



## A Story of Hope, A Labor of Love Lewis Martin

LEWIS MARTIN WAS DIAGNOSED WITH SPINAL MUSCULAR ATROPHY (SMA) as a seemingly healthy newborn baby 12 years ago. This diagnosis meant that over time, Lewis would suffer degeneration of the nerves in his spinal cord and without miraculous treatment, he would die far too young.

Lewis's parents, Harvey and Lorraine Martin, were willing to sacrifice everything to keep their son healthy, however with each new promising treatment came repeated disappointment. Yet they remained hopeful.

Finally, in December of 2016, the FDA approved the first drug for the effective treatment of this previously lethal disease. News of the drug spread quickly and the Martins again felt hopeful that an effective treatment had arrived.

However, the first barrier to receiving this care was the out-of-pocket cost: \$125,000 per dose. Not wavering in hope, Lewis's family was able to procure the drug through a charitable program offered by the drug manufacturer that allowed them free access for life. Then they faced the next obstacle. This medication must be delivered directly into the fluid that surrounds the spinal cord.

Like many children with neuromuscular disease, Lewis has metal rods in his back to protect him from spine deformity. Multiple doctors reviewed Lewis's case and concluded that it was impossible to administer the drug to Lewis because the

metal rods blocked access to the fluid around the spinal cord. Lewis's family kept praying.

Dr. Kevin Strauss, Medical Director at CSC learned of the Martin family's struggle. He was determined to find an answer. This is when he collaborated with Dr. Freeman Miller, a world-renowned specialist in the orthopedic treatment of children with neuromuscular disease. Dr. Miller works at Alfred I. duPont Hospital for Children but, for the last four years, he has periodically traveled to CSC to evaluate children as well. When Dr. Strauss told him about Lewis, Dr. Miller devised an innovative way to safely pass through the surgical hardware in Lewis's back to administer the drug.

Lewis traveled from Ohio to Delaware to have the surgery so the drug could be given. At this point, his disease was at an advanced stage. Lewis knew that the benefits from the treatment might be minimal. But when asked if he wanted to receive this treatment, he replied with hope, "It may not help me much. I know that. But someday when I have a child with SMA, they are going to be able to get this drug right away."

At 8:30 a.m. on June 2, 2017, Lewis was the first child in the world to receive this drug through a surgically placed spinal catheter. Lewis's struggles are not unusual for patients with SMA. If this approach is effective, it could open the therapy up to hundreds of more patients.



## SPECIAL DATES

### BBQ and Community Talk September 22

Rail Center | Mifflinburg, PA - Details inside

### Patient Fall Family Fun Day October 7

CSC, 10 a.m.-2 p.m. - Details inside

### Patient Family Advisory Council Meeting November 15

CSC, 7 p.m.-8 p.m.

### Extraordinary Give Fundraiser November 17

Lancaster, All Day Event

### Thanksgiving - Office Closed November 23 and 24

Call our office, check our Facebook page, or watch our website for event specific information and updates.



# Announcements and Letters From the Clinic

## Staff and Board News

The Clinic welcomes a number of new staff and board members! As CSC grows, it is important to ensure the organization has the resources and staff available to continue to provide high-quality, low-cost services.

### Jacob Petersheim

Joining the board of directors is Jacob Petersheim. Jacob is a minister in the Old Order Amish Church and has been active on the Leola auction committee for many years. He is the father of two children who benefited from the Clinic's services. Professionally he is a dairy farmer in Narvon, PA.

### Cindy Bo

Also joining the board is Cindy Bo, MBA. Cindy is the Chief Strategy & Business Development Officer at Nemours Children's Health System, Alfred I. duPont Hospital for Children. She is a passionate advocate for the wellbeing of children.



### Candace Kendig

Candace joined CSC as a Medical Receptionist in 2017. She earned her Associates Degree in Specialized Technology, majoring in Medical Assisting in 2006. Prior to working at CSC, she had 10 years experience working as an Administrative Medical Assistant for a specialty office located in Lancaster.



"I am passionate about working for the Clinic because it is very rewarding knowing that every day our work positively impacts the children and family."

### KaLynn Loeven

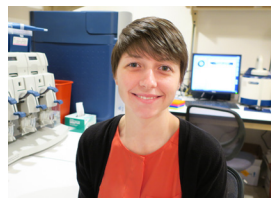
KaLynn joined the Clinic for Special Children in 2017 as a Laboratory Technician. She is responsible for performing genetic research through microarrays and the development of new testing assays.



