

CLINIC FOR SPECIAL CHILDREN NEWSLETTER

VOLUME I NUMBER 17

* LANCASTER COUNTY, PENNSYLVANIA *

Winter 2000

RAISING THE ADDITION TO THE CLINIC FRIDAY, DECEMBER 29, 2000

BUILDING A GIFT OF HOPE FOR THE FUTURE

The ground is broken, plans are finalized and timbers are measured. We are ready to raise the addition to the clinic by the new year to make room for our future... another doctor who will join us next summer ... for more children who seek our care ... and more space for work and study.

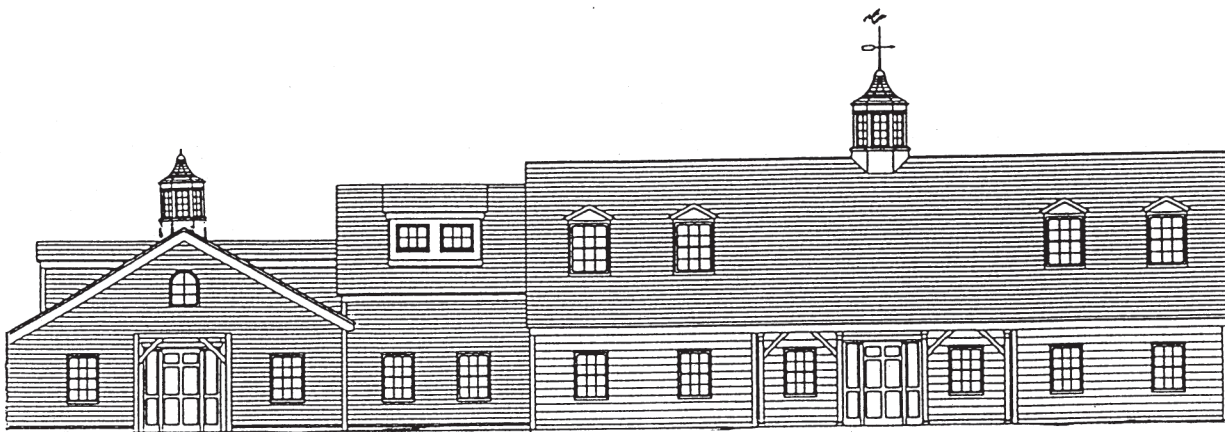
As we celebrate this joyous season we wish to offer our thanks to so many who support the clinic in many ways: gifts of money, of equipment, gifts of time, of talent in quilts, skill in furniture, toys, or baked goods for the auction, and gifts of encouragement. We thank families for the gifts of the children they bring to us. These special children light our lives, challenge our minds and deepen our thoughts. We thank them.

We wish for a New Year that will be bright and full of hope for each of you from all of us at the Clinic for Special Children.

ANOTHER CLINIC RAISING

We will celebrate the New Year this year by rolling up our coat sleeves to raise the new addition to the clinic. On Friday, December 29th, the timber frame for the addition will be raised by Riehl's Construction crew with help from volunteers. Riehl's raised the timber frame for the original clinic building in 1990 and expects to have the frame completed by the end of the day. The heavy fir timbers and oak braces and pegs are measured and cut to size and will be transported to the clinic site after Christmas. Although it would be nice to think so, they probably will not arrive by sleigh with bells and reindeer but by truck. For safety reasons, Riehl's will use a crane to lift the heaviest timbers in place but indicate there will be work available for volunteers who are interested.

All who wish to help either with labor, encouragement from the sidelines or food to fuel the work are welcome. If possible, please let us know if you plan to come so we can stir a big enough pot of stew.



ABOUT THE BUILDING...

The expansion will provide office space for another full time pediatrician who will join the Clinic's staff next July, two exam rooms, and storage room. Enclosure of the second stairway and the addition of an elevator will make all the existing space in the clinic much more accessible and useful. A large open room in the lower level of the addition will be used by the Special Hearts group of handicapped young people.

