



Hearing Again The Blank Family

Pictured: a cochlear implant

At 42 years old, Linda Rose Blank is rediscovering sound. Born with a rare genetic disorder called Usher syndrome type IIIB, caused by changes in the gene *HARS1*, Linda was able to hear and see in early childhood. Around the age of five, however, she began to experience gradual vision and hearing loss. By the time she was 19, Linda had lost both her vision and hearing completely.

"We first brought Linda to the Clinic for Special Children before it was even officially founded! Our first visits were at the original Clinic location in Willow Street," explained Linda's parents, Eli and Lizzie. "She was experiencing high fevers, hallucinations, and other concerning symptoms whenever she got sick. It wasn't until 10 or more years later that we received her official diagnosis."

For decades, Linda's family and close friends communicated with her primarily through American Sign Language, signing into her hands. Over the years, Linda and her family heard about cochlear implants as a potential therapy, but at the time, they were considered experimental and offered no guarantees for someone in Linda's situation.

Cochlear implants are small electronic devices that send sound signals directly to the auditory nerve, unlike hearing aids, which amplify sound. This bypasses damaged parts of the ear and helps the brain understand sound. "All of a sudden, one day, Linda told us that she wanted to get cochlear implants. We were stunned by her change of mind, but cautiously optimistic that they could help her," says Lizzie.

When Linda and her family met with audiologists to learn more, the doctors weren't certain the implants would be effective, primarily due to her age and the length of time she had been without hearing. True to her nature, Linda didn't give up. She sought a second opinion and received her first cochlear implant three years ago. Two years later, she received a second implant. Since then, she has continued to have the devices adjusted as her brain adapts to this new way of hearing.

"It's been amazing to watch the progress Linda has made. She recognizes more sounds every day, even when I call her name or say, 'It's time to eat.' Linda Rose is truly enjoying her cochlear implants and the renewed sense of hearing and freedom they've given her," share Eli and Lizzie.

Linda's parents and Dr. Grace Meier, her doctor at the Clinic, believe Linda's success is partly due to her having developed language normally during early childhood before experiencing hearing loss. "Language development is critical before the age of three. This is why it's so important to detect hearing loss early in children, because earlier interventions can significantly improve outcomes," explains Dr. Meier.

Today, Linda discovers new sounds every day and enjoys the freedoms her cochlear implants have provided. She works at a local bakery, enjoys reading Braille books, needlepointing, and helping with chores around the house. "I have to remind her to use her voice," Lizzie reflects. "It's a joy to see her keep improving a bit every day."



SPECIAL DATES

Finger Lakes Benefit Auction Saturday, October 4

Ontario Produce Auction | Stanley, NY

Community Benefit Dinner Tuesday, October 21

Martindale Fellowship Center
Ephrata, PA

The Extraordinary Give Friday, November 21

All Day
www.ExtraGive.org

Thanksgiving - Office Closed November 27 & 28

All Day

Christmas Eve - Office Closed Wednesday, December 24

Office closes at 1:00 p.m.

Christmas - Office Closed December 25 & 26

All Day

New Years Eve - Office Closed Wednesday, December 31

Office closes at 1:00 p.m.

New Years Day - Office Closed Thursday, January 1

All Day

Good Friday - Office Closed Friday, April 3

All Day

Clinic for Special Children 5k Saturday, May 16

Leola Produce Auction
Leola, PA

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



Staff News

Adam D. Heaps, MS, MBA



Congratulations to Adam D. Heaps, MS, MBA, Executive Director at the Clinic, on his 15th work anniversary!

Adam joined the Clinic in 2010 as a Laboratory Technician and has been the Executive Director of the Clinic since 2014.

He originally learned about the Clinic during his college years and was impressed by the Clinic's use of scientific technologies to directly impact patient care.

Thank you, Adam, for your dedication to the Clinic and for all that you do for the staff and families that we serve!

