



SPECIAL DATES

Auction Season is Here! **June 3 - September 9**

Find all auction dates, times,
and locations on page 3

Community Talks by CSC **April 22 | May 6 | May 31**

Find all lecture dates, times,
and locations on page 2

National Day of Prayer Breakfast **May 4 | 7am - 9am**

Proceeds benefit Clinic for Special Children
Harvest Drive Family Inn | Gordonville, PA

CODAS Family Day **May 4 | 10am - 2pm**

at Clinic for Special Children
Conference Room

Patient Family Advisory Council **May 9 | 7pm - 8pm**

at Clinic for Special Children
Conference Room

TNNT1 (Chicken Breast) Family Day **May 10 | 9am - 5pm**

at Clinic for Special Children
Conference Room

GM3 Family Day **May 18 | 9am - 4:30pm**

at Clinic for Special Children
Conference Room

Epilepsy Family Day **June 13 | 9am - 4:30pm**

at Clinic for Special Children
Conference Room

Cystinuria Family Day **June 20 | 12pm - 4:30pm**

at Clinic for Special Children
Conference Room

Special Education Family Day **July 6 | 9am - 3pm**

at Clinic for Special Children
Conference Room

Transplant Clinic Day **July 11 | 9am - 4:30pm**

at Clinic for Special Children
Conference Room

Patient Focus:

The Martins' Miracle

CONOR WAS DIAGNOSED WITH MAPLE SYRUP URINE DISEASE (MSUD) at 4 days of age. MSUD is a genetic disorder in which the body is unable to process proteins properly. Without proper management, the disorder can cause severe brain damage and even untimely death. The most effective long term treatment for MSUD is a full liver transplant.

After learning of the diagnosis, Conor's parents, Daryl and Julia, were overwhelmed with shock and a myriad of questions, "Will he survive this? Will he ever be able to thrive?" The Martins sought help from the pediatricians at the Clinic for Special Children. Fortunately, the Clinic was able to help Conor.

Dr. Katie Williams and Dr. Kevin Strauss created a treatment plan for Conor with the ultimate goal of transplanting his liver. Though Conor's MSUD was well managed, he struggled with the impacts of MSUD on his daily life including a highly restricted diet and frequent hospitalizations. The Martins' prayers were answered on Julia's birthday, when they received

a phone call with the news that a donor liver was available for Conor. Full of hope, faith, and anxiety, the Martin family rushed to the University of Virginia for Conor's transplant.

Since the surgery, Julia notices a marked difference in Conor's attention span and his improved ability to express himself. Most important to Conor, he is now able to eat protein-rich foods such as eggs, just like his brothers and friends. Today, anyone meeting 3-year-old Conor will experience his boundless energy and exuberance for life. He loves trains and is a fan of visiting the large Thomas the Tank Engine made of Mega Bloks at the Clinic. He loves reading, music and he has a savory tooth.

"We are truly grateful to the Clinic for being our medical home. CSC is a haven where we can receive not only the medical care Conor needs, but a place that focuses on the emotional needs of the whole family," says Julia. The Martin family hopes that their story may serve as an inspiration to others and a "testament to God's faithfulness."

Announcements and Letters From the Clinic

Staff and Board News

We would like to welcome **Keturah Beiler, RN** to our clinical team. Keturah earned her associates degree



and nursing certification through HACC. As a part-time registered nurse with the Clinic, she will be organizing and administering immunizations and assisting with

general patient care. "Having grown up in a Beachy Amish household, it is exciting and fulfilling for me to think of giving back to members of the Plain community who have influenced who I am today."

This year, we welcomed community liaison, **Lavina King** to the CSC staff. Fluent in Pennsylvania Dutch and a local resident of Strasburg, Lavina helps to serve as a link between the staff and the Amish/Mennonite Communities. Please find her personal introduction letter to the right.

Clinic for Special Children's co-founder, **Caroline Morton** resigned from the board in January 2017. Caroline served on the staff of CSC from the Clinic's inception until her retirement in early 2016. We are deeply grateful for her significant contributions to CSC over the past 28 years and we congratulate her on her full retirement. Thank you, Caroline!



Enos Hoover, a 27-year member of CSC's board, retired his board position at the end of 2016. Enos is the father of special children and was the chairman of the Leola Auction Committee for most of the auction's history. He is still involved with the auction committee and we appreciate Enos's continued service and dedication to the mission of CSC.