When the clinic was first built we planned to use space on the lower level for expansion as the needs of the clinic grew. In the intervening years that space found worthwhile use in keeping with the clinic's mission to serve the community with respect to research and treatment of genetic disorders. The lower level is used by Dr. Alan Shuldiner for his ongoing studies of the genetic basis of diabetes which is very common in the local Amish population. Related to this research are studies about osteoporosis directed by Dr. Elizabeth Streeten of the University of Maryland at Baltimore, and genetic studies of myopia directed by Dr. Dwight Stambolian, University of Pennsylvania. These various studies are all linked and provide screening and referrals to individuals in the Amish community. Dr. Andrew Warren of Johns Hopkins also uses the clinic to work with patients with mental illness.

The design for the addition was developed by Stuart Rosenberg Architects of Philadelphia. Stuart volunteered the design for the original building in 1990 which looks as if it always belonged here with its cedar siding, stone foundation and bank barn style fitting the slope of a hill in the middle of an Amish farm. The addition will reflect the original design in a smaller dimension joining the main building with a connecting link that will house the second stairway and an elevator which are required to improve access to all floors of the building. Working with Stuart Rosenberg on the design details is Brian Kuhns. We thank both of them for their vision and hard work. John Stoltzfoos of Strasburg is the Project Manager for construction. John will coordinate the work schedule and subcontractors and will direct volunteers for various jobs. For those who are interested in volunteering with labor or any building materials, please contact John at (717) 687-9062 and leave a message or (717) 203-7002 or call the clinic at (717) 687-9407.

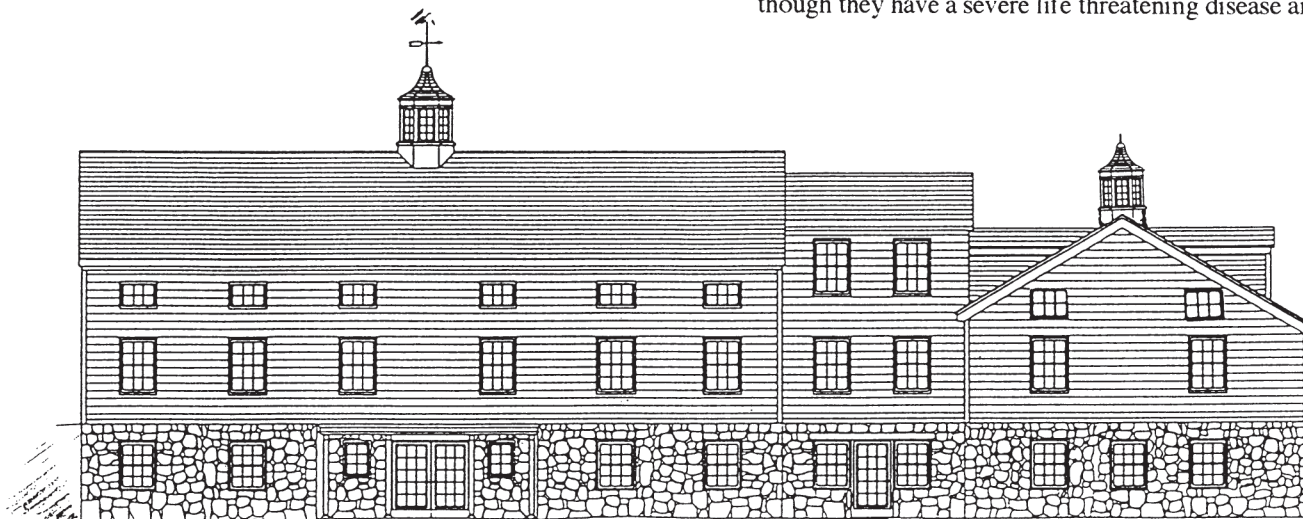
ABOUT OUR FUTURE....