Grace L. Meier, MD



Congratulations to Dr. Grace L. Meier, Family Medicine Physician, on her 5th work anniversary at the Clinic!

Dr. Meier joined our team in August 2020 and was hired as our first physician specially trained in family medicine, allowing her to see patients of any age.

She was first introduced to the Clinic as part of a special program with Penn Medicine Lancaster General Health as part of her residency training.

Thank you, Dr. Meier, for your years of compassionate and devoted care for the families who visit us at the Clinic.

Flu Shot & Measles Flu Shot Information

We're approaching that time of year when yearly viruses start going around! The best way to protect yourself and your family during this time is to avoid exposure, practice good hand-washing, and get your annual flu shot.

We recommend that anyone over six months of age receive a flu shot each year. Please call

us at 717-687-9407 to schedule your or your child's flu shot. We offer flu shots to our patients and their immediate family members.

Measles Reminders

There continue to be regional measles outbreaks across the country. There have been several cases in Pennsylvania. We encourage measles vaccination (MMR vaccine) amid the current outbreak.

In addition to the MMR vaccine, we regularly offer vaccine clinics for anyone uninsured (you don't have to be a Clinic patient). The cost is \$20 per person, and the fee covers all vaccines needed in one visit. To schedule, call us at 717-687-9407.

If you have an upcoming appointment at the Clinic and you or a family member is experiencing fever, red eyes, cough, and a full-body rash that starts on the head, please call our office at 717-687-9407 before coming in for your appointment, because the measles virus is highly contagious.

Appointment Reminder

We understand that life can often be unpredictable, and sometimes you'll need to miss a scheduled appointment.

Often, if we know you can't come, we can offer your appointment time to a family who is waiting for care. Please call us at 717-687-9407 as soon as possible if you are unable to make a scheduled appointment.

We appreciate your understanding!

Volunteering at the Clinic

Are you interested in giving back to the community? We offer a variety of volunteer opportunities tailored to individual skills, interests, and relevant licensure or certifications.

Volunteer activities may include assisting with events (such as our annual 5k race), landscaping, cleaning, making phone calls, preparing mailings, administering vaccines, performing blood draws, data entry, and more.

We are currently looking for volunteers to help with our Cherished Lives program. We need

volunteers to help with childcare during monthly groups for mothers who have experienced the loss of a child.

To learn more about how you can get involved, please contact us at 717-687-9407, email us at queries@clinicforspecialchildren.org, or visit our website at www.ClinicforSpecialChildren.org/contact/volunteers.

New Board Member

Meg Frizzola, DO, FAAP



We are pleased to announce that Dr. Meg Frizzola, Chief Medical Officer of Nemours Children's Health, Delaware Valley, will be joining our Board of

Directors effective October 1, 2025.

Dr. Frizzola is a seasoned, forward-thinking physician executive known for her strategic insight and collaborative leadership. In her current role, she oversees the physician workforce at Nemours, sets performance benchmarks, and drives the clinical strategy, direction, and growth of the organization across the Delaware Valley.

With over two decades of service at Nemours, including her pediatric residency and critical care fellowship, Dr. Frizzola brings deep institutional knowledge and unwavering commitment to pediatric care.

We are thrilled to welcome her to our board and look forward to partnering closely in pursuit of our shared mission.

2026 CSC 5k

Saturday, May 16, 2026

Save the date! We are excited to host our 2026 Clinic for Special Children 5k at the Leola Produce Auction in Leola, PA, on Saturday, May 16, 2026.

Registration and more details will be released in the coming months. If you're interested in supporting the race as a volunteer or sponsor, please reach out to us at the Clinic at 717-687-9407 or queries@clinicforspecialchildren.org.

Announcing our 2026 Outreach Clinic Dates

At the heart of our mission is the commitment to providing affordable and accessible care. Our outreach clinic program, expanded for 2026, allows us to extend our mission by bringing our services closer to patients, meeting families where they are and reducing barriers to care.

