



# Clinic for Special Children

## NEWSLETTER

VOLUME I NUMBER 37

\* LANCASTER COUNTY, PENNSYLVANIA \*

SPRING 2015

*As the Clinic for Special Children begins its 26th year we continue to focus on planning for the future. Leadership of the organization is progressing with the Board's guidance from the founders, Holmes and Caroline Morton, to a team of key staff members who will continue the vision of the Clinic. We now serve patients with over 150 different genetic disorders. Many children require specialized care for specific problems that go beyond the services offered by CSC. In order to better serve our patients we have developed partnerships with institutions and specialists who can work with us to provide access to the services needed. This issue of the Newsletter acknowledges our collaborative partners and describes the benefits they provide for our patients.*

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### 2015 Benefit Auctions

June 6, Union County, PA

June 27, Shippensburg, PA

July 11, Shiloh, Ohio

September 12, Blair County, PA

September 19, Lancaster County, PA

*Quilts, sporting goods, furniture, sewing equipment, wood crafts, handmade toys and landscaping plants will be available for buyers at each of the auctions. A wide choice of food including chicken barbecue, freshly made pies, donuts, whoopee pies in various flavors, ice cream and many other delicious treats will be featured. Breakfast is available starting early and most of the auctions open at 8:30 am. Remarks by Dr. Morton, Dr. Strauss and Dr. Williams are scheduled around 11:00am with special items, quilts and furniture sales immediately following remarks. We are very grateful to the families and many other volunteers for their time and effort to organize each of these auctions to benefit the Clinic for Special Children. This support is very much appreciated.*

### PLEASE JOIN US

June 6, Union County, PA

Buffalo Valley Produce Auction, 22 Violet Road, Mifflinburg

June 27, Shippensburg, PA

Leinbach's Auction, Rt.#11, Shippensburg, PA

July 11, Shiloh, OH

Blooming Grove Produce Auction, Free Rd. This auction supports the Clinic for Special Children and the Das Deutsch Center in Middlefield, OH.

September 12, Blair County, PA

Morrison's Cove Produce Auction, Rt. #36 South of Roaring Spring, PA. This auction supports CSC and the new Central Pennsylvania Clinic for Special Needs (CPAC).

September 19, Lancaster County, PA

Leola Produce Auction, Brethren Church Road (north off of Rt.# 23), Leola, PA

\*This will be the 25th Annual Benefit Auction held in Lancaster County for the Clinic for Special Children!

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We need your support!



## CPAC AUCTION

May 30th is the 2nd Annual Benefit Auction for the Central Pennsylvania Clinic for Special Needs (CPAC) in Belleville, Pa at the Belleville Auction grounds.



The Central Pennsylvania Clinic (CPAC) operates as a separate organization from CSC with its own funding, staff and volunteer board of directors. Support for the new clinic which will serve children and adults in the central Pennsylvania region has been growing. Last year the first auction was very successful and completed the \$400 K matching challenge from the University of Pittsburgh Medical Center (UPMC). The CPAC board has hired a nurse and hopes to hire other core staff including a physician in the next few months. Services for children are available through the CSC Outreach Clinic with Dr. Morton at the existing CPAC site in Belleville until plans for a full staff and new building can be developed.

*Looking ahead to 2016 ~~~~~  
We are planning ahead to let everyone know  
that the Annual Benefit Auction held in  
Lancaster County at the Leola Produce  
Auction will shift dates in 2016 from the  
third Saturday in September to the third  
Saturday in June!!!!!!*

## OUTREACH & RESEARCH

### Interest Growing in Kentucky

In April **Dr. Morton** met with families, community leaders and midwives in Kentucky and also with physicians at Vanderbilt University to explore the idea of a regional clinic to serve children from Plain communities with special needs. Many families from the Plain communities in Kentucky look to CSC to help care for their children with metabolic disorders and other inherited conditions. CSC has referred patients requiring immediate acute care to the medical center at Vanderbilt which is in proximity to families living in southwestern Kentucky. We will continue to encourage and support further considerations regarding accessible services for special needs families in Kentucky.