Leon Hoover, owner and operator of Hoover's Bernina Sew LLC in Mifflinburg, PA, joined CSC's board in October 2016. Leon serves as chairman of the Union County Auction Committee. Leon says, "Working with all different communities and church groups is my greatest joy. The Clinic for Special Children is very special to me and I want to do the most I can to help."

Community Talks

Caring for Special Children in Your Communities

A Talk by the Clinic for Special Children

Please join us for a lecture by the Clinic for Special Children staff on coming together to support special children.

Topics include:

- Saving healthcare costs
- Improving the quality and effectiveness of medical care in your community
- What is new and exciting at the Clinic for Special Children!
- How the Clinic's model of care creates a medical home for children living with rare genetic conditions
- How CSC makes difficult-to-access specialty medical services accessible to children with special needs
- How innovations in healthcare are being used to keep the children in your communities healthy
- What you can do to help

Refreshments and fellowship to follow talks. All are welcome.

2pm-4pm | April 22, 2017

**Fairview Reception Center
141 Jackson Road, Lebanon, PA 17042**

2pm-4pm | May 6, 2017

**Martindale Mennonite Fellowship Center
352 Martindale Road, Ephrata, PA 17522**

7pm-9pm | May 31, 2017

**White Horse Fire Company
111 White Horse Rd, Gap, PA 17527**

Patient Family Advisory Council

Recently the Patient Family Advisory Council (PFAC) held its first meeting. The PFAC is a collaborative group of patients, family members, clinicians, and staff members that meet regularly with the purpose of positively influencing organizational policy, programs, and practices of CSC. Members provide patient and family insights to help the Clinic recognize and address organization strengths and opportunities. We are still interested in new members so if you or your family has a patient history with CSC and would be interested in participating, please contact:

Kim Calderwood, Communications Manager: 717-687-9407

A Letter from Lavina

"Greetings in Jesus name. He is faithful and supplies our every need."

I enjoy writing letters so I decided to write for the newsletter and tell you about myself.

We live along Bunker Hill Road., right close to the Clinic. I started working for the Clinic in October 2016, as the 'community liaison' who serves as a link between the staff and the Amish/Mennonite communities. I also do some office work. Sometime I go with the doctors and nurses to make house-calls. I enjoy what I do and feel privileged to be part of the Clinic staff.

I have a deep compassion for all of these special needs children and it's such an inspiration to meet with the families and make new friends.

Having EVC syndrome myself, I know the feeling of being different. But I have learned we each need to be our own kind of beautiful.

God has blessed me with a husband and a son, Leroy. Leroy is our miracle indeed! He was born 10 weeks premature weighing only 1 lb 11 oz at birth. He spent 11 weeks in the hospital. How we rejoiced the day we brought him home! He is now 14 years old and a picture of health. Praise God!

We also had another son that lived only for about 15 minutes. He was a perfect baby, just too tiny to survive. A year later I had open-heart surgery to repair my EVC heart-defect. I also had my mitral valve replaced with a mechanical valve.

I'm actually off work right now as I had knee surgery in January. Hopefully I'll be back to work before too long.

May the joy of the Lord be your strength."

- A friend, Lavina King

Auction Season is Here!

Please join us this auction season for days of fellowship, family, and good food! Handmade quilts, handcrafted furniture, wooden crafts, sporting goods, handmade toys, and garden plants will be available. A variety of food choices will be featured including chicken barbeque, freshly made pies, donuts, whoopie pies, ice cream and more! Proceeds directly support the mission of the Clinic for Special Children.

For information about how to donate items or monetary gifts for our auctions, please call the contacts listed to donate to a specific auction.



"Every day, there is a growing need for the Clinic and also growing support. This safe haven extends beyond the Clinic staff, beyond the Clinic walls, and into the surrounding community. All of this to ensure that your children, and your children's children, will always have a place to go." – Katie Williams, MD, PhD

Mark Your Calendar for our 2017 Benefit Auctions

7:00 AM Breakfast | 8:30 Auctions Begin

Physician Remarks and Quilts to Follow

Union County Auction - 6/3

Buffalo Valley Produce Auction
22 Violet Road
Mifflinburg, PA 17844
Contact: Leon Hoover | 570-966-2414

Lancaster County Auction - 6/17

Leola Produce Auction
135 Brethren Church Road
Leola, PA 17540
Contact: Mark Martin | 717-733-3070

Shippensburg Auction - 6/24


Shippensburg Auction Center
1120 Ritner Highway
Shippensburg, PA 17257
Contact: Elvin Oberholtzer | 717-532-9088

