



Navigating CAH Together The Blank Family

Pictured (L to R):
Mahlon & Seth Blank

As members of the Old Order Amish community, Susie and Aquilla Blank had heard of the Clinic for Special Children, but never imagined they would one day need the Clinic's services themselves. When their third child, Seth, was born in September 2021, the attending midwife noticed concerning symptoms and encouraged the family to call the Clinic right away.

When Susie and Aquilla called, they were connected with Dr. Laura Poskitt, Medical Director. After speaking with the family, Dr. Poskitt suspected Seth had a rare genetic disorder called Congenital Adrenal Hyperplasia (CAH) and urged the family to go to their local hospital and send a blood sample to the Clinic for urgent testing.

CAH is a group of rare genetic disorders affecting the adrenal glands, which sit on top of the kidneys. The condition causes a problem in three hormones made by the adrenal gland. Without treatment, CAH can lead to loss of body salt, dehydration, vomiting, low blood sugar, seizures, and life-threatening adrenal crises. Treatment typically includes steroids and a high salt diet.

Within hours of Seth's birth, the Clinic's on-site laboratory confirmed the diagnosis of CAH. After spending several days in the hospital, the Blank family came to the Clinic for Seth's first appointment.

"Dr. Poskitt spent a lot of time with us during that first visit, explaining CAH and how to care for Seth," shares Susie. "The nurses and staff at the Clinic have been so helpful, as well as Dr. Grace Meier, who now sees both Seth and Mahlon."

"Since we were surprised to learn CAH was in our family, Aquilla and I decided to do the Plain Insight Panel™ test to learn more about which genetic disorders we were carriers for," Susie explains. "It was a relief to know we weren't carriers for any other disorders before Mahlon's arrival."

When the Blank family was expecting another baby (Mahlon) in 2023, they chose to have an ultrasound to determine if their baby might also have CAH.

"We preferred knowing ahead of time that Mahlon would have CAH," Susie shares. "It helped us emotionally prepare for his birth and allowed us to make a plan ahead of time. This time, we were prepared, sent a blood sample to the Clinic soon after his birth to confirm the diagnosis, and gave him a shot at birth so he was able to avoid hospitalization."

"Giving our babies salt and steroids is certainly not something we ever imagined," the Blank family shares. "We were not well acquainted with the medical world, and it was very hard to accept at first. But we are grateful beyond words for the doctors, staff, and knowledge at the Clinic. If this medicine helps our children live happy and healthy lives, we praise God for this gift."

Today, Seth and Mahlon are best buddies (as pictured above). They love playing in their sandbox and enjoy trucks, trailers, and tractors. At the Clinic, they especially love the toy area in the waiting room, and Seth always asks to have his blood draw first so he has more time to play afterward!



SPECIAL DATES

Ohio Benefit Auction Saturday, July 11

Blooming Grove Auction, Inc.
Shiloh, OH

Missouri Benefit Auction Saturday, August 15

Ed Good Family Farm
Memphis, MO

Labor Day - Office Closed Monday, September 7

All day

Blair County Benefit Auction Saturday, September 12

Morrison's Cove Produce
Roaring Spring, PA

Finger Lakes Benefit Auction Saturday, October 3

Ontario Produce Auction
Stanley, NY

Community Benefit Dinner Tuesday, October 20

Martindale Fellowship Center
Ephrata, PA

The Extraordinary Give Friday, November 20

All day
www.ExtraGive.org

Thanksgiving - Office Closed November 26 & 27

All day

Events are subject to change due to severe weather conditions, restrictions, or unforeseen circumstances.



Staff News

Amy Albright, MS, CGC



Congratulations to Amy Albright, MS, CGC, Genetic Counselor at the Clinic, who is celebrating her 5th work anniversary!

Amy joined our team in 2021 and has since helped hundreds of families navigate genetic testing options and understand their results.

Thank you, Amy, for your continued dedication to the Clinic and compassionate care!

Julia Goroff, DO



Congratulations to Dr. Julia Goroff, Pediatrician, for being named to the Pennsylvania Medical Society's 'Top Physicians Under 40'

list!