## Outreach Clinics

CSC continues to schedule outreach clinic days to see patients in **Somerset County** every three months and in **Belleville** once a month. Each will be attended by Dr. Strauss (Somerset) and Dr. Morton (Belleville) with CSC nurse, Christine Hendrickson. The following is the tentative schedule for the next few months. Appointments are made by contacting Christine at the CSC office: 717-687-9407.

### Belleville Clinic Days:

**June 17 & 18**  
**July 22 & 23**  
**August 19 & 20**  
**September 23 & 24**  
**October 21 & 22**  
**November 18 & 19**  
**December 16**

### Somerset Clinic Days:

**August 3 & 4**  
**October 26 & 27**

We hope these outreach services help families who live far from the Clinic in Strasburg and also serve to promote the concept of the need for more permanent local clinics that address the complex care of children with special needs due to genetic conditions. With CSC's commitment to make care for children with special needs more effective and affordable, the outreach services will continue until local clinics and services can be developed.

## Research and Family Days

May 15: EVC Day ( Ellis Van Creveld Syndrome)

June 19: CHH Day ( Cartilage -Hair Hypoplasia)

June 26: CAH Day (Congenital Adrenal Hyperplasia)

July 9 & 10: Translational Medicine and Plain Populations at F & M

July 14: Transplant Day

August 18: Cochlear Implant and Hearing Loss Day

September 16: NIH Annual Visit

November 12: Midwife Conference

## TRANSLATIONAL MEDICINE & THE PLAIN POPULATIONS CONFERENCE #3

July 9-10, 2015  
Franklin & Marshall College Lancaster, PA

In 2013 the Clinic and F & M College sponsored the first conference to bring together those who are engaged in clinical services and research of genetic conditions in plain populations in North America. The idea of the conference was to share

progress in research, clinical insights, and promote communication among the various clinics and medical centers. In 2014 the second conference was coordinated by the Das Deutsch Center in Middlefield, OH with sponsorships from Case Western Reserve Medical Center and UPMC's Center for Rare Disease Therapy. The Clinic is pleased to keep the ball rolling and is coordinating the third conference with generous support from F & M College. The conference will be held at F & M on July 9th and 10th. Following are some of the topics and speakers with a complete list available soon along with registration materials on our web site:

- \*Transitional Clinical Services and Family Practice -  
Stephen D. Ratcliffe, MD, MSPH, LGH
- \*Translational Research at an Undergraduate Institution -  
Robert N. Jinks, PhD, F & M
- \*Glimpses Into the Genetics of Mental Illness -  
Sander Markx, MD, Columbia
- \*Ethics and Therapeutic Non-Compliance - Olivia Wenger, MD
- \*Genetic Disorders in the Plain Communities of Ohio -  
Heng Weng, MD, PhD, DDC
- \*Developing an Effective Cross-Cultural Board -  
Herman Bontrager, CSC
- \*Models for Community Focused Rural Health Centers -  
D. Holmes Morton, MD, CSC
- \*Genomic Medicine and Subspecialty Services -  
Kevin A. Strauss, MD, CSC & Robert O'Reilly, MD, Nemours duPont
- \*Therapeutic Tissue Transplant -  
George Mazariegos, MD & Kyle Soltys, MD, UPMC
- \*Pulse-ox Screening in Midwifery Services -  
Katie B. Williams MD, PhD, CSC
- \*The Management of Genetically High Risk Cardiac Patients -  
Devyani Chowdhury, MD, CSC
- \*MELAS Syndrome in Plain Populations -  
Gerald Vockley, MD, PhD
- \*Organizing and Analyzing Clinical Exome Data -  
Erik Puffenberger, PhD & Karlla W. Brigatti, MS, CSC & Claudia G. Gonzaga- Jauregui, PhD



POSTAGE STAMP QUILT

## COLLABORATIONS

An element of our current five year plan was to develop affordable and accessible ways to address the complicated needs of our patients. The following articles describe some examples of our collaborative efforts.

### COCHLEAR IMPLANTS: THE VALUE OF COLLABORATION

Kevin A. Strauss, M.D.

Cochlear implants (CI) have transformed the management of deafness in children. According to the Food and Drug Administration (FDA), as of December 2012, approximately 324,200 people worldwide have received implants, including 38,000 children in the United States. Cochlear implants are a powerful tool for helping children gain the ability to hear and develop communication skills equal to those of children born with normal hearing.

