CLINIC FOR SPECIAL CHILDREN NEWSLETTER

VOLUME I NUMBER 22 * LANCASTER COUNTY, PENNSYLVANIA * SUMMER 2005

CHILDREN ARE OUR TEACHERS

The children we care for have always been our teachers. Most of what we know about the treatment of a variety of genetic disorders has come from the sustained effort to provide medical care for children who come to us with problems. What these children teach us as we care for them is their gift to all of us – in Lancaster County, throughout Pennsylvania, and to children with similar problems in other places around the world. We are constantly challenged to come to a better understanding of the complex relationship between a gene mutation and the many medical problems that arise from the mutation. When the Clinic for Special Children was first founded 16 years ago our efforts were largely focused upon children in Lancaster County who had Glutaric Aciduria and Maple Syrup Disease. Our experiences in Lancaster County and our publications have made the Clinic an international resource for the diagnosis and treatment of these disorders. But, over 16 years, families brought children to us with many other difficult problems, and we have tried to learn to help them as well. Children with unexplained mental retardation, uncontrollable seizures, life threatening infections caused by immune deficiencies, dystonias, sudden loss of vision and hearing, malnourishment, kidney disease, and medical problems associated with Down syndrome, cartilage hair hypoplasia, and Ellis van Creveld syndrome.

Consider the Lilies

In this issue of the Newsletter we discuss new approaches to treating old disorders, and the discovery of new genetic syndromes. We describe publications and lectures that are part of our ongoing effort to educate physicians and help patients elsewhere. But, the most important question posed by this Newsletter is How can we sustain the work at the Clinic for Special Children for the next 5 years, 10 years, and beyond? Who will replace those of us who started the Clinic, and care for the next generation of special children? How can we interest other physicians to care for adults with genetic metabolic disorders? How can we use the remarkable new technologies of genetics and medicine to help our patients when business practices and public policies seem to offer these technologies only to those willing and able to pay a very high price? How can we maintain a high level of medical care for uninsured Plain families when the cost of medicines, hospitalizations, dental care, and essential surgeries increase much, much faster than the price of milk?

PLANNING FOR THE FUTURE

Over the past year we have been working on the Clinic's next five year plan. This plan is intended help us anticipate what we need for the Clinic to successfully continue its mission to care for children with various genetic disorders. We looked at staffing needs - Will we have enough staff to do the work as the work grows? What supplies or equipment will we need or have to replace in the next few years? We looked at funding needs - will there be enough support over the small income from the fees we charge to keep the Clinic operating and capable of finding better treatment for our patients ? What should we do to encourage other physicians and those still in school to develop their interest and increase their knowledge in taking care of children (and adults) who have extensive and complex medical needs? What else should we do as a pediatric specialized clinic to help families take care of their children? How can we help keep the cost down for families who are often faced with large hospital bills? We hope our strategic plan will provide a framework to help us work toward a sustainable future for the clinic to continue to serve the needs of children and families for years to come. The following describes four primary goals identified in our plan. (A full printed copy of our plan will be available in late summer.)

GOAL I. Provide at an affordable cost the most effective diagnosis and comprehensive care for children with biochemical disorders and other heritable conditions who seek help at the clinic. This first goal represents our major focus of providing comprehensive medical care for children. It identifies the need for another full time physician within five years as the demand for services increases; the need to seek collaborative relationships with other physicians and research centers to benefit our patients; to work effectively with other community resources to improve services for our patients; and to seek cost effective solutions to attaining the best care possible.

GOAL II. Expand the capability of the Clinic's laboratory to adapt and incorporate new technology that will serve the needs of the Clinic's patient population. Under this goal we will assess the need for additional laboratory staff to work with Dr. Puffenberger; determine new equipment that may be necessary as new diagnostic methods are developed, also the need for upgrades or replacement of existing equipment to maintain excellence in current laboratory performance.

GOAL III. Further develop the Clinic's capacity to stimulate research and to serve as a resource for education and training in clinical genetics. This goal is intended to guide the Clinic as we develop our potential to stimulate clinically oriented research based on the needs of patients and to expand clinical and biochemical genetics training opportunities at the Clinic; under this goal we will develop course material for teaching purposes, more fully develop our web site as a resource and establish a Medical Advisory Board with nationally known medical experts to advise the Clinic regarding research and training.

