about many things, among them the essays of Kentucky farmer Wendell Berry. In his recent book, *Life is a Miracle*, Berry talks about propriety, and defines it as "appropriateness to the purpose or circumstances, suitability; rightness or justness; aptness." Much of modern medicine and science suffers from a lack of propriety--a lack of *aptness* or *rightness* in dealing with the complex needs of patients, families, and communities that live with crippling problems. In a world increasingly skeptical about the value of scientific discovery, The Clinic for Special Children reminds us that science, thoughtfully applied, is a powerful means to alleviate human suffering and protect that which we value most: each other.



HOLMES MORTON, M.D., KEVIN STRAUSS, M.D. AND ERIK PUFFENBERGER, PhD

LABORATORY DIRECTION

Erik Puffenberger, PhD., assumed the position of Laboratory Director at the Clinic on January 1, 2001. Dr. Puffenberger has been on staff for the past two years as Assistant Laboratory Director. We are very fortunate to have Dr. Puffenberger's skill and insight as a geneticist and molecular biologist. He has developed a significant number of new diagnostic tests for genetic diseases. Erik is also our in-house computer expert and troubleshooter.

~ AUCTION TIME ~

Summer brings auction activity in three locations. Orders for chicken to barbecue, calls for baked goods, quilts to finish, furniture to varnish, crafts to finish, and wagons to polish. The auctions each year provide the clinic with funds needed to operate the clinic in such a way that families will not be heavily burdened by high medical costs, at least from the clinic. Most of the families who bring their children to us are from the plain community and do not have insurance. Fees charged at the clinic are made more affordable with the help of auction funds. We are able to offer our services at a fraction of the cost billed at other medical facilities. Auction funds also help us research ways to improve diagnosis and care for children with unusual and complex medical conditions and helped us expand the clinic building and staff. We depend on the auctions for support each year and thank all those who contribute with time, donations, and bids! The clinic has had a big year with our expansion project and we need support this year. Please join us for these truly special events.

BLAIR COUNTY AUCTION - SEPT 1

Mennonite families in the Blair County region are planning the 5th Annual Benefit Auction for the clinic on **Saturday, September 1, 2001 at 9:00 am**. The event will be held at the Morrison Cove Produce Auction on Rt 36 six miles

south of Roaring Spring, PA. Among items donated for the sale are a horse breaking cart, handmade furniture including a six door oak hutch and 42 inch round oak pedestal table and quilts. We are very grateful to families in the central region of Pennsylvania for their work to support the clinic. For more information or to donate items, please call one of the following; (814) 793-3634; (814) 793-3010; (814) 224-5442.

LANCASTER COUNTY AUCTION - SEPT 15

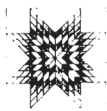
Saturday, September 15, 8:30 am will be the 11th Annual Benefit Auction in Lancaster County held at the Leola Produce Auction facility on Brethren Church Road north of Rt #23 in Leola. Items donated for sale this year include two carriages both made in the community especially for our auction. One is a black full size, 2 seat spring wagon with lights and the other is an Amish family carriage.

A 1/16 scale model electrified steam engine will be up for sale. Among quilts already donated will be a unique "Trail of Stars" pattern, postage stamp, appliqued patterns, all white, an "Emma's Homestead" applique design, "Leafy Log Cabin" and many other patterns. Each year the number and variety of furniture items donated has increased. The furniture is locally handcrafted in cherry, oak, and pine and will include two new oak bedroom sets, 5 ft. oak hutch, dining tables including a new cherry pedestal table, chests, chairs, a cradle. Outdoor furniture, garden items, sheds and swing sets will also be available. And of course, the food. It will be abundant and delicious - chicken barbeque, pork roast, subs, donuts, soft pretzels, pies and baked goods, lemonade, and ice cream made on site. The gavels will go into action at 8:30 am, **quilts will start at 11:00 am, large furniture at 11:30am, lawn furniture at 1:00pm.** We will pause around noon for Dr. Morton to give a few remarks. If you have items you wish to donate, please call one of the following: (717) 626-4863; (717) 354-5415; (717) 656-9694.

SHIPPENSBURG AUCTION - JULY 21

The Third Benefit Auction in the Shippensburg area was held on July 21 with great success. Barbequed chicken and baked goods disappeared very quickly. A new 2 seat spring wagon was donated for the sale as were many beautiful quilts, garden items, furniture, artwork and crafts. We thank all those who helped in Shippensburg and attended the sale. Your help is very appreciated.