Although overwhelming evidence shows the benefits of CI, this therapy imposes daunting financial and logistical challenges. The high costs of CI put it out of reach for many children, reflected in the fact that only half of all CI candidates in the United States receive them. The most important barriers to CI in the Amish and Mennonite populations served by the CSC include limited use of home technology (e.g. electricity, telephones), poor access to specialized CI centers, and lack of health insurance. As a consequence, the use of CI therapy among Plain communities was exceedingly rare prior to 2013.

To address these challenges, we turned to our team of collaborators at the **Nemours Alfred I. duPont Hospital for Children**. Led by **Dr. Robert O'Reilly**, the Nemours audiology team provides hearing and language services at the CSC every month and is committed to giving deaf children access to the best therapies possible. To this end, Dr. O'Reilly and his team of specialists designed a streamlined approach to diagnosing hearing loss at the CSC, inserted CI devices at a fraction of their normal cost, and taught families how to do postoperative language rehabilitation at home.

Working with local audiologists in Pennsylvania, Ohio, Kentucky, and elsewhere, the Nemours team was able to restore hearing to 11 deaf children over the last 2 years. The average age at implantation was 2.1 years; 73% of these children had a molecular cause of hearing loss confirmed by the CSC lab. The combination of streamlined genetic testing, home-based language rehabilitation training, and discounted hospital services reduced the cost of CI by \$132,483 to \$136,233 per child, representing a total cost savings of 1.5 million dollars.

We are grateful to Dr. O'Reilly and his team for their dedication to the CSC mission and the families we serve, and hope their example will clear a path to CI therapy for many other children.

### Other Collaborations

**LGH** - Family Practice Residents at **Lancaster General Hospital** will begin a new training rotation in genetics at the Clinic for Special Children. Clinic medical staff are also collaborating with LGH medical staff in caring for adult age patients with genetic conditions when hospitalization is required.



**NIH** - Each year two Genetics Fellows from the **National Institutes of Health** will spend a month of their fellowship at the Clinic working on specific research projects or clinical case studies.

## **REGENERON PHARMACEUTICALS COLLABORATION**

Erik Puffenberger, PhD, Karlla Brigatti

A “genetic diagnosis” informs us about the specific gene that is involved in disease, and can allow us to design therapies and treatments to improve health. We know the specific genetic cause for many medical conditions in the children who come to the clinic. Unfortunately, for nearly half of our patients, we do not know the specific gene that causes the patient’s troubles.

In cases where the causative gene is not readily apparent after examination of the child, we can consider a test called “whole exome sequencing” or WES. Unlike targeted gene testing which identifies changes in a single gene that causes disease, WES examines essentially all the coding regions of our estimated 19,000 genes (known as the exome) for variants that might cause disease. We often call this testing a “family exome study” because we compare the DNA variants in the patient with the variants in close relatives such as parents and siblings. Every individual has thousands of genetic variants that have been inherited from our parents. Are the changes unique to the patient or inherited from one or both parents? This comparison allows us to sort through the large number of variants to determine which specific change is likely causing disease. Through this breakthrough in testing, we are now able to find a specific genetic diagnosis in more patients than ever and even identify new genetic disorders (that is, diseases that have not been described previously in the medical literature).

WES is fairly new and costs several thousand dollars when performed through a commercial laboratory. This testing was cost-prohibitive for families at the clinic until the fall of 2014, when the clinic entered into a research agreement with the **Regeneron Genetics Center**, a laboratory at **Regeneron Pharmaceuticals** in Tarrytown, NY. This alliance permits access to free WES for clinic patients as well as operating support for the clinic to sustain the collaboration. The first 24 family exome studies have been submitted, and the WES data has been returned to the clinic. Laboratory Director Dr. Erik Puffenberger is busy with the analysis of the genetic data, laboratory technician Mindy Kuebler works to confirm the findings, and genetic counselor Karlla Brigatti works with the lab and medical teams to get these results back to the families. Both Mindy and Karlla were hired through funds provided by Regeneron to support the WES collaborative study.