GOAL IV. Secure long term financial stability for the Clinic. This goal will help us develop a measure of financial security to insure that the clinic will function in its mission for years to come. We must increase donations by individuals and foundations to help support the clinic's services that are not covered by fees or proceeds from the benefit auctions. Approximately one third of our annual operating expenses need to be met through contributions. We also need to increase the Clinic's Endowment Fund which helps fund the clinic's research and educational projects as well as providing the clinic with the long term financial security it needs to insure its continued operation and success.

GIFTS FROM THE PAST

Our last five year plan helped us increase our staff to include another pediatrician, Dr. Strauss, our laboratory director, Dr. Puffenberger, and another very caring and capable nurse, Christine Hendrickson. Mim Echternach also joined the staff part-time to complement the office manager's work for full time coverage of the front desk. The previous plan also included the addition to the building which gives the clinic more room to function now and in the future and needed space for the *Special Hearts* Group that meets here three days a week. **We met all of our goals in the previous plans, thanks to the extraordinary support from so many through their generous gifts to the clinic and through the amazing growth over 15 years in community support from the auctions.** We hope this support continues to grow from the communities we serve and from so many who faithfully share their generous gifts with the Clinic. Our progress so far would not have been possible without this support. The dreams and goals for the Clinic for Special Children would never have been realized without the thoughtful, generous and faithful support from so many.

We hope the generous support that has made the Clinic's growth and success possible in the past will continue to help us realize our future plans. Contributions can be sent directly to:

The Clinic For Special Children
P.O. BOX 128
Strasburg, PA 17579

OUR SEASON OF SUPPORT

Sounds of summer include hearing of preparations for the benefit auctions for the clinic that take place in July and September. Sights of summer include the new quilts made with care, new furniture and crafts, new sheds, swing sets and wagons made ready for the sales. We look forward to these events for many reasons including food, fun, and fellowship. We remind ourselves also that the clinic is able to continue to do its work to care for children with genetic conditions due to the community's support through these auctions every year. The auctions keep our doors open to the families who need us and keep the cost of our medical services affordable, especially for those who do not have insurance. Every year for 14 years so far, the benefit auctions consistently provided about one-third of the funds needed to run the clinic. As the needs of the clinic grew, so did support from the auctions.

New families to the clinic may not realize that the fees we charge for our services are already discounted through the support we receive each year from the benefit auctions and through many other donations. We have not increased our fees of $35 for an office visit (usually one hour's time) and $70 for the new patient first visit, for about ten years. For the specialized services we provide, the complexity of our patient's needs and the time given during appointments, comparable services elsewhere often cost ten times these rates. The fee for an amino acid level is still $50 with results available usually the day we receive it. Elsewhere it costs patients several hundred dollars and results take more than one day. We are able to provide our services in this way in part because we run the clinic as efficiently as possible as a non-profit organization, but mostly because of the support we receive for the clinic through the auctions every year and through the donations of many individuals and foundations.

A SAMPLER FROM LAST YEAR'S EVENT

The rain from Hurricane Ivan dampened everything in sight but not the spirits of the faithful supporters who attended the auction last September in Lancaster. The crowd may have been less as the storm prevented many from attending, but everything sold by the end of the day, including a record number of 98 quilts, several priceless specially crafted turkey callers, and at least 18,000 donuts made under a flapping tent that day. We were very thankful for the invention of big rolls of plastic that kept everything dry through the night. Dr Morton's talk reflecting on how all of us have to cope with "rainy days" at some point in our lives was especially moving. We learned that even in the worst weather, the clinic has many faithful friends.

The auction in Shippensburg in July brought growth in support from that region of the state. Beautiful quilts, furniture, a spring wagon and landscaping plants were featured. On a hot summer day, the home made ice cream was especially enjoyed ....and quickly. At Morrison Cove in Blair County, support also increased as that auction brings many families together from the Amish community in Somerset County, families from Miffln, Centre and other central Pennsylvania counties to join those from the Blair County region. Families from all of these areas seek help for their children from the clinic. Several of the most recent diagnostic breakthroughs that provided new information on genetic conditions, and new possibilities of treatment involved children from these regions of Pennsylvania. Many families became aware of the clinic and sought help for their children through friends involved with the auctions in Blair and Shippensburg.

FOR THOSE WHO HELP.....