Below, you'll find the planned 2026 outreach clinic dates. A few important details: Outreach clinics are available only to established patients who have previously been seen at our main Clinic in Gordonville. All visits require a scheduled appointment, walk-ins cannot be accommodated.

If you are an eligible patient family interested in scheduling an appointment at an outreach clinic in your area, or have any questions about our outreach clinic program, please call us at 717-687-9407.



2026 Dates

Pennsylvania

Mifflinburg

Dr. Vincent Carson & Dr. Julia Goroff
Monthly on 3rd Thursdays

Jan. 15th, Feb. 19th, March 19th, April 16th, May 21st, June 18th,
July 16th, Aug. 20th, Sept. 24th, Oct. 15th, Nov. 19th, Dec. 17th

Newville

Dr. Grace Meier
*April 21st &
November 3rd*

Somerset

Dr. Laura Poskitt
*March 2nd - 3rd, June 8th - 9th,
August 3rd - 4th, November 9th - 10th*

New York

Penn Yan

Dr. Grace Meier
April 10th & October 2nd

Missouri

Memphis

Dr. Vincent Carson
August 14th

EXTRATM GIVE



Friday, November 21
ExtraGive.org

Scan the QR code
for a shortcut to
our giving page!



The **Extra Give** - Lancaster County's largest day of online giving - is on **Friday, November 21st**! Help the Clinic **raise \$75,000 in 24 hours** for our mission. You don't need to be located in Lancaster County - we have donors from all over the country who support us through the ExtraGive.

Every dollar you donate on November 21st via the ExtraGive will be stretched by a pool of more than \$500,000 from local sponsors.

Giving is simple - here are **three ways you can support**:

Give Online

Visit www.ExtraGive.org anytime from 12:00 a.m. to 11:59 p.m. and search for 'Clinic for Special Children' to donate online.

Call us

Call us at 717-687-9407 between 9:00 a.m. and 5:00 p.m. to donate with a credit card over the phone.

Create a giving page

Create your own fundraising page at www.ExtraGive.org: Search 'Clinic for Special Children' and click the Fundraise button. Set up your page before November 21st & help spread the word!



Understanding Hearing Loss

Causes, supports, & treatments

Pictured: Jevon, a patient of the Clinic who experiences hearing loss due to CODAS syndrome

Hearing loss has many causes, including genetic changes, infections, age-related changes, ear damage, and more.

At the Clinic, we've identified over 50 genetic variants in Plain communities that can lead to hearing loss—either on its own or as part of a broader genetic condition. More than 10 of these genetic variants can cause hearing loss present at birth without any other health conditions and the baby may seem otherwise completely healthy.

Most hearing loss occurs in the inner ear or along the auditory nerve, which carries sound signals to the brain. We most commonly see hearing loss that is present from birth (congenital), but it can also develop later in life (acquired).

Understanding the type and cause of hearing loss, whether congenital or acquired, is important. It can help guide the best treatment approach. For infants, early diagnosis can be critical to developing language and communication skills.

Causes of hearing loss

While we primarily focus on genetic causes of hearing loss at the Clinic, we're also aware that certain illnesses can lead to permanent hearing loss, especially when left untreated. Infections like measles, chicken pox, cytomegalovirus (CMV), Lyme disease, mumps, and severe ear infections can all damage parts of the ear or auditory nerve, resulting in hearing problems.

Genetic causes of hearing loss occur when changes in the body's instructions—our genes—affect how the ear develops or functions. These changes can lead to problems with inner ear development, the auditory nerve, or the tiny cells that help us process sound.

Another common cause of hearing loss is aging. Over time, the delicate hair-like cells in the inner ear that carry sound signals to the brain can wear out or become damaged, making it harder to hear clearly. These are just some of the many possible causes of hearing

loss, and understanding the underlying reason is key to finding the right support and treatment.

Support and treatments for hearing loss

For many causes of hearing loss, there are effective treatments and interventions that can make a real difference in quality of life.