Through this project, we have begun to identify a definitive diagnosis in many patients who have been waiting for a genetic diagnosis. In several cases, the conditions are new to medical science, and we will work with Regeneron to publish our findings so that others can benefit from our research. By identifying the root genetic cause of disease, we can tailor medical management or consider new therapies to help our patients. We

anticipate that the next three years will be fruitful ones. Ultimately, this project may finally provide families the answer to the troubling question of “*What is wrong with my child?*”

## **SUB SPECIALTY SERVICES NOW AT CSC**

The following sub specialty services or referrals are available for CSC patients:

### **Cardiology Care for Children:**

Dr. Devyani Chowdhury, Cardiology

### **Akron Children’s Hospital:**

Dr. Dennis Weiner, Orthopedics

### **Nemours/A.I. duPont:**

Dr. Robert O’Reilly, Ear, Nose, and Throat

Dr. Thierry Morlet, Audiology

Dr. Jonathan Salvin, Ophthalmology

Dr. William Mackenzie, Orthopedics

Dr. Freeman Miller, Cerebral Palsy

Denise Peischl, Wheelchairs and Mobility

Dr. Joshua Zaritsky, Nephrology

Dr. Aaron Chidekel, Pulmonology

### **Penn Medicine:**

Dr. Gordon Baltuch, Neurosurgery

### **Pittsburgh Children’s Hospital:**

Dr. George Mazareigos, Liver Transplantation

Dr. Kyle Soltys, Liver Transplantation

Dr. Rakesh Sindhi, Liver Transplantation

### **Penn State Hershey Children’s Hospital:**

Dr. Peter Lee, Endocrinology

## **“Wishlist” for 2016**

In addition to the sub specialty services listed above, CSC staff have recognized the need for other specialized services that will address the needs of our patients. Collaborative services we hope to engage in the coming months include:

### **Nemours/A.I. duPont:**

- Immunology/Oncology/Hematology

- Neuropsychology and Educational Assessments

### **Philhaven:**

- Child Psychiatry and Behavioral Medicine

## **Wellness Screening for Babies Born Out of Hospital**

Dr. Katie Williams

Newborn pulse oximetry is a simple and noninvasive tool used to measure blood oxygen levels in newborn babies. Low oxygen levels can be a sign of structural heart defects or serious illness in the baby. Abnormal oxygen levels are usually detectable before the baby shows any signs of illness or stress. Pulse oximetry is a screening tool routinely used in hospital nurseries, but many infants born at home or a birthing center do not have access to this life-saving tool. Approximately 4,500 infants are born out of hospital each year in Pennsylvania, including many patients served by the Clinic for Special Children.

For the past year, **Dr. Chowdhury and Dr. Williams** have been working with midwives throughout the state to initiate a newborn pulse oximetry screening program for babies who are delivered at a birthing center or at home. Generous donations from **Abby's Foundation, the Hershey Rotary, and the Ronald McDonald House** have allowed us to purchase high-quality pulse oximeters for this program. Over the next several months, Dr. Chowdhury and Dr. Williams will provide training workshops for midwives throughout the state to improve understanding of newborn pulse oximetry and provide training on how to use the meters. We hope this "wellness screen" will help to ensure that every baby has a healthy start!

We are grateful for the support received from Abby's Foundation, Hershey Rotary, and the Ronald McDonald House that make this program possible.

## 2014-2015 RESEARCH FELLOWS

### AVERY FELLOWSHIP

*The Clinic for Special Children created a one year fellowship to honor the legacy of Dr. Mary Ellen Avery. Dr. Avery who died in December, 2011, was Physician-in-Chief at Children's Hospital, Boston, and visited the clinic several times. She was one of Dr. Morton's most highly respected teachers.*

**Aarti Rao**, the current, 2014-2015 Avery Fellow, will conclude her fellowship in June as she prepares to enter medical school later in the summer. Aarti came to the Clinic last summer from Swarthmore College with a Bachelor's of Arts in Honors Sociology, Anthropology, and Biology. Aarti's interest in public health research grew from her experience in fifteen villages of Chura, Rajasthan in northern India. Aarti assessed the utilization of maternal and newborn health services, then developed and distributed "Emergency Birth Plans" for women in villages with high rates of infant mortality. The following essay by Aarti describes her fellowship year at the Clinic for Special Children and the impact it has had on her plans and thoughts for her future.