Blooming Grove Auction - 7/8

Blooming Grove Auction Inc.
1091 Free Road
Shiloh, OH 44878
Contact: Leon Newswanger | 419-896-3336

Blair County Auction - 9/9

Morrison's Cove Produce
174 Windy Acres Ln.
Roaring Spring, PA 16673
Contact: Paul Ray Fox | 814-224-5442



Translational Medicine: A Medical Home in Dover

Pictured Above (L-R): Matt Demczko, MD and Mike Fox, MD

A New Clinic Inspired by CSC

The Clinic for Special Children has enjoyed the privilege of working closely with two physicians who are helping lead efforts to open a new medical clinic in Dover, Delaware to serve the local Amish community. The new clinic will be the first of its kind to offer services directed toward children with special needs in southern Delaware. Designed and managed to closely replicate the Clinic for Special Children in Strasburg, the vision of the clinic is to provide a local, comprehensive medical home for medically complex Amish and Mennonite children in the Dover area, and to improve the health of the communities that they serve by utilizing translational research and modern technologies. The clinic will be owned and operated by Nemours, a non-profit pediatric health system. Over time, it is the hope of the clinical team to also provide patients access to pediatric subspecialists (cardiology, endocrinology, etc.) close to home for their patients. Apart from the physicians who are leading this effort, CSC's current physician team will serve as consultants and advisors to the new Nemours team when necessary. The Dover clinic has a tentative opening scheduled for late July.

Meet the Physicians

Dr. Mike Fox is a 2007 graduate of Franklin & Marshall College, where he majored in Biochemistry & Molecular Biology with a minor in Public Health. He took part in the inaugural course taught at F&M by Drs. Morton, Strauss, and Puffenberger, entitled "Plain People and Modern Medicine." After his graduation from F&M, Dr. Fox received the inaugural Eyler Fellowship to conduct research at the Clinic for Special Children during the summer prior to matriculation into medical school. He received his medical degree from the University of Pittsburgh School of Medicine, having graduated in 2011.

After completing his residency training in pediatrics at the Children's Hospital of Pittsburgh of UPMC, he spent an additional year afterwards serving as Chief Pediatric Resident. Dr. Fox then joined the faculty at the Children's Hospital of Pittsburgh of UPMC and University of Pittsburgh School of Medicine. In 2016, he joined the faculty at Nemours/A.I. du Pont Hospital for Children as a member of the Diagnostic Referral Division and as a Clinical Assistant Professor of Pediatrics at Sidney Kimmel Medical College at Thomas Jefferson University.

Dr. Matt Demczko recently completed a six month fellowship with the Clinic for Special Children. Dr. Demczko is a 2008 graduate of Franklin & Marshall College where he majored in biology with a specific focus in genetics and religious studies. Through one of his courses, Introduction to Genetics, he became very interested in the genetics of rare disease, eventually helping to teach and recruit fellow students to the class. He received his medical degree from Jefferson Medical College in Philadelphia and completed his pediatric training through Nemours/A.I. DuPont Hospital for Children with an additional year spent serving as chief resident. It was this experience and training that introduced Dr. Demczko to the collaborative vision between CSC and Nemours to open a pediatric clinic that will predominantly focus on treating Amish children with rare genetic disorders in the Dover, Delaware community.

In preparation for opening the new Dover clinic, CSC agreed to host Drs. Fox and Demczko for six month fellowships, giving them the unique opportunity to learn how to care for Amish and Mennonite children living with rare genetic disorders.

Dr. Demczko completed his fellowship this past fall and Dr. Fox will complete his fellowship with CSC this summer. Since completing his fellowship, Dr. Demczko has been working full-time with the Division of Diagnostic Referral Services at duPont, caring for children with complex medical conditions. He recently presented to the entire Nemours hospital community about cartilage hair hypoplasia (CHH) based on his experiences caring for these patients at both CSC and duPont. He also gave a guest biology lecture at F&M on genetic susceptibility, and in particular his work with a new disease recently identified in Dover, Delaware.

We would like to extend a thank you to Dr. Demczko and Dr. Fox for their contributions to CSC patients and staff during their time with us and we wish them all of the best in the next steps of their endeavor!

clinicforspecialchildren.org

"My work is worship. You only get so many breaths in this life and you can't waste a minute. Challenge the status quo and go make a difference in the world "

- Dr. Devyani Chowdhury



Collaborator Spotlight: Dr. Devyani Chowdhury Cutting-Edge Cardiology Care with a Heart for Philanthropy

DR. DEVIYANI CHOWDHURY, globally recognized cardiologist and founder of Cardiology Care for Children, serves as an example of what can be achieved in medicine when social and cultural barriers are overcome. Dr. Chowdhury volunteers her time to the Clinic for Special Children and provides life-saving cardiology (heart) services for CSC's patients that would otherwise be difficult to access or afford. You can find her most Thursday afternoons at the Clinic.