We are deeply grateful to Dr. Goroff for the innovative and accessible care she provides to families at the Clinic.

Justin Hersh



In May, we welcomed Justin Hersh as our new Research Associate! He will be stepping into Erin's former role, as she moves to our nursing

team.

Justin will work within our research team and support the Clinic's active research agenda. He'll be involved in data collection and analysis, coordinating study details, and more!

In his spare time, Justin enjoys watching movies, listening to music, playing video games, and going to amusement parks & riding roller coasters.

Samuel Miller, MS, CGC



We're delighted to welcome Samuel Miller, MS, CGC, to the Clinic! Samuel joined our team in April as a part-time Genetic Counselor.

In this role, Samuel assists in new patient triage and intake, provides genetic counseling services, and manages the logistics of the molecular diagnostics service. He also assists physicians with genetic testing decisions and patient evaluations.

When not at the Clinic, Samuel enjoys camping, hiking, playing games, and gardening.

Erin Sweigert



We're excited to share that Erin will be attending nursing school starting in August at Wilkes University as part of their Accelerated

Bachelor of Science in Nursing program!

Erin joined our team in 2023 as our Research Associate and is switching roles to our nursing team as a Medical Assistant as she pursues her education in nursing.

Jessica Townsend, LPN



We welcomed another new member of our team earlier this year! Jessica Townsend, LPN, joined our nursing team as a Licensed

Practical Nurse (LPN).

In this role, Jessica will assist in providing day-to-day clinical and administrative services, including rooming patients, phlebotomy, scheduling appointments, and much more!

In her free time, Jessica enjoys collecting

mini art prints and spending time with her dog, kids, and grandkids!

Board of Directors News

New Chair and Vice Chair

Earlier this year, the Clinic for Special Children's Board of Directors elected a new Chair and Vice Chair as part of the leadership transition planning for the retirement of longtime Board Chair, Herman Bontrager.

Leon Hoover, formerly Vice Chair, is now serving as Chair of the Clinic's Board of Directors. Herman, formerly Chair, will serve as Vice Chair until his planned retirement in October 2026. We deeply appreciate Leon and Herman for their continued dedication to the Clinic and their service on the Board of Directors.

Appointment Cancellations

As we head into the busy season of weddings and harvest, we kindly ask that you let us know as soon as possible if you are unable to keep your appointment. The best way to notify us is by calling our office at 717-687-9407.

While we request a minimum of a 48-hour notice for cancellations, **we appreciate hearing from you as soon as a scheduling conflict arises.** Our schedule at the Clinic is very full, and we maintain a wait list of patients who are eager to see our doctors. Thank you for helping us care for all families in a timely manner.

Measles Update

As local measles cases are still occurring we ask that if you have an upcoming appointment and you or a family member is experiencing fever, red eyes, cough, and a full-body rash that starts on the head, please call us at 717-687-9407 before coming in, because the measles virus is highly contagious.

We also encourage the measles vaccination (MMR vaccine), especially amid the current outbreak.



New Specialty Services at the Clinic

Maternal-Fetal Medicine & Physical Therapy

We are very excited to share two brand new specialty services coming to the Clinic in collaboration with Nemours Children’s Hospital, Delaware!

Maternal-Fetal Medicine

Our mission at the Clinic has always been to prevent disease and improve quality of life whenever possible. Increasingly, we are recognizing that symptoms of certain genetic conditions can begin before birth and can benefit from monitoring and, in some cases, treatment during pregnancy.

Starting in September 2026, the Maternal-Fetal Medicine team from Nemours will be coming to the Clinic every other month as a visiting specialist! This includes the ability to do detailed ultrasounds on-site on these days.

Our shared goal is to support complex prenatal cases and collaborate closely with community midwives and other healthcare providers to help give babies with rare genetic disorders the best possible start.

Mothers who may benefit from this new specialty service include those who are carriers for a genetic condition that may need treatment or monitoring during pregnancy, mothers who have abnormal ultrasound findings and may benefit from a genetic consultation, or women who are expecting a baby with certain congenital malformations, such as heart disease, that may indicate delivery in a specialized hospital setting.