From Aarti Rao....

*Last summer, I packed my life into my Toyota Prius and journeyed 2,650 miles from the traffic-ridden city of Los Angeles to begin my year as the Clinic for Special Children's 2014-2015 Avery Fellow. As a newcomer to Lancaster County, I welcomed the expanses of lush farmland, seemingly endless supply of whoopie pies, and comforting "clickety-clock" of horse and buggy carriages. My interest in working at the Clinic stemmed from my research in the Churu District of Rajasthan, in northern India. Surrounded by Rajasthan's barren desert lands – where temperatures regularly reach 115 degrees Fahrenheit –*

*Churu's farming communities struggle; their general health indicators, literacy rates, and life expectancy are worse than the national average. I spent two consecutive summers collecting written survey data and interviewing village women to study the utilization of maternal and newborn health services. By documenting women's narratives, I learned about how the insidious reach of historically-rooted caste discrimination and the unpredictability of a farming income bar many women from accessing adequate maternal health services.*

*My experience working with an isolated population in Churu showed me how overlooked communities can fall through the cracks. When I learned about the Avery Fellowship during my senior year, I knew that it would be a rare chance to work with an isolated population again—but far closer to home. During my fellowship year, I conducted a broad, public health assessment of the Clinic's patient population, and interviewed patients as part of an ongoing study examining the genetic basis of depression. From analyzing hundreds of survey responses, to training alongside 4<sup>th</sup> year psychiatry residents at Columbia University, this year has been an invaluable, whirlwind of an experience.*

*Working along with Clinic staff and members of the Plain population, I developed a survey aimed to assess the overall health needs of the Clinic's patient population. The survey covered a range of topics, including: standards of postnatal care, awareness about genetic testing, access to general health services, and the financial burden of healthcare costs. As I inputted countless check-marked responses into a spreadsheet, answers to closed ended "yes or no" questions slowly came together, allowing me to understand how financial burdens, location, and personal beliefs can influence an individual family's health. Although Churu's farming community drastically differs from the Plain Population, many practices and barriers, such as midwifery and the lack of affordable transportation, remain common. These similarities suggest that certain trends within rural healthcare extend beyond global and cultural boundaries.*

*In addition to deepening my interest in understanding the social determinants of health, my research in Churu also motivated my current study of mental illness. While the survey data enabled me to quantify maternal health seeking behavior, interviewing women about the intimacies of their birthing experiences introduced me to the debilitating effects of depression. Although I had never formally studied psychology at Swarthmore, Dr. Strauss encouraged me to pursue this budding interest. During my first month at the Clinic, I joined an ongoing collaboration with the Columbia Psychiatry Department. Through a combination of exome sequencing (sequencing the subset of DNA that codes proteins) and psychiatric assessments of a single extended family, our project team hopes to identify genetic variants that are associated with mental illness. Given that an estimated 26% of U.S. adults suffer from an episode of mental illness every year, we hope that the application of genetics will eventually allow physicians to implement a preventative approach by identifying individuals who are predisposed to psychiatric disease.*

*In preparation for this study, I spent a few months training at Columbia University under the guidance of Dr. Sander Markx. I learned to perform psychiatric assessments using a structured clinical tool named the SCID (Structured Clinical Interview for DSM). As with many structured questionnaires, the SCID can be memorized and administered robotically. The challenge lies in tailoring the questions to an individual's unique experience – in asking the unscripted and probing the unsaid. I began my*



*training by observing psychiatry residents interview patients. Intimidated by their medical degrees and years of clinical practice, I watched silently, constantly wracking my brain to keep up with confusingly similar yet distinct terms, from “schizophrenic” to “schizoaffective” and “schizophreniform.” After repeatedly interviewing Dr. Markx – who reenacted various unforgettable patient personas – and then independently interviewing patients at Columbia, I headed back to Lancaster County. Armed with multiple copies of the SCID, I drove to our subjects’ homes, thankful for the opportunity to enter their lives and listen to their stories.*