We are always amazed at the dedication and effort given by the volunteers who coordinate the auctions in each area and by the many volunteers who help, who make the quilts, the furniture, the wagons, the food. Not only do they bring essential support to the clinic each year, but their energy and commitment give the clinic staff, board members and most importantly, the patients' families a tremendous lift in spirit and determination.

We thank all who help and invite more to join in.

WHAT, WHERE AND WHEN FOR 2005

SHIPPENSBURG: Saturday, July 16TH This will be the 7th year for the auction in Shippensburg, PA, held at Leinbach's Produce Auction located one mile north of Shippensburg on Rt.#11. The auction committee reports there will be a new spring wagon in addition to quilts, furniture and much good food. Please call 717-532-9088 for information or about donating items for the sale.

BLAIR COUNTY: Saturday, September 10th Mennonite families in Blair County, PA, and Amish families in Somerset County look forward to the 9th annual benefit auction to support the Clinic. The event is held at Morrison Cove on Rt.36, six miles south of Roaring Spring, PA. This auction will also feature beautiful hand made furniture, quilts, farm equipment, plants, many other items and great food. The auction will begin at 9:00 am. Contact 814-793-3634, 814-793-3010 or 814-224-5442 for more information about the auction or to arrange donation of items for sale.

LANCASTER COUNTY: Saturday, September 17th Auction #15 for the Clinic will be held at the recently expanded Leola Produce Auction facility as always on the third Saturday in September. The event will begin at 8:30 am, quilts and large furniture will start selling after brief remarks by Dr. Morton and Dr. Strauss around 11:00 am. Lawn furniture and gift certificates will be sold at 1:00 and everything else in between and all day. Chicken barbecue, subs, pork roast, ice cream, fresh lemonade, soft pretzels, pizza, donuts and baked goods all will be available during the day. There will be new sheds, beautifully made furniture, and many lovely hand made quilts. If you have items you wish to donate, please call one of the following: (717) 626-4863; (717) 354-5415; (717) 656-9694. The Leola Produce Auction is located on Brethren Church Road, north off Rt. #23 in Leola (between Lancaster and New Holland).

Bargello Quilt in blue and yellow made for this year's auction

PLEASE JOIN US FOR ONE, TWO, OR ALL THREE AUCTIONS THIS YEAR. WE NEED YOUR SUPPORT.

MORE HELP COMES OUR WAY .....In addition to the three auctions in Pennsylvania last summer there was a fourth auction for the Clinic for Special Children in July, 2004, in Shiloh, Ohio, where we keep in touch with several families. It was a wonderful surprise to receive support from this community and we are very grateful for their help.

ALSO... The Hammer Family Fun Day was held on June 1st to support the clinic's work with children with Maple Syrup Disease. This is the second year the family sponsored the event near their home in Springfield, NJ. Thank you to the Hammer family and their many friends.

GIFT OF FRIENDSHIP

Noted photographer, Bill Coleman, recently published a collection of his photos in a book titled ***The Gift of Friendship.*** The book is dedicated to the Amish families and to the Clinic for Special Children. We thank Bill Coleman for his many gifts of support to the clinic over the years and for his help to families in his area. Published by Ronnie Sellers Productions in Portland, Maine, the book can be found in bookstores or on Amazon.

MRI PROJECT PROVIDES INSIGHT

Detection, treatment, and prevention of central nervous system disease is a major focus of the work at the Clinic for Special Children. We rely on computed tomography (CT) and magnetic resonance imaging (MRI) to learn about how specific disorders affect the structure and function of the developing nervous system. Recent developments in computer software allow a standard MRI scanner to produce *functional* information about the brain, including its water distribution, chemical composition, blood flow, and energy use. The ability to view these patterns deepens our understanding of metabolic brain diseases and improves our ability to prevent neurological disability.

In the spring of 2005, thanks to a gracious donation from the A.J. Stamps Foundation in Philadelphia, we were able to purchase a new computer workstation at the clinic dedicated to functional analyses of CT and MR images. As part of the foundation grant we hired a consultant, Dr. Jelena Lazovic, recently awarded her doctorate in MRI physics from Hershey Medical Center. Dr. Lazovic did an exceptional job developing and implementing the analytical methods. The new workstation will be a powerful and useful research tool for many years to come. It will undoubtedly help us reveal new and important concepts about the effects of metabolic derangements on the young brain.