KaLynn earned both a Bachelor of Science degree in chemistry in 2009 and a Bachelor of Arts degree in Biology in 2010 from Saint Francis University in Loretto, PA. Prior to joining the Clinic, she was employed as a senior chemist working in the method feasibility/development of pharmaceutical raw materials at Eurofins Lancaster Laboratories. Originally from the Reading area, she enjoys living in Lancaster with her husband.

"The Clinic struck me as a unique opportunity to combine my skills in the laboratory with a motivation to serve. As I learned more, I felt excited to become a part of a team which combines patient care and genetic research to improve the quality of life for a vulnerable population."

### Ashlin Rodrigues



Ashlin joined the Clinic for Special Children in 2017 as a Laboratory Technician. She is responsible for running several clinical assays

including amino acid quantification by HPLC and DNA isolation from whole blood. She also performs targeted mutation detection through Sanger sequencing and high resolution melting curve analysis.

Ashlin earned a Bachelor of Science degree in biology from Misericordia University in 2013. Prior to joining the Clinic, she worked at Rutgers University as a Senior Lab Technician performing microarray preparation and analysis. From there she took a position as a Cell Processing Specialist at Novartis Pharmaceuticals. At Novartis she assisted in the development of a CAR T-Cell immunotherapy used to treat pediatric acute lymphoblastic leukemia.

"The Clinic gives me the opportunity to see the impact my work has on patients first hand, which was something I was never able to experience in an industry setting. It is evident that everyone here is passionate about what they do and will go through great lengths to provide the best care to patients. I'm excited to serve alongside the talented clinic staff and to directly see the importance of my work everyday."

## Patient Fall Family Fun Day!

Hosted by CSC's Patient Family Advisory Council

October 7

10 a.m. - 2 p.m.

Clinic for Special Children

535 Bunker Hill Road, Strasburg, PA

Patients and their families are invited to join the CSC staff for a FREE day of fellowship and fun! Get to know the CSC staff, physicians, supporting specialists, and their families! Enjoy activities at the Clinic between 10am and 2pm: hayrides with antique tractors, children's activities, tours of the Clinic, delicious food including hot dogs, french fries, ice cream, and more!

The hosting Patient Family Advisory Council is a group of patients, family members, clinicians, and staff members that meet bimonthly with the purpose of adding a patient voice to the Clinic's programs and practices.

## CSC Talk & Benefit Dinner

Caring for Special Children in Your Communities

September 22

Dinner at 5 p.m., Talk at 7 p.m.

Rail Center

224 Young Road, Lewisburg, PA 17837

Come and enjoy a BBQ chicken and sausage sandwich benefit dinner and learn about what the Clinic for Special Children does to help make medical care more accessible for the Plain communities. Talk by CSC staff members Kevin Strauss, Erik Puffenberger, and Adam Heaps.

## It's Flu Shot Season

Please call the office at 717-687-9407 to schedule your flu shot. Anyone over six months of age is encouraged to get the shot. We offer shots to our patients and their immediate family. The cost is \$20 per person. The best way to protect yourself and your family is to avoid exposure, practice good hand-washing, and receive an annual flu shot.

# 2017 Auction Recap

THANK YOU to all who came out to our benefit auctions and helped to make this season such a success! Most of the Clinic's funds come from donations or revenue from special events such as our auctions. Thank you to our auction committee members, volunteers, donors, and all of our supporters who helped to make these special events possible.

Please visit our website for the most current auction information:

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

Making up 60% of CSC's revenue, funds raised from our annual benefit auctions and charitable donations make it possible for the Clinic to continue to provide affordable, specialized care to children living with rare genetic disorders not just in Lancaster County, but also world wide.



*"Hope cannot shield us from suffering in this life. Rather, hope is what allows us to endure suffering without losing our sense of joy. Hope is an expression of the kind of strength and courage that can only come from deep, and abiding love. Because being loved by someone gives us strength, while loving someone deeply gives us courage."*

*- Kevin Strauss, MD, CSC Medical Director*

## Mark Your Calendar for our 2018 Benefit Auctions

7:00 a.m. Breakfast | 8:30 Auctions Begin  
Physician Remarks and Quilts to Follow

### Union County Auction - 6/2/18

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

### Lancaster County Auction - 6/16/18

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

### Shippensburg Auction - 6/23/18

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

### Blooming Grove Auction - 7/14/18

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

### Blair County Auction - 9/8/18

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



## AMISH RESEARCH CLINIC

921 VILLAGE ROAD

# Translational Medicine: Brain Body Connection

### A Collaborative Study

The Clinic for Special Children has a longtime interest of studying the genetic risk factors for emotional health in both the Amish and Mennonite communities. We hope that, in turn, the knowledge we gain through these studies will help people for generations to come, all over the world. This work often involves many families with individuals who have struggled with mental wellness as well as their loved ones who have not.