For young children, early support is critically important. Ideally, hearing loss is diagnosed at birth or shortly after so that children can begin services by six months of age. Early support, like speech therapy or learning American Sign Language (ASL), helps build strong communication and language skills. After age three, it becomes much harder for the brain to develop language, so early intervention is critical.

Assistive devices, such as hearing aids or cochlear implants, can help people experiencing hearing loss. Hearing aids make sounds louder so the ear can detect them more easily. Cochlear implants bypass damaged parts of the inner ear and send sound signals directly to the auditory nerve and brain. Cochlear implants are primarily for people, especially children, facing severe to complete (profound) hearing loss.

Some types of hearing loss caused by structural issues in the ear (like fluid backup or repeated infections) may benefit from surgery, such as placing ear tubes.

One of the newest developments is gene therapy for hearing loss caused by certain genetic variants. This treatment aims to fix or replace the faulty gene to restore hearing - treating the root cause rather than just the symptoms. Although still in its early stages, gene therapy for hearing loss is currently being evaluated in several human clinical trials. Some studies have already reported encouraging preliminary results, including restoring hearing function with improved speech perception and enhanced ability to localize sound.



Bridging the Gap in Newborn Hearing Screening

A collaboration with the PA Dept. of Health & Nemours Children's Health

All babies born in Pennsylvania, whether in a hospital or at home, are screened for hearing loss at birth. The screening tests are quick, painless, and usually done while the baby is sleeping. If a baby does not pass their initial screening and a repeat screening, they are referred to the Pennsylvania Department of Health (DOH) to connect them with doctors for follow-up care and additional testing.

However, because many Amish and Mennonite families do not carry traditional health insurance, the DOH struggled to find providers who could offer them care. Many babies in the Plain community are born to midwives who do not work in major health care systems that employ audiologists (hearing doctors). Many larger health systems do not accept referrals for specialty care, like audiology, if the child is not already an established patient in their health system. This left many Plain families in need of time-sensitive care with nowhere to turn.

Because children begin to lose the ability to naturally acquire language after age three, it's critically important for families to receive timely follow-up care and a diagnosis after a failed hearing screen. Since Plain families could not see an audiologist in the current systems, their children could not be diagnosed with hearing loss and have early treatment that could give them the best chance at speech development.

To help close this gap, the DOH partnered with our team at the Clinic for Special Children and Nemours Children's Health System to ensure Plain families can now access the specialized hearing care they need. Dr. Shannon McGee, an audiologist from Nemours who already visits the Clinic monthly to see patients, generously agreed to support this program as well.

Dr. McGee explains why it was important to her to support our collaborative program to help identify and diagnose babies with hearing

loss from the Plain communities, "Early identification and intervention can help children achieve normal or near-normal developmental milestones. It is well established that babies who are diagnosed with hearing loss and begin intervention services before six months of age tend to have better outcomes in communication, education, and social development."

Launched earlier this year, the new program allows the Clinic to serve as a referral site for Plain families across Pennsylvania whose babies need follow-up care after not passing their initial hearing screenings. The DOH helps connect these families with us, and Dr. McGee sees them at the Clinic within three months to perform a specialized hearing test called an ABR (auditory brainstem response).

The ABR is a quick and painless test that measures how the auditory nerve responds to sound using small earphones placed in the baby's ears. If the baby passes the ABR, no further hearing care is needed. If they do not pass, the family will receive a same-day genetic consultation and a visit with a Clinic doctor to explore next steps and determine if there is an appropriate diagnosis.

"When we recognized this gap in care for Plain families, we knew it was our responsibility to help with a solution. We are sincerely grateful to Dr. McGee, Nemours, and the PA DOH for partnering with us in the shared mission of making audiology care more accessible for Plain newborns. Our hope is to identify hearing loss as early as possible so that children can receive timely interventions and treatments that significantly improve their quality of life," shares Alexis McVey, BSN, RN, CPN, Nursing Director at the Clinic.