LIVER TRANSPLANT AS TREATMENT FOR MAPLE SYRUP DISEASE

In June a meeting at the Children's Hospital of Pittsburgh Starzl Transplant Institute reviewed the protocol and preliminary results of 6 cases of liver traansplant in Maple Syrup Disease patients performed at the hospital. The management protocol for MSD and the liver transplants were the result of a two year collaboration between the Clinic for Special Children and the Starzl Institute. Dr. George Mazariegos of the Starzl Institute presented the results of the 6 cases. Metabolic cure was apparent in all cases as an immediate and sustained increase in dietary leucine tolerance progressed to unrestricted protein diets. In addition to biochemical stabilization, all patients have shown unanticipated neurological benefits of stabilized plasma amino acid concentrations. Decreased hyperactive behavior, better attention span, improvements in gross and fine motor skills have been observed. Formal studies are in progress to document and explain these effects of liver transplants. It appears liver transplant provides adequate control of Maple Syrup Disease to allow a normal diet and prevents systemic metabolic intoxication and cerebral edema during illnesses. The stabilization of blood amino acid concentrations is associated with significant improvements in brain function. We do not recommend liver transplant for all patients with MSD. Risks, benefits and costs must be assessed on a case-by -case basis and measured with access to specialized treatment. For some patients with out access to appropriate care, transplant is a reasonable, cost effective treatment.

LABORATORY RESEARCH UPDATE

As outlined in the last newsletter, our collaborations with Translational Genomics Research Institute and Affymetrix continue. This research allows us to localize and identify disease mutations in groups of similarly affected children. We previously reported that Affymetrix, Inc., had donated 100 DNA microchip arrays to the clinic. These arrays were used to map and identify the gene for Swarey syndrome (i.e. sudden infant death with dysgenesis of the testes). Due to the success of these first studies, we have continued the effort to identify the genes for several other disorders seen in clinic patients. As you may recall from previous newsletters, these DNA arrays provide genotype information used in mapping (or localizing) disease genes to specific chromosomal regions. Once the disease gene is localized, we can search through the list of genes found in that same chromosomal region for an appropriate candidate gene to sequence. The arrays require special (and expensive) instrumentation and training. We are collaborating with the Translational Genomics Research Institute (TGen) in Phoenix, AZ, to genotype our patient samples using the DNA arrays. Once genotypes are generated, we analyze the data provided by TGen to locate the position of the disease gene in the human genome. Previously, we mentioned preliminary data localizing the genes for three different disorders found in clinic patients.

One of those disorders, a form of temporal lobe epilepsy and mental retardation which we now call CDFE (cortical dsyplasia and focal epilepsy), has been localized to a small region on chromosome 7q36. We used four Amish patients, all closely related to one another, to pinpoint the gene to this location. The DNA arrays indicated that the genotypes of all four patients were identical in this region. This indicated that they inherited this part of chromosome 7 from a common ancestor and that the disease gene would be in this small interval.

We generated a gene list for this small, shared interval. Two genes, CENTG3 and CNTNAP2, were chosen for sequence analysis based on their expression patterns in the body and their putative functions. We found no mutations in CENTG3 in the patients, but we did identify a homozygous single base pair deletion in CNTNAP2 in all four patients. This is a severe mutation causing complete loss of function of the CNTNAP2 gene. The gene encodes a protein called Caspr2 which is thought to be important for proper localization and function of potassium channels in the brain. Mutations in potassium channels have been associated previously with epilepsy in both the laboratory mouse and humans.

The identification of the mutation causing CDFE has allowed us to screen all our seizure patients for this disorder. This identified six additional children who had this particular condition. Interestingly, we found patients in both the Mifflin and Juniata County Amish as well as the Lancaster County Amish. This suggests that a common ancestor carried the mutation into both populations sometime in the past several hundred years. The CDFE study results have been described in two research papers which we have submitted for publication in a scientific journal.

The gene for a second disorder, for which we presented preliminary mapping information in the last newsletter, was also identified in the past year. This condition involved developmental delay associated with congenital/progressive hypomyelination in the brain. Initial mapping suggested the gene resided on chromosome 6. Further work demonstrated conclusively that this disorder, found in two Mennonite second cousins from Maryland, was a previously identified condition known as Salla disease. This disorder was first described in patients from Finland and it is a mild form of sialic acid storage disorder. Surprisingly, the two Mennonite children we identified with this condition had the same mutation as the Finnish patients. This suggests that the mutation is quite old and is probably found in many European populations. The results of this work will be published in a forthcoming issue of the American Journal of Medical Genetics.