Dr. Chowdhury smiles as she speaks fondly of her childhood days in India spent chasing butterflies and loving nature in her rural hometown. Where she grew up in India, there were no schools. To have an education was a rare privilege and she, along with many other children in the town, dreamt of attending school. Local children would come together to create and learn, often times sitting on the floor, writing on wooden boards with ink, and dreaming of their futures. It was then, before she attended a formal school, before she could speak English, that Dr. Chowdhury knew she would some day study medicine. From a young age, her mother wanted to make sure that Devyani worked hard and respected the challenges women often face in India, serving as her main source of support and encouragement in her pursuit of an education and a successful career.

Her father was employed as an engineer for a power plant company near the Himalayas. This is where a group of wives of the working men decided to come together and open a local school for their children. All courses were originally taught in the Hindi language and English was not spoken.

When Dr. Chowdhury was in the 5th grade, her family moved to Delhi. Moving to the big city was a big change from her small town upbringing. Though she was very bright, she had difficulty getting into a good school because she did not yet speak English. When she was finally accepted into a school, she put a lot of effort into her studies and focused on achieving her dream of studying medicine. Through a lot of hard work, Dr. Chowdhury learned English and ranked #1 in her school at graduation. Dr. Chowdhury took the national medical exam and ranked #50 in her country, allowing her to attend the medical school of her choice. She attended medical school in India and later decided to specialize in cardiology.

After graduation, Dr. Chowdhury accepted a residency in Long Island, NY, eventually becoming a chief resident and cardiology fellow before earning her cardiology certification. Becoming a doctor not only served as a great inspiration to women everywhere who hope to pursue medicine, but also fulfilled her grand-

mother's greatest dream for her granddaughter and her family.

Dr. Chowdhury's heart for philanthropy began well before her service to CSC. Using her cardiology education, she completed several mission trips to India to perform life-saving cardiac surgeries in underserved communities. Believing strongly that every child's parent loves them just the same and that no parent should have to lose their child because they cannot access or afford medical services, she proceeded to set up a pediatric surgery program for small, indigent populations in India. At the same time, she volunteered her time for Mother Theresa's orphanage for abandoned girls. When asked what inspires her to give of herself so freely, she says "I have a duty. The whole universe is my home. It is crazy to think that a person's future may be decided by imaginary lines on a globe. I hope that someday we can do away with that." She carries that philosophy through her medical practice today.

In 2008, Dr. Chowdhury began collaborating with the pediatricians from the Clinic for Special Children to help solve complex cardiology problems in Amish and Mennonite children living with genetic disorders. She says "I volunteer my time for CSC because I cannot put a dollar value on the unique experience that I've gained working with the Clinic. It has made me a better doctor." She especially enjoys making home visits to patients as her trips remind her of her childhood spent in a small rural town.

She credits Dr. Kevin Strauss, Medical Director at CSC, as being instrumental to her professional development and a valued partner in research. Dr. Chowdhury recently earned international recognition for her efforts to provide life-saving newborn cardiology screening technology to rural areas and underserved populations in the US. She is now working on spreading this technology to rural areas in Botswana and Pakistan.

Beyond her cardiology work, Dr. Chowdhury is a wife and mother of three. Her husband has been her biggest fan, giving her the support and independence she has needed to succeed through each step of her personal and professional journey. When asked how she balances running her medical practice with her philanthropy, cutting-edge research projects, and family life, she replies, "My work is worship. You only get so many breaths in this life and you can't waste a minute. Challenge the status quo and go make a difference in the world."