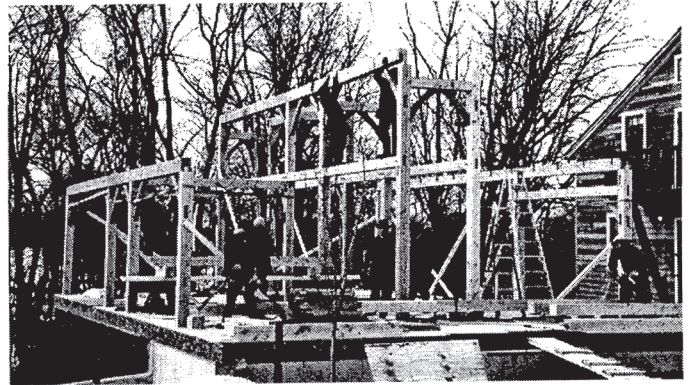
***PLEASE JOIN US AT ONE OF OUR AUCTIONS
FOR FOOD, FRIENDSHIP, AND SUPPORT!***



ADDITION RAISED AND COMPLETED

In spite of cold weather and predictions of a snow storm before midnight, the beams for the clinic's new wing were raised with volunteer help on December 29, 2000. With the aid of automobile headlights and hot chocolate, workers managed to finish not only the timber frame structure but also the roof by 9:00pm. The snow storm never arrived.

Volunteers joined the work project during the winter months to help the clinic addition take shape. Many winter mornings



were filled with a steady supply of donuts, coffee, and soup to keep volunteers warm and nourished for their work. Under John Stoltzfoos' expert management, hard work and attention to detail the building addition bloomed by spring and is in full use this summer. We added two offices, two exam rooms, room for formula supplies, a small waiting area, an elevator for better access to all three floors, and a large general purpose room in the lower level for use by the Special Hearts group.

We are very grateful to John and to so many who gave time, effort and materials for our building project. Many subcontractors and suppliers gave us every consideration in their business with the clinic. A few donated their materials or work entirely, many others gave us discounted prices. Donations to help us meet the cost of this addition were very generous and came from throughout the country - from Massachusetts, Rhode Island, California, Texas, many other states as well as close to home in Pennsylvania. We were able to complete this addition without incurring any debt and are very grateful to all who made this possible. Dr. Morton often says, "There is much work to be done to help special children." This awesome structure built with the help of many, where vaulting timbers seem to lift our vision and spirit provides a place for this work to continue and grow. We feel very blessed and offer our profound thanks.



NEW WEB SITE:

<http://home.dejazd.com/csc/index.html>

The clinic now has a web site to share information such as background information about the clinic, information for clinical and laboratory services, dates for auctions, etc. We are in the process of developing the site and will add and update information frequently.

THE CLINIC FOR SPECIAL CHILDREN, INC.
P.O. BOX 128
STRASBURG, PENNSYLVANIA 17579

11th Annual Benefit Auction

to support

THE CLINIC FOR SPECIAL CHILDREN

*Quilts Handmade Toys Furniture Crafts Baked Goods Chicken Barbeque
Donations Appreciated*

September 15, 2001

Bring your checkbook, no credit cards accepted

Time: 8:30 am Location: Leola Produce Auction, Brethren Church Road, Leola, PA

Directions: From PA Turnpike, exit 21 Rt. #222 south, exit to Rt. #772 south east, left on Peace Rd., 2nd right.

From Lancaster: Rt #30 east to Rt. #23 east, turn left (north) on Brethren Church Rd. past Leola.

From Rt. 30 (Gap): right to Rt.#772 (Newport Rd.) north west to Rt. #23, right on #23 (New Holland Pike), left on Brethren Church Rd. Auction is approximately 1 mile.

The Clinic for Special Children is a non-profit diagnostic and primary pediatric medical service for children with inherited metabolic disorders in Lancaster County, Pennsylvania. The clinic serves Old Order Amish, Mennonite and other families with children who suffer from a high incidence of genetic diseases such as glutaric aciduria and maple syrup urine disease. Clinic services include diagnostic, genetic and metabolic laboratory testing, comprehensive pediatric medical care designed to prevent devastating effects of metabolic diseases, clinical research to improve treatment, and services to support the needs of parents. The Clinic is funded through a combination of fees for services, benefit auction proceeds and private contributions. The Clinic is tax exempt under IRS 501 (c)(3), ID # 23-2555373.

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

Clinic for Special Children Board of Directors:

Holmes Morton, MD President

John A. Hostetler, PhD Vice President

Richard I. Kelley, MD, PhD Secretary

Caroline S. Morton, Treasurer

Enos Hoover

John Riehl

Leonard Hurst

Staff:

Holmes Morton, MD, Director

Caroline S. Morton, EdM, Executive Director

Kevin A. Strauss, MD, Pediatrician/Genetics Fellow

Erik G. Puffenberger, PhD, Laboratory Director/ Geneticist

Donna Robinson, RN, CPN, Nurse Practitioner

Deborah LaBerge, RN, MSN, Immunization Program

Rebecca Smoker, Office Manager, part-time

Miriam Echternach, Assistant Office Manager, part-time

Richard I. Kelley, M.D, PhD, Consulting Geneticist