This program highlights the Clinic's ability to reduce barriers to care, provide affordable and responsive healthcare, and be here for families when they need us most. Thank you to the DOH and the Nemours team for partnering on this critical collaboration!

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
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
Alexis McVey, BSN, RN, CPN | Nursing Director
Andrea Patel, RNC-NIC | Nurse
Donna L. Robinson, MSN, CRNP | Nurse Practitioner
Anne Thomas, LPN | Licensed Practical Nurse
Sarah Thomas, RMA | Medical Assistant

LABORATORY

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

RESEARCH

Karla W. Brigatti, MS, CGC | Research Director
Joelle Williamson Clark, MPH
Clinical Research Manager
Ashlin Rodrigues, MS | Clinical Research Analyst
Kevin A. Strauss, MD
Head of Therapeutic Development
Erin Sweigert | Research Associate

DEVELOPMENT

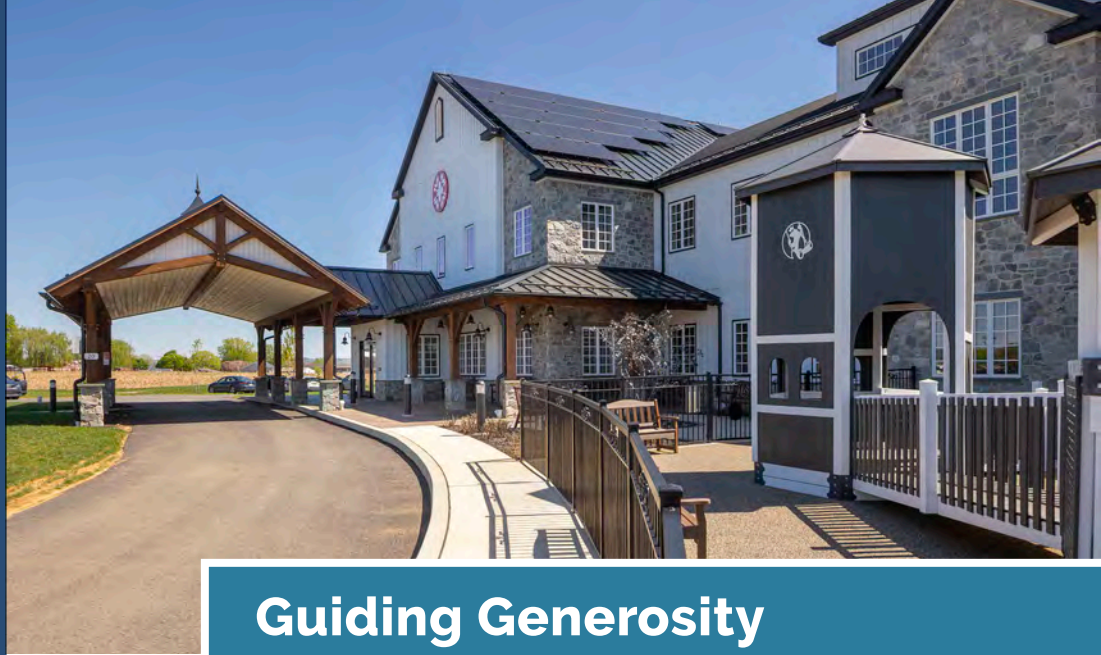
Skye Gawn | Development Associate
Renny Magill, CFRE | Development Director
Julia Martin | Development Associate
Kelly Woodson | Event Manager

ADMINISTRATION

Kimberly Broadbent | Accounts Payable Clerk
Kelly Cullen | Marketing & Communications Manager
Adam D. Heaps, MS, MBA | Executive Director
Jessica Snyder, PHR, SHRM-CP
Human Resources Generalist
William Van Ess, MS, CFE | Accounting Manager

Board of Directors

Cindy Bo, MBA | Secretary
Herman Bontrager | Chair of the Board
Elam Esh
Meg Frizzola, DO, FAAP
Leon Hoover | Vice Chair
Mark Martin | Treasurer and Chair-Finance Committee
Jacob Petersheim
Jonathan H. Salvin, MD |
Chair-Conflict of Interest Committee
Stephen Tifft, MD
Glen Zimmerman | Chair-Development Committee
Glenn Zimmerman



Guiding Generosity Spotlight on our Development Committee

Every quarter, a dedicated group of community members, patient family representatives, and seasoned fundraisers gather at the Clinic with one shared goal: ensuring the Clinic has the resources needed to carry out its mission.