A FIVE YEAR PLAN

The expansion of the Clinic this year is a key part of the five year plan developed by the Clinic's Board of Directors to accommodate the need for growth in staff, provide necessary space, and insure the clinic's financial security for the future. The goal of the plan is to map progress toward achieving full potential as a center for diagnosis, treatment and research of rare genetic disorders that occur within the population of this region of Pennsylvania. Most of the children we treat are of Amish and Mennonite heritage. However, the diseases that are prevalent here also occur in other regions of the country and in children of many various backgrounds. Increasingly the Clinic is requested to consult in the diagnosis and treatment of children with rare disorders such as maple syrup disease, glutaric aciduria, and Crigler- Najjar disease from other states and countries.

Unlike most centers which specialize in genetics, the Clinic was designed not only to provide specialized diagnosis, laboratory work and consultation, but also to provide primary medical care to children for all their medical needs however minor or critical. This comprehensive approach has given the Clinic an opportunity and advantage of learning more about disease processes related to metabolic disorders through observation in many different circumstances and timely intervention for more effective treatment. When we moved into the present building, we thought we would see and treat children with a dozen to two dozen different genetic conditions. To date we have seen and treated children with over 80 different genetic conditions. Our work has led us toward a greater role in teaching others about what we have learned. We hope with the expansion in staff and facilities we will be able to do more in sharing progress through lectures, publications and conferences and in educating students of medicine.

Our research effort is defined and driven by the needs of our patients and directly benefits them. Much of the research we do is focused on understanding more fully how complicated metabolic diseases 'work' and how treatment can be more effective not only to manage the disorder but to give the child the greatest chance for normal growth and development. Many of the children we care for are "normal" in many ways even though they have a severe life threatening disease and take



special formulas or medications. They run and play normally, do well in school, some make straight A's, and they look forward to a full, productive and meaningful life. Other children we care for have hopeless conditions. While providing medical care, we also study these diseases and continually search for clues and information which may some day lead to successful treatment.

Our five year plan calls for a second and potentially, a third pediatrician who specializes in rare genetic disorders. Next summer we will welcome Dr. Kevin Strauss to our staff to join Dr. Morton on a full time basis. (Dr. Strauss will be introduced more fully in our next newsletter.) Dr. Richard Kelley, Kennedy-Krieger Institute and Johns Hopkins University Hospital, continues to work with the Clinic as a consulting clinician and geneticist one or two days a month.

The third facet of the five year plan calls for growth of the endowment fund to give the Clinic financial security and a source of annual income from investment interest to help finance yearly operating expenses related to research and education. The fund was initiated in 1991 with a generous gift from the Philip Reed Foundation. The fund has since grown through additional major gifts, dividends and interest to reach nearly one third of the goal of 1.5 million. Major gifts are sought for this fund which will insure financial stability for the clinic for its long term future and provide a continuous source of operating revenue to finance research and educational activities. Until the endowment fund reaches its goal, interest earned is applied to growth of the fund.

ABOUT OUR SUPPORT...

The Clinic has been blessed with generous support since it was founded in 1989. Many individuals from all regions of the U.S. faithfully contribute. Some first learned about the clinic and Dr. Holmes Morton's efforts to treat Amish and Mennonite children through an article by Frank Allen in the Wall Street Journal in September, 1989. Some are family and friends, classmates and teachers. Others come to know the clinic through families who seek medical care here for their children. Approximately one-third of the clinic's annual operating expenses are met by contributions of individuals and foundations.

Another 30% to 40% of our yearly operating expenses are met by the revenue generated by the auctions each year. As the clinic has grown so has the annual auction. Now there are three auctions in different regions of Pennsylvania. Funds from the auctions and charitable donations allow us to operate and keep fees for patient services at a minimum rate. For some services such as laboratory tests, our fees are a fraction of what comparable services cost in other medical centers. Most of the families who use the clinic do not have insurance and do not participate in federal or state aid programs. Reasonable fees are appreciated and help make care more accessible. However, our fee schedule accounts for the smallest percentage of income to meet annual operating costs, approximately 25% to 30%, and underscores the importance of the auctions and other contributions for operational support.

During the next year we are having a carefully planned and needed growth spurt. We are building... building staff, building space, and building the clinic's future through the endowment fund. We do not plan to grow like this every year or to grow so that it changes the fundamental and personal way in which we operate and serve children. But, we need to grow in a way that we can continue to provide state of the art medical care, laboratory services, and support research and education that is based on the needs and experiences of our patients.