Physical Therapy

Starting August 21, 2026, the Physical Therapy (PT) team from Nemours will be visiting the Clinic every month to see patients! At the Clinic, we care for many individuals who could benefit from regular physical therapy, and we are very excited to offer this service on-site.

Patients referred for this service by their Clinic doctor will meet with the Nemours PT team and receive a personalized physical therapy treatment plan, including exercises to continue at home.

The PT team will also encourage caregivers and family members to attend sessions so they can learn how to properly support exercises at home and help patients maximize the benefits of therapy. The Nemours PT team has worked hard to make this service affordable for self-pay families.

If you have any questions about these new specialty services coming to the Clinic, please call us at 717-687-9407 or email queries@clinicforspecialchildren.org. We are deeply grateful to the Nemours Children’s Health team for their continued collaboration and dedication to the families served by the Clinic for Special Children.

Remaining 2026 Benefit Auctions



Most auctions will feature CSC remarks and quilts midday.

Events are subject to change due to severe weather conditions, restrictions, or unforeseen circumstances.

Saturday, July 11

Ohio Auction

Breakfast at 7:00 a.m., auction at 9:00 a.m.

Blooming Grove Auction Inc.

1091 Free Road, Shiloh, OH 44878

Contact: Michael Newswanger | 419-896-2184

Saturday, August 15

Missouri Auction

Airplane Candy Drop at 9:30 a.m.

Auction at 10:15 a.m.

Friday Evening Event

Aug. 14 | Food + Children’s Auction
(starts at 5:00 p.m.)

Ed Good Family Farm

10507 County Road 813, Memphis, MO 63555

Contact: Harlan Burkholder | 660-341-4113

Saturday, September 12

Blair County Auction

Breakfast at 7:00 a.m., auction at 8:30 a.m.

Friday Evening Event

Sept. 11 | Starts at 4:30 p.m.
Rib Dinner & Auction Preview

Morrison’s Cove Produce

4826 Woodbury Pike, Roaring Spring, PA 16673

Contact: Mervin Martin | 814-793-3529

Saturday, October 3

Finger Lakes Auction

Country breakfast at 6:30 a.m., auction at 8:00 a.m.

Friday Evening Event

Oct. 2 | Starts at 4:30 p.m.
Grocery & Craft Auction + Rib Dinner

Ontario Produce Auction

4860 Yautzy Road, Stanley, NY 14561

Contact: David Fox | 585-526-5913

The Plain Insight Panel™ Testing

The Plain Insight Panel™ (PIP) carrier screen test will be available from 9:30 a.m. - 2 p.m. at each auction. Cost is \$350 per person, or \$650 for couples (need to test at the same time).



About CAH

by Dr. Laura Poskitt, Medical Director

What is CAH?

Congenital Adrenal Hyperplasia (CAH) is the name for a group of different genetic conditions where the body cannot make cortisol. Cortisol is a steroid hormone made in the adrenal glands, which are small organs above the kidneys. Cortisol plays an important role in managing your immune system, helping you grow, activating your body's stress response, and keeping your blood sugar normal. In some kinds of CAH, the adrenal glands also have trouble making aldosterone, which is important for balancing electrolytes and blood pressure, and testosterone and estrogen, which are important for puberty and fertility. At the Clinic for Special Children, we care for a very rare form of CAH caused by a genetic difference in an enzyme called 3-beta-hydroxysteroid dehydrogenase (HSD3B2) deficiency. This is a very severe form of CAH where the adrenal glands have trouble making all of the important steroids (cortisol, aldosterone, testosterone, and estrogen). This genetic change is found in the Amish community and affects about 1 out of every 2,500 Amish babies born in Lancaster County. HSD3B2 is very rare in the general population, with fewer than 100 people reported in medical literature worldwide.

How is CAH treated?