We are currently working on over a dozen separate mapping projects. Most notably, we recently mapped and identified the mutation causing a disorder known locally as "Pretzel" syndrome. Using seven different families, each with at least one affected child, we mapped the disease gene to chromosome 7 and subsequently identified a large deletion in a gene that encodes a protein kinase. Further laboratory studies are in progress and we hope to describe these findings in a scientific journal in the next few months. Erik G. Puffenberger, PhD

WORK IN PROGRESS

Papers recently submitted to journals by Dr. Strauss, Dr. Morton and Dr. Puffenberger from the Clinic:

1) Management of chronic non-hemolytic hyperbilirubinemia and prevention of kernicterus: Observations about Crigler-Najjar syndrome. This papers summarizes a 16 year experience at the Clinic managing the disorder of bilirubin metabolism called Crigler-Najjar disease. We present detailed case studies and discussions related to care of the jaundiced newborn, molecular testing, chronic phototherapy, mechanisms of brain injury, and provide and updated table of medications that are unsafe and safe in the jaundiced patient.

2) Genome-Wide SNP Arrays as Rapid and Inexpensive Diagnostic Tools: Mapping and Molecular Characterization of Salla Disease in Two Old Order Mennonite Patients. Each year in Pennsylvania between 1-3% if all children, 1,500-4,500 per year, will have problems of development that lead them to see pediatricians, neurologists, or geneticists. The complaints include weakness, low tone, slow to sit-up or walk, slow to talk, clumsiness etc. Expanded Newborn Screening provides an answer for 25-50 of these children, but for the vast majority Screening, Genetic and Neurological Testing provides not insight. The index case reported in this paper had been to three medical centers and had had more than $18,000 in testing done, and no answers. This paper describes a new, rapid, inexpensive approach to searching the cause of such disorders in our patients.

3) The natural history of cortical dysplasia and focal epilepsy syndrome (CDFE) caused by a mutation of contactin associated protein-like 2 (Caspr2) This paper describes the cause of a new, inherited form of seizures and mental retardation. Patients with the disorder have been cared for at the Clinic for many years. Past studies had failed uncover the underlying cause. It is now apparent that the cause of this from of temporal lobe seizures could have only been found using SNP techniques. We expect that other mutations in Caspr2 complex will cause similar seizure disorders throughout the world.

RECENT LECTURES:

Translating Genetic Testing into Genetic Medicine: A Pediatrician's Perspective presented By Dr. Morton at the Alabama Newborn Screening Conference in June, 2005.

Genes, Biology and Disease: New Perspectives on Old Problems, presented by Dr. Morton as the keynote address for the Annual Meeting of Commonwealth of Pennsylvania University Biologists (CPUB), April, 2005.

Genetics in Primary Care, presented by Dr. Morton, Dr. Strauss and Dr. Puffenberger for the Family Practice Review Course sponsored by Temple University and Lancaster General Hospital, Spring, 2005.

Molecular Genetics in Clinical Practice, presented by Erik Puffenberger, PhD. at the New York Academy of Sciences, Winter, 2005

Genetics and physiology: lessons from a rural clinic, presented by Dr. Strauss at the University of Wisconsin Medical Center, Madison WI, Pediatric Grand Rounds

Integrating advances in newborn screening into the care of high-risk populations, presented by Dr. Strauss at the Waisman Genetics Center, Madison, WI, Lecture to Genetics Dept. and members of State Health Dept. NB screening Lab/Advisory Board, Winter 2004

Translational physiology in the medical clinic.presented by Dr. Strauss at Penn State College of Medicine, Hershey PA, Departments of Neuroscience and Neurosurgery, Spring 2005:

DOWN SYNDROME STUDY

Down syndrome is a well-known genetic disorder caused by the presence of an extra copy of chromosome number 21 in all cells of the body. With a birthrate in all populations of slightly more than 1 in 1000 births, Down syndrome is the most common genetic cause of developmental disability in all countries and more prevalent than all but a few of the most common Amish and Mennonite genetic disorders that we see at the Clinic for Special Children. Although the Clinic was first established as a center for the care and study of metabolic disorders (genetic diseases of the body's chemistry) the generosity of the community has enabled the Clinic in recent years to care for other non-metabolic genetic disorders, including an increasing number of children with Down syndrome.