We recently partnered with the University of Maryland to take our work in mental wellness to a deeper level. Dr. Elliot Hong is leading the Brain Body Connection study, attempting to understand brain differences that contribute to our chances of developing mental illness. This study is open to all members of the Amish and Mennonite communities ages 12 or older. It combines detailed brain imaging using a special MRI system with a variety of simple tasks that measure things like memory, attention, and reaction time. Fasting blood and saliva samples are also taken. These tests are critical to our deeper understanding and may scientifically validate what we already sense from our experiences: serious emotional stress can interfere with our memory, concentration, and other important mental functions.

Participation is completely voluntary and takes place over two days: one in Lancaster at the Amish Research Clinic or the Clinic for Special Children for tests that measure thinking, senses, reasoning, and emotions. The second visit is at the Maryland Psychiatric Research Center (MPRC) in Catonsville, Maryland, where the MRI is performed and brain waves are measured. The University of Maryland research team provides transportation to and from the facilities, all meals, and \$800 to each participant to help cover his or her time and effort with the testing, interviews, and travel.

If you or a loved one has questions or is interested in participating in this study, you can call Sue Shaub at 717-392-4948.

## Glutaric Aciduria Type 1 Outcomes Study Underway

By Katie B. Williams, MD, PhD

Glutaric Aciduria Type 1 (GA-1) is a genetic condition that affects how the body breaks down protein from the foods we eat. Children with GA-1 typically appear healthy at birth and begin to grow and develop as expected. However, if untreated, children with GA-1 usually have a stroke-like injury to the basal ganglia, (deep structures in the brain that control muscle tone). This injury can occur suddenly, often when a child is ill, and usually before the child is two years of age. GA-1 is very rare in the general population, but affects about 1 in 400 babies from the Amish community.

When the Clinic for Special Children was founded, there was no known treatment for GA-1 and almost all children with GA-1 suffered from basal ganglia injury. Over time, however, the Clinic designed a special medical formula and hospital treatment for children with GA-1 who are ill. Together, these treatments have drastically improved outcomes for children with GA-1. Today, most children with GA-1 are healthy without any signs of basal ganglia injury.

The Clinic is collaborating with Danone Nutricia Research to study the long-term outcomes for children with GA-1 that have been cared for at the Clinic using the current medical formula and hospital treatment plan. We are studying basal ganglia injury rates, overall nutrition, and learning abilities for children with GA-1.

If you have a child with GA-1, you may be asked if we can draw additional blood samples at your next visit to include in the research study. If you have a child with GA-1 age 5 years or older, we will invite your child and a sibling of similar age to have a formal evaluation to determine their learning abilities, communication skills, and attention span. Our hope is that children with GA-1 are just as healthy and able to learn as their brothers and sisters.

We hope this study will help us better understand the progress that has been made as well as identifying where there is room for improvement. The medical food foods developed and used by CSC are some of the few in the world that have been systematically studied and that information has helped children with GA-1 all over the world.

Thank you to all of the families who have already participated in the research study. Your efforts help to ensure we are providing the best possible care for children with GA-1!

"The patients and families have been the best part of my experience so far, by far. I have learned much more about the communities and culture and appreciate the degree that these families and communities take care of each other and their children."

- Dr. Salvin



## Collaborator Spotlight: Jonathan Salvin, MD

### Pediatric Ophthalmology

DR. JONATHAN SALVIN, MD, is a pediatric ophthalmologist at Nemours/A.I. duPont Hospital for Children. He has been at Nemours for 12 years where he practices "full service" pediatric ophthalmology, taking care of kids with a whole range of eye problems from strabismus (misaligned eyes), amblyopia ("lazy eye"), cataracts, glaucoma, eyelid and orbital diseases, genetic and metabolic diseases, and routine eye care such as refractive errors. Dr. Salvin sees patients in the office setting and but can also operate on them if needed. That is one of the things he loves about his job – the variety of things he gets to see and treat. Mostly, he loves spending the day around children because they "make you laugh and keep you on your toes!" Many eye diseases require long-term care, so he also gets to know the patients and families well while watching the kids grow up. He finds it extremely rewarding to "see a child who I saw in the NICU as a preemie weighing less than a pound who is now in school and being a normal kid."