CAH is treated by taking medicine that mimics the body's natural steroids. This means a child with HSD3B2 CAH will take at least two medicines every day for life. They will need to take extra medicine while sick and often need to be hospitalized for special IV fluids and IV steroids called "stress dose" (high dose steroids). Doctors need to watch bone growth and blood work carefully to make sure each child is on just enough medicine but not too much to cause side effects. Some boys with HSD3B2 are born with differences in genital development - these children can get surgery to repair these differences.

How is CAH diagnosed?

HSD3B2 can be diagnosed in a few ways. Most infants are diag-

nosed several days after birth because parents notice they are not growing well, not eating well, and have a lot of vomiting and sleepiness. In those cases, since they cannot make aldosterone, the blood sodium is dangerously low, and the blood potassium is very high. Sometimes, infants will get quite sick within hours after birth with low blood sugar, low blood pressure, and seizures.

CAH is a condition that is tested through the state newborn screening (NBS) heel prick test. This test looks for the very common form of CAH called 21-hydroxylase deficiency. NBS does not, however, check for the specific type of CAH found in the Amish. Only about one in four babies with HSD3B2 are caught on NBS. Three out of four babies with HSD3B2 are diagnosed by physical signs (body differences in the diaper area) or by poor growth and feeding troubles. Through the Plain Insight Panel™, the Clinic's genetic carrier screening panel, parents can find out if they are both carriers for this condition BEFORE they have an affected baby. If we know both parents are carriers, we can do rapid testing at birth and arrange quick treatment, so hopefully the baby can stay safe after delivery.

What is new in CAH?

Over the past few years, our team has been researching this rare type of CAH. We have learned a lot about which medicines work well and at what doses work best. We are working on publishing these findings so that doctors around the world can learn how to treat patients, even if it's a new disease for that team. We always try to share our knowledge more broadly! Even with all we've learned, there are many things about treating CAH that are still tricky. There are some new medicines for 21-hydroxylase deficiency (the common type of CAH worldwide) that have reduced side effects while also improving symptoms of CAH. Since we always want to be learning and growing, the Clinic hopes to study how these new medicines might benefit children and adults we care for with HSD3B2.



Collaborator Spotlight

Shawn D. Safford, MD, MBA
UPMC Children's Harrisburg

Dr. Shawn Safford has called Central Pennsylvania home for most of his life. He attended Penn State University in State College before earning his medical degree from the University of Pennsylvania in Philadelphia. He completed fellowships in general surgery, pediatric surgery research, and pediatric surgery. Along the way, he served in the U.S. Navy aboard the USS *Harry S. Truman* and USNS COMFORT before becoming Chief, Pediatric Surgeon at Walter Reed National Military Medical Center.

After years away for training and military service, Dr. Safford returned to Central Pennsylvania and is now a pediatric surgeon at UPMC Children's Harrisburg and President of the Pennsylvania division of the American Trauma Society. Through these roles, he remains deeply focused on improving the safety and care of children across Pennsylvania.

"I had heard of the Clinic's work for many years before I had the privilege of partnering with your team," shares Dr. Safford. "Anyone who cares for children in this part of Pennsylvania knows the Clinic by reputation and what it has meant to families across the region." Dr. Safford's relationship with the Clinic has grown over the years through his work with our Medical Director, Dr. Laura Poskitt. Together, they have collaborated across the full spectrum of conditions cared for at the Clinic. "Congenital Adrenal Hyperplasia (CAH) has been a meaningful part of this work, alongside many other diagnoses, and I am grateful for the trust the Clinic has placed in me," explains Dr. Safford.

For CAH, the surgical option Dr. Safford is most often asked about is bilateral adrenalectomy, a procedure that removes both adrenal glands. For children with the most severe forms of the disease, whose hormone levels remain difficult to manage despite the best medical treatment, this surgery can dramatically simplify daily life and reduce the risk of serious health complications related

to adrenal crisis. Like many surgeries, however, it is a significant decision with lifelong implications and is not the right choice for every family facing CAH. For the right child, though, the procedure can be transformative.