*Overall, this year has given me insights into the dynamic layers of healthcare; the importance of understanding the influence of socioeconomic and cultural factors on health, as well as valuing the intricate details of an individual’s story. After I complete my fellowship, I will be headed to the Icahn School of Medicine at Mount Sinai. While I am still unsure of what I will specialize in, my Avery Fellowship has undoubtedly influenced how I hope to practice medicine. I hope to carry on Dr. Avery’s legacy of the physician as a social advocate. More broadly, I hope to continue pursuing the Clinic’s unique mission by working hard to prioritize the health needs of underserved populations that must overcome psychosocial, geographical, and economic barriers to access medical care.*

*We congratulate Aarti and wish her all the best in medical school.*

The 2015-2016 Avery Fellow is **Kendra Poirier**, a recent graduate of Franklin & Marshall College with a major in



Public Health and Biology and a minor in German. She was a varsity swimmer at F & M and also played rugby. Kendra volunteered in Dr. Jinks’ research lab at F&M during her junior year. She also worked at Women and Babies Hospital at Lancaster General

Health within the Performance Improvement Department and spent time in the neonatal intensive care unit. She was also a student intern at the Hershey Medical Center in the biochemistry department. Kendra is from Hilltown, PA and will begin her fellowship at CSC in late summer.

*We are grateful for the many individuals and private foundations who have supported the Avery Fellowship. If you are interested in learning how you can support this program, please contact Matt Sware at 717.687.9407.*

**Thank you**

## SUMMER RESEARCH STUDENTS

Two research fellows were accepted for summer projects at the Clinic. **Sarah Wang**, a senior from the Rochester Institute of Technology will work with Dr. Puffenberger in the CSC lab from June through August. **Michael Setzer**, a student at Johns Hopkins University will spend June and part of July at the Clinic working on projects related to genetic counseling.

## STAFF NEWS

Last fall we welcomed two new members to the CSC staff:

**Karlla Brigatti** joined CSC this past October as our first genetic counselor. With Karlla’s help, the families we serve will gain a deeper understanding of new diagnosis, risks within their family, and how our team is working towards treatments and preventative strategies. Karlla also helps to organize research efforts at CSC.



**Mindy Kuebler** joined CSC this past November as a laboratory technician. With the growth of the clinic’s molecular lab (DNA testing), Mindy is responsible for daily clinical research testing

including DNA isolation, sequencing, cytoscanner arrays, and light scanner assays. Mindy is also helping to verify samples sent for exome sequencing, our most advanced tool for identifying new disorders. Mindy also coordinates the clinic’s journal club where new scientific literature is presented and discussed to keep our team up to date with the latest advances.



These recent additions to our staff were made possible through a new collaborative initiative with **Regeneron Pharmaceuticals**.

**Abby Benkert**, CSC Laboratory Technician and former Avery Fellow, will be leaving the CSC staff this summer to enter medical school at Tufts University. We congratulate Abby on her many achievements which includes the very recent acceptance for publication of: **Severe salt-losing 3-beta-hydroxysteroid dehydrogenase deficiency: treatment and outcomes of**



**HSD3B2 c.35G>A** homozygotes. The article was accepted by the **Journal of Clinical Endocrinology and Metabolism**. This manuscript details clinical features, therapeutic strategies, and management recommendations for our congenital adrenal hyperplasia (CAH) patients. The majority of the data was collected as part of Abby’s Avery Fellowship project.

**Congratulations and our very best wishes to Abby!**

MORE CONGRATULATIONS:

**Dr. Morton** was honored at the **2015 Healthcare Heroes** event with the **Lifetime Achievement Award** sponsored by Central Penn Parent. The award was presented in March at the annual event in Harrisburg, PA.

## NEW TO THE CSC BOARD OF DIRECTORS

We are very pleased to announce the appointment of **Richard A. Fluck, PhD** to the Clinic's Board of Directors.

Dr. Fluck has worked at Franklin & Marshall College in the biology department for more than 30 years, teaching courses such as Cell Biology and Cell Physiology. From 2005-2011, he served as Associate Dean of the Faculty and was involved in establishing the partnership between F&M and CSC. Dr. Fluck's leadership contributed to the first successful proposal to the Howard Hughes Medical Institute (HHMI), which supports education and research projects for the college and the clinic.



Dr. Fluck also serves on the Lancaster General Health Institutional Review Board (IRB). All CSC research projects fall under the LG Health IRB, which reviews and approves studies in order to protect the patients we serve.