Dr. Salvin attended medical school at Jefferson Medical College (now Sidney Kimmel Medical College at Thomas Jefferson University), completed a general medicine internship at Lankenau Hospital, his ophthalmology residency at Geisinger Medical Center, and then a pediatric ophthalmology fellowship at Children's National Medical Center in Washington, D.C.. Throughout his life, he had several influences on his decision to pursue medicine. Most notably was in 10th grade when he had the opportunity to take a unique physiology class, one of the few in the country with a human cadaver for dissection. He found the whole experience remarkable, being able to study the anatomy of a person who had given themselves for education.

Also leaving a deep impression on him was pediatric ophthalmology attending at Geisinger, Tom Wilson. Not only did Dr. Salvin admire his intelligence, he thought that Tom was a great communicator with the pediatric patients and their families. One of his favorite phrases of advice was "explain that like you are talking to my grandmother." Explaining to the parents what's going on with their child is one of the most important parts of taking care of children. Much better outcomes are achieved when parents understand their children's conditions and are part of their care plans.

Dr. Salvin learned about the Clinic for Special Children after Dr. Kevin Strauss (CSC Medical Director) approached Nemours' ophthalmology division several years ago, inviting several physicians to the Clinic for a tour. Dr. Salvin took that opportunity to visit CSC and was immediately astounded by what was being done there and how. He was already seeing a number of the Plain community patients in Wilmington, so his offer to extend his services to CSC seemed like an obvious extension of his practice. Plus, working with CSC would create the opportunity to get involved with some of the rare diseases and research opportunities. Dr. Salvin began visiting patients at the Clinic about 4 years ago and it remains one of the most enjoyable days of his month.

"The Clinic staff is amazing from the front desk to all the doctors. Everyone has been friendly and welcoming and collaborative. My days there are busy, but much quieter than days in the hospital clinic in Wilmington. The slower pace allows me to spend more time with the patients and families."

Dr. Salvin's favorite part of his experience with CSC is his work with the patient families. "I have learned much more about the communities and culture and appreciate the degree that these families and communities take care of each other and their children. These are kids often with significant disabilities and they are never seen or treated as a burden to the family or community. The patient families ask very good questions and understand their children and their diseases better than many in health care."

Extending his experience to his professional practice, Dr. Salvin says, "I have learned practicality in medicine beyond anywhere else I have practiced. I have always tried to consider what is truly needed/necessary in what I do, but since coming to the CSC, much more so. Because health care is another financial consideration to many in the community, what and how we do things becomes part of the decision process on what needs to be done and what does not. It has changed how I approach ordering tests, discussing possible surgery, and long term considerations, not only for the CSC patients, but for all of my patients. In today's changing medicine landscape of decreasing insurance benefits, etc., I think many of us need to start thinking this way. It challenges us to use more thought and evidence-based practice, rather than reflexively order testing."

In addition to participating in the audience of several educational family days and presenting at CSC's midwife conference, Dr. Salvin has not missed our Lancaster County Auction since his family made it an annual tradition years ago! "It's one of our my family's favorite events of the year and it's on the calendar and blocked off as soon as we know the date. Now, it is even more of a fun experience as I see CSC families there that I know and see the kids outside of the office setting. My daughter loves going and we usually will make out with more than a few 'gifts' from the day!!" Outside of ophthalmology, Dr. Salvin spends time with his wife, Karen and 4 3/4 year old daughter (she is very specific about her age), Laurel. They travel as much as they can. Prior to Laurel being born, he traveled with his wife to Africa, Asia, Europe, South America, and even the Arctic and Antarctica! Dr. Salvin is an avid photographer, mostly of wildlife and nature which is part of the motivation for some of the traveling as well.

Thank you to Dr. Salvin for his 4 years of service to CSC and the invaluable impact he's had on our staff and the patient families!



# 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

Candace Kendig  
Medical Receptionist

Lavina King  
Community Liaison

Yalonda L. Kosek  
Office Coordinator

KaLynn Loeven  
Laboratory Technician

Erik G. Puffenberger, PhD  
Laboratory Director

Donna L. Robinson, CRNP  
Nurse Practitioner

Ashlin Rodrigues  
Laboratory Technician

Kevin A. Strauss, MD  
Medical Director

Katie B. Williams, MD, PhD  
Pediatrician

Millie Young, RNC  
Nurse

## Board of Directors

Cindy Bo, MBA  
Chair-Charity Committee

Herman Bontrager  
Chairman

Richard Fluck, PhD  
Secretary, Chair-Development Committee

Leon Hoover

Leonard Hurst

Mark Martin  
Treasurer

Jacob Petersheim

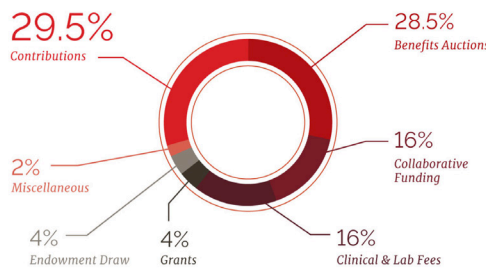
Stephen D. Ratcliffe, MD, MSPH

Jacob Zook



# Growth and Development

The Clinic is funded from four major sources of revenue—annual auctions, donations from caring people just like you, collaborative relationships, and fees for services paid by patient families.