Another common need Dr. Safford helps address for Clinic families is feeding support for children who cannot safely take nutrition by mouth. For many conditions seen at the Clinic, this is a challenge that families regularly face. For these children, Dr. Safford performs laparoscopic placement of gastrostomy tubes (G-tubes), a surgical technique that uses smaller incisions. "A well-placed gastrostomy can be the single change that lets a child grow, gain strength, and thrive at home," shares Dr. Safford. Beyond CAH, Dr. Safford sees referrals from the Clinic for a variety of pediatric general and thoracic surgeries: hernias, abdominal or chest wall problems, and the occasional complex case where a child's underlying genetic diagnosis shapes the surgical plan.

When asked about his goals in working with Clinic families, Dr. Safford explains, "My goal is simple: to provide these children with surgical care that is excellent, unhurried, affordable, and respectful of who they are and where they come from."

Beyond the operating room, Dr. Safford stays busy on his farm. He and his wife, Kristine, along with their four children—Amelia, Ben, Liz, and Franny—raise sheep and care for their land.

"The farm is our anchor. It's where we slow down, where our children learn what hard work looks like, and where I'm reminded every day that the families I care for in clinic are not so different from my own," shares Dr. Safford.

"I'm a longtime supporter of the Plain communities of Central Pennsylvania. In addition to my work with the Clinic, I serve on the Amish Safety Committee in Lancaster. These have been some of the most meaningful relationships of my career."

Our Staff

MEDICAL

Amy Albright, MS, CGC | Genetic Counselor
Vincent J. Carson, MD | Pediatric Neurologist
Jennifer Giacoio, CMAA | Patient Navigator
Julia A. Goroff, DO | Pediatrician
Candace Kendig, RMA | Practice Manager
Grace L. Meier, MD | Family Medicine Physician
Samuel Miller, MS, CGC | Genetic Counselor
Laura Poskitt, DO | Medical Director
Peggy Riehl | Medical Receptionist
Dawn Sheets, GCA, CMAA | Genetic Counseling Assistant
Susan Walther, MS, CGC | Genetic Counselor

NURSING

Keturah Beiler, BSN, RN, CHPPN
Cherished Lives Program Manager
Christine Hendrickson, RN, BSN, PED-BC
Outreach Program Manager
Donna L. Robinson, MSN, CRNP | Nurse Practitioner
Erin Sweigert | Medical Assistant
Sarah Thomas, RMA | Medical Assistant
Jessica Townsend, LPN | Licensed Practical Nurse

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Alanna Koehler, PhD | Assistant Laboratory Director
KaLynn Loeven | Laboratory Scientist II
Erik G. Puffenberger, PhD | Laboratory Director
Sean Schreckengast | Laboratory Scientist I

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Joelle Williamson Clark, MPH
Clinical Research Manager
Justin Hersh | Research Associate
Ashlin Rodrigues, MS | Clinical Research Analyst

DEVELOPMENT

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Renny Magill, CFRE | Development Director
Julia Martin | Development Associate
Kelly Woodson | Event Manager

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Kelly Cullen | Marketing & Communications Manager
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Jessica Snyder, PHR, SHRM-CP
Human Resources Manager
William Van Ess, MS, CFE | Accounting Manager

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Glenn Zimmerman



Auction Leads Pottstown Couple to Support the Clinic by Renny Magill, Development Director

Avowed boosters for their hometown, Pottstown, PA, Carl and Sylvia Landis enjoy traveling from Montgomery to Lancaster County to visit and have a meal at Yoder's Buffet & Restaurant in New Holland. During one of these visits, Sylvia found an article about the Lancaster County benefit auction for the Clinic for Special Children. Disappointed that the date had passed, she nonetheless visited the Clinic's website, and interest piqued, reached out to our staff to arrange a visit to our facility in Strasburg at the time.

For the Landises, the discovery is more than a passing interest. In the early 1980s, the Landises adopted siblings from an orphanage in the Azores, Portugal. After the boys were with them for several years, they noticed an unusual development that was present before puberty. This led them to seek answers and treatment at the Children's Hospital of Philadelphia (CHOP) and ultimately a diagnosis of Congenital Adrenal Hyperplasia (CAH) at Geisinger.