Dr. Fluck was originally from the midwest where his father worked as a corn breeder in Minnesota and Iowa. He and his wife Sandy have three children and four grandchildren and reside in Lancaster.

We welcome Dr. Fluck to the Clinic for Special Children and are grateful for his academic rigor, scientific knowledge, community spirit and longstanding friendship.

## LEAVING THE BOARD OF DIRECTORS



After 25 years of faithfully serving on the Clinic's Board of Directors as one of the founding directors and skillfully recording all of the minutes through those years, **Dr. Richard Kelley** has concluded his service as an active member of the board. He is the first person named as a "Director Emeritus" which means he is always welcome to visit the Clinic and at-

tend board meetings as an honored guest. We hope he visits often from his new home in Massachusetts! We thank Rik for his many years of support and wisdom in guiding the Clinic through its growth and development.

*Pictured L to R: Frank Allen, Dr. Kelley and Dr. Morton, 1991 Clinic Dedication Day.*

## A LEGACY GIFT TO SUPPORT CSC

For the clinic's first 20 years, a retired schoolteacher from West Chester, PA read our newsletter and followed our progress. The schoolteacher visited CSC in the early 1990's and was impressed by Dr. and Mrs. Morton's vision. While she did not have children of her own, she became an annual supporter of CSC because she was devoted to helping children with special needs. She also understood the clinic's unique service offering because her father was a local doctor. We had not heard from her for many years until we received the sad news of her passing in 2014.

To our surprise, our schoolteacher friend had always intended to support the clinic upon her death with an estate gift. She designated the clinic as a beneficiary of her estate – a gift valued at over \$250,000. We are astonished and humbled by her generosity, and her legacy will live on in our work and mission! We are very grateful to her and to others who have so generously thought of the Clinic and

If you would like to discuss a planned gift for CSC, please contact Matthew Sware at 717.687.9407 or [msware@clinicforspecialchildren.org](mailto:mswire@clinicforspecialchildren.org).

### MATCHING GIFT

**We are very pleased we have another matching gift challenge from a local family foundation! Please help us meet the challenge of \$25,000 in donations before December 1st.**

**THANKYOU!**

*Garden Day*  
**Saturday, June 20, 2015**

1:00PM – 5:00PM – Garden cleanup, weeding, planting, and mulching. Volunteers can RSVP to the Clinic at 717 687-9407.



*Thank You for digging in!*

### Staff

Holmes Morton, M.D., Founding Director, Senior Pediatrician  
Caroline S. Morton, Founding Director  
Kevin A. Strauss, M.D., Medical Director  
Katie E. Williams, M.D., PhD, Pediatrician  
Erik Puffenberger, PhD., Lab Director  
Adam Heaps, Administrative Director, Laboratory Scientist  
Karlla Brigatti, Genetic Counselor  
Matthew Sware, Development Director  
Donna Robinson, CRNP, Pediatric Nurse Practitioner  
Christine Hendrickson, RNC, Nurse  
Millie Young, RN, Nurse  
Abby Benkert, Lab  
Mindy Kuebler, Lab  
Erica Sue Eisenbise, Office Manager  
Yalonda Kosek, Medical Receptionist



Clinic for Special Children  
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Strasburg, Pennsylvania 17579

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#### MISSION

*Provide comprehensive local medical care, integrate the science and the practice of medicine, and share knowledge to improve the health of children who suffer from genetic disorders.*

## 2015 Benefit Auctions

June 6, Union County, PA

June 27, Shippensburg, PA

July 11, Shiloh, Ohio

September 12, Blair County, PA

September 19, Lancaster County, PA

#### CLINIC FOR SPECIAL CHILDREN

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STRASBURG, PENNSYLVANIA 17579

717 687-9407

[www.clinicforspecialchildren.org](http://www.clinicforspecialchildren.org)

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

#### Board of Directors:

Herman Bontrager, Chairman

Enos Hoover

Leonard Hurst

Richard Fluck, PhD.

Mark Martin, Treasurer

Caroline S. Morton, Secretary

D. Holmes Morton, M.D.

Stephen Ratcliffe, M.D.

Jacob Zook

Kevin A. Strauss, M.D., Ex-Officio

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