Clinic for Special Children

Our Staff

Keturah Beiler, RN
Part-time Nurse

Karlla Brigatti, MS, LCGC
Genetic Counselor

Kim Calderwood, MA
Communications Manager

Vincent Carson, MD
Pediatric Neurologist

Adam D. Heaps, MS
Executive Director

Christine Hendrickson, RNC
Nurse

Lavina King
Community Liaison

Yalonda L. Kosek
Office Coordinator

Mindy Kuebler, MS
Laboratory Technician

Erik G. Puffenberger, PhD
Laboratory Director

Donna L. Robinson, CRNP
Nurse Practitioner

Kevin A. Strauss, MD
Medical Director

Christine Stickler, JD
Development Director &
General Counsel

Katie B. Williams, MD, PhD
Pediatrician

Millie Young, RNC
Nurse

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Richard Fluck, PhD
Secretary

Leon Hoover

Leonard Hurst

Mark Martin
Treasurer

Stephen D. Ratcliffe, MD, MSPH

Jacob Zook
Vice Chairman



Small Community Project Makes a Big Impact! Pulse Oximetry

Pulse oximetry is a simple and noninvasive screening test which measures blood oxygen levels and is used to detect cyanosis or blueness. Cyanosis can be a sign of serious heart defects, lung disease, and infections in newborn babies that frequently cannot be seen by the naked eye, even by experienced midwives or obstetricians. As per the Pennsylvania State law, pulse oximetry screening is required on all newborn babies, regardless of their place of birth to detect serious heart defects. Babies born in the hospital have easy access to pulse oximetry, however, those delivered out of hospital have different challenges. The screening test is only reliable if performed using the right equipment and by personnel that are trained to perform the test.

Since 2015, collaborating doctor from Cardiology Care for Children Dr. Chowdhury and CSC pediatrician Dr. Williams have been working with local midwives to implement a pulse oximetry screening test, a “wellness screen” for newborns born out of the hospital. To meet the unique needs of out-of-hospital births, the recommended pulse oximetry program was modified to screen babies for overall wellness versus just for serious heart defects. This required that the screening be performed before the midwife leaves the mom and the baby, typically when the baby is 3-5 years old, and a second screening be done as per the required protocol at 24-48 hours.

Through generous donations from Pennsylvania Department of Health, Ronald McDonald House Charities, Abby’s Foundation, and Hershey Rotary we purchased 51 pulse

oximeters for screening. Workshops were held to provide training to the midwives. Currently, 33 midwives and 1 large birthing center in Pennsylvania have pulse oximeters from our program. The midwives are attending deliveries in Pennsylvania, Maryland, and Delaware. So far, over 1,200 babies have been screened and 3 newborns with heart or lung problems were identified and brought to care before they became critically ill. The project has demonstrated that the screening can be performed by midwives in the out of hospital births.

This program resonates well internationally. It has a strong appeal in countries where a large number of births are out of hospital and there is very high neonatal mortality. The expectation is that this screening test would help identify babies at risk and then get them to medical attention and care. The project was first presented by Dr. Chowdhury in 2015 at the Global Health Forum in Geneva, Switzerland. Since then, some developing countries have expressed an interest in implementing the program. Dr. Chowdhury will present the results of the study in July at the World Congress of Pediatric Cardiology and Cardiac Surgery in Barcelona, Spain.

Thank you to the generous donors, committed midwives and the community for making this project a huge success and taking a leadership role on the global health stage – small projects in small communities can make a big difference!

Devyani Chowdhury, MD and

Katie Williams, MD, PhD

clinicforspecialchildren.org

Patient Bulletin Board

We are now featuring
YOUR artwork, photos,
poetry, or letters! If we
may feature yours in our
next newsletter, please
send it to:

535 Bunker Hill Road
Strasburg, PA 17579



This Clinic is a special place
How I enjoy meeting each new face
Some come in, almost in despair
Others just need a little extra care

We are all learning more each day
To help your dear Children in some way
If sometimes the answer we don't know
Please be patient, we are hoping to grow

To be accepted just the way God made me
Has always meant so much you see
We are on this "earth" to help each other
So let's be kind to each sister and brother

God has picked you to be a special Mom & Dad
To these special-children, I'm sure they are glad
We are on a journey that is homeward bound
Then you will be rewarded, when Jesus gives a crown.
by L.K.





Clinic for Special Children

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The Clinic for Special Children is a Section 501(c)(3) Public Charity for US Federal and State Tax purposes (Tax ID #23-2555373). Donations to the Clinic are tax deductible. Donors should consult their tax advisor for questions regarding deductibility. A copy of the Clinic's registration and financial information may be obtained from the PA Department of State by calling toll free, 1-800-732-0999.



Clinic for Special Children 2017 Staff

Front (L-R): Christine Stickler, Christine Hendrickson, Kevin Strauss, Katie Williams, Karlla Brigatti, Kim Calderwood
Back (L-R): Erik Puffenberger, Mindy Kuebler, Millie Young, Vincent Carson, Donna Robinson, Yalonda Kosek, Adam Heaps
Not Pictured: Keturah Beiler, Lavina King