We thank all who give us support through auctions or charitable gifts. It is very much appreciated and vital to our ability to operate the clinic and help it grow.

SPEAKING OF AUCTIONS...

The auctions held in July and September were great successes and gave us a boost for our building fund. The auction held in Leola on September 16th grew again this year with 1593 bidding numbers issued and an estimated crowd of over 6,000 during the course of the day. At least 15 states were represented on license plates parked in the field. (The children are still hoping to find one from Alaska or Hawaii.) Quilts were beautiful and 80 brought high bidding this year. Donuts were plentiful, about 18,000 of them came out of the oven and sold. Sheetz donated over 3600 freshly made subs. At all three auctions furniture accounted for a growing percentage of items sold, most of it made by local craftsmen. The auctions in Blair County and in Shippensburg were also well attended and offered beautiful quilts, great food, and all three events featured spring wagons specially made for each sale.

Our thanks to all who made the auctions possible with much time and hard work. And, our thanks to many who attended and bought generously.

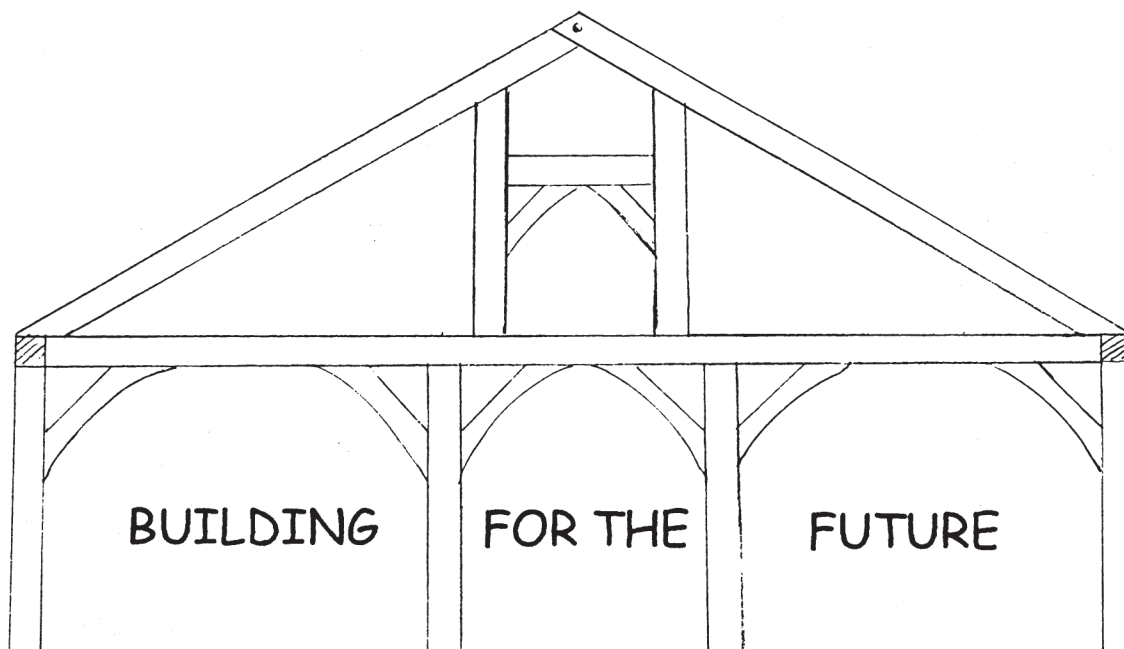


Clinic raising in 1990, photo by Jim Stansbury

Help us build for the future. We welcome donations to the clinic's building fund, the operating fund, or major gifts to the endowment fund.

As a charitable organization registered in Pennsylvania and a non-profit organization under IRS 501 (c)(3), all donations to the clinic are tax deductible. The Clinic also accepts gifts of stocks and trusts.

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



ABOUT THE CLINIC:

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

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

The Clinic for Special Children is a registered charitable organization. In accordance with Pennsylvania law, we are required to advise you 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.