Recently, a genetic colleague from the Netherlands, Dr. Raoul Hennekam, recommended that one of his medical students, Sonja van Hattem, spend a 4-month research traineeship with us to study a genetic disorder of mutual interest. In view of the Clinic's increasing number of patients with Down syndrome, and recognizing that the needs Down syndrome children in the plain communities might be different than in Philadelphia or Amsterdam, Sonja decided to undertake a comprehensive survey of the healthcare and educational experiences of Amish and Mennonite Down syndrome children and adults in Lancaster County. After spending two weeks in Baltimore at the Down Syndrome Clinic of Kennedy Krieger Institute, learning about up-to-date medical care for Down syndrome, Sonja came to Strasburg and began her work by contacting all of the Down syndrome families currently listed with the Clinic. By asking those families to contact other Down syndrome parents in the county, Sonja eventually had a list of 36 families with a Down syndrome child or adult who were willing to be visited in their homes. Sonja also developed a comprehensive heath and education questionnaire to be completed by the participating families. During April and May, we met with each of the 36 families and learned about their experiences raising a child with Down syndrome. We also visited two Amish "special schools" to speak with the teachers and observe how they taught their Down syndrome students.

Although persons with Down syndrome can have any medical problem that anyone without Down syndrome can have, physicians recognize that individuals with Down syndrome have a higher than average risk for certain disorders, such as congenital heart disease, hypothyroidism (low thyroid), impaired vision and hearing, and immune system problems. Children with Down syndrome also have slow intellectual development and require various therapies during infancy and special education throughout their school years. We were especially interested in learning 1) how well physicians and other specialists had educated families about the specials needs of persons with Down syndrome, 2) how well the families had been able to meet these needs, and 3) in what ways the Clinic could work in the future to assure that all Amish and Mennonite children with Down syndrome get the best care possible.

After almost three months working in the county, visiting families from Narvon to Kirkwood, Sonja's work was done. Overall, we were pleased to see how healthy and happy most of the Down syndrome children were, and how well many had done in school, certainly as well as Down syndrome children from other communities. However, we also found that most children had not had the regular healthcare screening recommended for Down syndrome, often because their parents were not aware of these needs, but also because of limited access to or high cost of the special services. In addition, whereas some of the highest achieving Down syndrome students were natural students and excelled in the Amish Special schools, others seemed to have lost the good head start they had been given in the first three years by the "infant stimulation" programs at the S. June Smith and Schreiber Centers.

Sonja van Hattem with Dr. Richard Kelley at the Clinic

Sonja's studies revealed that the greatest obstacle to good medical care for Amish and Mennonite Down syndrome individuals was the incomplete education of most parents about Down syndrome, and that much if not most of that obstacle was a healthcare system that failed to provide adequate parental education when the diagnosis of Down syndrome was first made. In addition to developing special written materials on Down syndrome, the Clinic plans to work with other experts and agencies in the county to assure that there are effective ways that parents can be informed about the special medical and educational needs of Down syndrome. We also plan to assemble a top-quality Down syndrome resource center, with many books and other materials to lend parents, and to develop a teacher training program for the Amish special schools, perhaps as soon as the coming school year. We wish Sonja the best for her continued medical studies, and we hope that she will return in the future to visit again with the many Down syndrome friends she has made.

THE CLINIC FOR SPECIAL CHILDREN
PO BOX 128
STRASBURG, PENNSYLVANIA 17579

2005 ANNUAL BENEFIT AUCTIONS

Quilts ~ Furniture ~ Crafts ~
Baked Goods~ Barbecue

SHIPPENSBURG, PA ~ JULY 16

BLAIR COUNTY, PA ~ SEPTEMBER 10

LANCASTER COUNTY, PA ~ SEPTEMBER 17

The Clinic for Special Children is a private, non-profit medical service for children with genetic disorders established to provide comprehensive pediatric medical care, diagnostic and laboratory services to children of Old Order Amish, Mennonite and other families who suffer from heritable diseases. The Clinic seeks to improve the lives of children through more effective treatment and diagnostic methods, to further clinical research and develop educational resources to bring about better treatment and outcomes for children with genetic conditions.

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

WEB SITE: www.clinicforspecialchildren.org

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.