We work hard to keep clinic fees to a minimum to ensure the families we serve can afford the consistent care they need. Amish and Mennonite communities work together to raise funds by hosting auctions that take place across Pennsylvania and Ohio. From quilts, to hand-made furniture, to whoopie pies, these events are a time of fellowship for the communities we serve and reminds everyone of the importance of our mission. Private philanthropic donations allow us to conduct research, provide community education, and coordinate patient care. This year, CSC's patient visits have increased by 21% over last year. Your support enables CSC to continue to provide patients with timely, affordable, and effective care!

## We Need Your Support

### Ways you can support the Clinic:

#### 1. Support our auctions by:

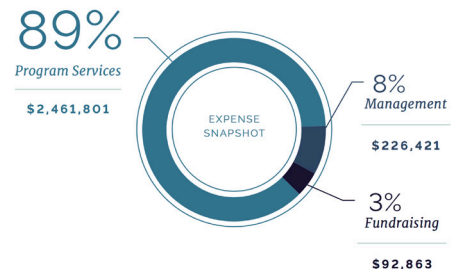
- Attending our benefit auctions
- Donating items to our auctions
- Sharing the auction with others

#### 2. Provide social support

- Refer special children to CSC's service
- Support families of children with special needs

#### 3. Make a monetary donation

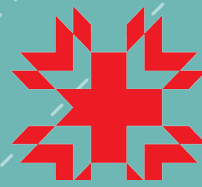
- Mail a donation to CSC
- Donate through our website



## Matching Challenge!

A local family foundation is matching donations dollar by dollar up to \$12,500!  
**PLEASE HELP US MEET THIS CHALLENGE BY DECEMBER 31ST!**

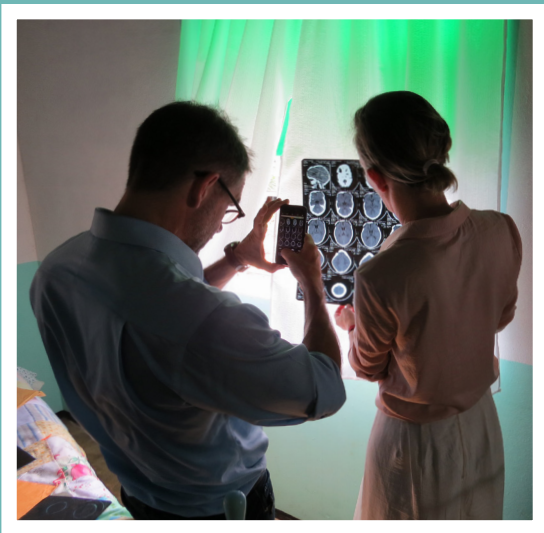
To make a donation to the Clinic, please mail us a check in the envelope included in this newsletter. Every dollar given makes a difference in supporting the Clinic. In fact, 89% of your donation goes directly to program services.



Clinic for  
Special Children

## Bulletin Board

Dr. Kevin Strauss and Karlla Brigatti were invited to Mexico as part of a unique opportunity to extend their medical expertise internationally.



Volunteers from Armstrong Flooring helped landscape CSC this fall as part of United Way's annual Day of Caring.



A group of students from Juniata College majoring in biology and public health spent an educational day with CSC.



Driving past CSC, you'll notice our new road sign! Our new sign was donated by a caring patient family.



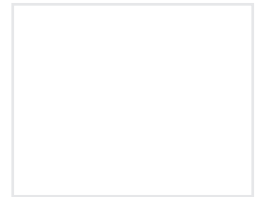
# Clinic for Special Children

535 Bunker Hill Road  
PO Box 128  
Strasburg, PA 17579

tel (717) 687-9407

fax (717) 687-9237

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



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.



"I have the privilege to bear witness every day to the power of love between parent and child, sometimes forged in the crucible of challenge and tragedy. Special children instill all of us who love them with gifts of patience, humility, and gratitude for blessings we all accept as a matter of course."

- Karlla Brigatti, CSC Genetic Counselor

*Charles H. Harkins*  
*To 50 B Rn Harris 300 90*