This Development Committee, a formal subcommittee of our Board of Directors, provides guidance and recommendations to Clinic staff on the best ways to raise vital funds and share our story.

The committee brings together people from diverse backgrounds to help ensure all donors are valued and respected. Their insight helps us connect with different audiences, identify giving trends across communities, discover new resources, and much more.

Earlier this year, we were thrilled to welcome two new members to the committee: Carolyn Sauder and Jim Shenk. Learn more about them below!

Carolyn Sauder



Carolyn's connection to the Clinic began when her four-day-old daughter, Leah, was diagnosed with maple syrup urine disease (MSUD). Leah became a Clinic patient, received a life-saving liver transplant in 2013, and today is thriving as a 10th grader.

Even before joining the Development Committee, Carolyn generously supported the Clinic's fundraising efforts by coordinating the Friday night volunteer meal at the Lancaster County Benefit Auction and assisting with the planning and execution of the annual Community Benefit Dinner at the Martindale Fellowship Center.

Reflecting on her new role, Carolyn shared: "I'm excited to be serving on the Development Committee as the Clinic continues to serve our community and beyond. They have been a great resource for our family."

Jim Shenk



Jim first learned about the Clinic through local newspaper coverage in its early years. Now retired, he brings decades of fundraising experience, including with Mennonite Central Committee in relief, development, and peacebuilding, and 20 years as Director of Development for WellSpan Philhaven, where he also oversaw planned giving.

During his time at Philhaven, Jim partnered with the Green Pastures Board to raise funds for two major building projects and ongoing support to provide hardship aid for Plain community patients.

On his interest in the Clinic's mission, Jim shared: "I am deeply inspired by the Clinic's success in treating complex medical disorders and by the potential of philanthropy to fuel groundbreaking research and further life-changing treatments—not only for the Plain Community, but for people around the world."

2025 Benefit Auction Season

THANK YOU!

We are sincerely thankful to everyone who organized, attended, or supported this year's benefit auctions! The auctions play a vital role in funding our work, making it possible for us to continue serving families who rely on our care.

Enjoy a collection of highlights from the 2025 auction season! A heartfelt thank you to the dedicated volunteers who make these events possible each year. Your hard work and support are deeply appreciated.





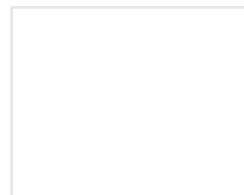
**Clinic for
Special Children®**

PO Box 500
Intercourse, PA 17534

tel (717) 687-9407

fax (717) 687-9237

ClinicforSpecialChildren.org



You can unsubscribe from our newsletter mailing list by calling us at 717-687-9407, emailing queries@clinicforspecialchildren.org, or mailing us (Clinic for Special Children, Attn: Newsletter Removal, PO Box 500, Intercourse, PA 17534).



The Clinic for Special Children is a Pennsylvania non-profit corporation and a 501(c)3 public charity for US federal and state tax purposes (Tax ID # 23-2555373). The official registration and financial information of The Clinic for Special Children, Inc. may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1 (800) 732-0999. Registration does not imply endorsement.

Hearing Health at the Clinic

Read about a young woman's journey of learning to hear again, explore information on hearing loss, and discover a new collaborative program at the Clinic.

2025 ExtraGive

On Friday, November 21st we have just 24 hours to raise \$75,000!
Learn more inside about how you can make a difference and join hundreds of others in supporting the Clinic on this day.

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.