"While it was helpful to receive a diagnosis, there wasn't an effective treatment at that time," Sylvia notes. Further, the Landises found it challenging to travel so far for appointments and treatments, and wished that an option like the Clinic for Special Children would have been available, and close by, to them in those days.

The discovery of the Clinic sparked their hope – the hope that other families will find answers to genetic and complex medical conditions and compassionate and accessible care. Sylvia notes that learning about the Clinic has been like "watching miracles" take place. They continue to be inspired by the Clinic's approach of providing compassionate care and finding answers to questions that will improve the quality of life for current and future patients.

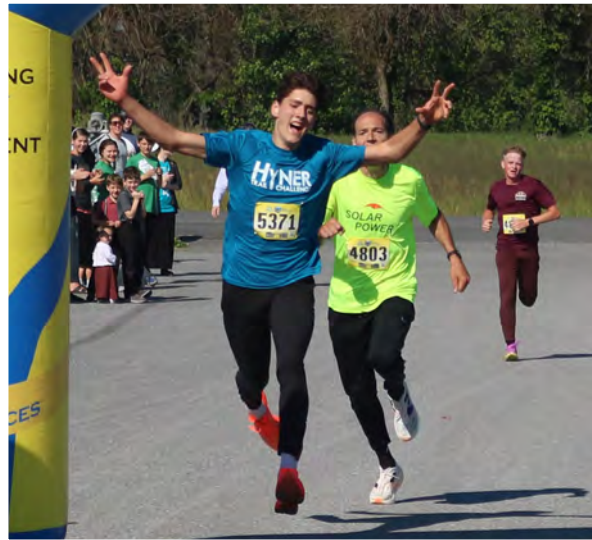
The Landises count themselves as fortunate and appreciate the opportunities that their life has granted them. Sylvia is a retired teacher in the Pottstown school district, and Carl had a varied career, starting as a teacher and moving into manufacturing, engineering, and then financial planning in the late 1980s. He continues to work, and it's his involvement with financial planning that has helped shape their support for numerous organizations, including the Clinic. Carl encourages people to learn how to maximize the benefits of giving – both for the organizations and for themselves as donors.

The Landis's first contributed to the Clinic during the *Keeping the Promise: Building Hope* capital campaign, and annually support the Clinic's mission through a qualified charitable distribution from an IRA. Sylvia mentioned that she learned an important lesson from her mother, who was fond of saying, "Do your giving while you're living, then you're knowing where it's going." Whether it is their support for the many organizations in and around Pottstown, or the Clinic for Special Children, the Landises have found a way to humbly and thoughtfully make a profound impact in their world.

2026 Clinic for Special Children 5k THANK YOU!

On Saturday, May 16, 2026, we hosted our largest race yet at the Leola Produce Auction! More than 700 participants joined us for the 5K, new 1.5-mile Family Walk, and Kids Color Fun Run, helping us break attendance records by the hundreds.

Together with the support of more than 40 sponsors, we raised over \$60,000 to support the Clinic. Thank you to everyone who participated, the volunteers who made the day possible, and our generous sponsors. A special thank you to **Nemours Children's Health**, our Presenting Sponsor, as well as Platinum Sponsors **Kline Kreider & Good** and **Leacock Rentals** for their incredible support.





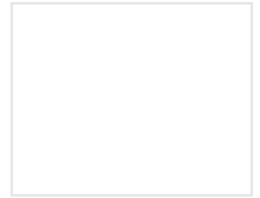
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Caring for CAH

This issue features a specific rare genetic disorder we see at the Clinic, called Congenital Adrenal Hyperplasia (CAH). Read a family's story and learn more about the condition from our Medical Director.

2026 5k Recap

We had a record number of participants join us on Saturday, May 16th for our 2026 Clinic for Special Children 5k! View fundraising results and photos inside.

The Clinic's Mission

Improving the quality of life for those with genetic or complex medical conditions through innovative research, accessible laboratory services, and compassionate care.