Clinic for Special Children®

Newsletter

ISSUE #69 FALL 2026

A Clearer Path Forward
The Stauffer Family

"Our decision to get testing done through the Clinic's Plain Insight Panel™ (PIP) was the right decision for our family," reflect Justus and Ruth Stauffer. While their initial motivation for testing was to find answers for their first son, Brandon, the information they gained from the PIP ultimately helped guide care decisions for their later sons, Darren and Nolan.

The PIP test, developed and offered through our on-site laboratory, screens people from the Plain community (Amish and Mennonite individuals) for more than 1,400 genetic changes known or suspected to cause disease. For many of the genetic disorders we see at the Clinic, a child is only at risk of having a condition if both parents are carriers for the same disorder. Justus and Ruth's results showed that they were both carriers for two genetic conditions: an immune disorder called IL7R-related severe combined immunodeficiency (SCID) and a disorder called FLVCR1-related Posterior Column Ataxia with Retinitis (PCARP), which can cause vision loss and difficulty with balance and coordination.

This information not only gave the family answers about Brandon, who was diagnosed with PCARP, but also helped them understand that their future children could inherit one or both of these disorders. While expecting their second child, Darren, the Stauffers attended a SCID Family Day hosted by the Clinic, where they met other families and specialists from Children's Hospital of Philadelphia (CHOP). When Darren was born, he was diagnosed with SCID the same day through rapid genetic testing performed by our on-site laboratory. This allowed the family to quickly begin the care and treatment they needed through the Clinic and CHOP.

"After our experiences with both Brandon and Darren, we decided to get answers even earlier when expecting our third child, Nolan. We had an amniocentesis during pregnancy so we could have a diagnosis before he was born. We were able to plan even further ahead, especially knowing how much stress is involved when your baby has SCID, with things like isolation and hospital visits," shares Ruth.

When an amniocentesis showed that Nolan also had SCID, the Stauffer family was relieved to have answers before he was born and to begin planning for his treatment early. SCID is often treated with a bone marrow transplant, which requires finding a suitable donor. Because Nolan was diagnosed before birth, the Stauffers were able to begin the donor search early, giving them more time to prepare for his treatment and care.

"The PIP gives you the key to unlock early care. It sets the stage for your family to potentially save thousands of dollars and, most importantly, could help save your child's life," share Justus and Ruth. "The Clinic has been critical in connecting us with the specialists we need and coordinating our family's care. The collaboration between the Clinic and CHOP has been seamless, and we are deeply grateful."

Today, Brandon, Darren, and Nolan are all doing well and are active boys. The older brothers love riding their bikes and playing together. "What is most important to us is that our boys enjoy life as much as possible."

SPECIAL DATES

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

Christmas Eve - Office Closed
Thursday, December 24
Office closes at 1 p.m.

Christmas - Office Closed
December 25 & 28
All day

New Years Eve - Office Closed
Thursday, December 31
Office closes at 1 p.m.

New Years Day - Office Closed
Friday, January 1, 2027
All day

Good Friday - Office Closed
Friday, March 26, 2027
All day

Clinic for Special Children 5k
Saturday, May 15, 2027
Leola Produce Auction | Leola, PA

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, who was recently promoted to the new role of Genetic Counseling Manager!

In this role, Amy will focus on supporting team development and streamlining genetic counseling operations across our clinical and laboratory teams.

Vincent Carson, MD

Congratulations to Dr. Vincent Carson on 10 years with the Clinic!

For the past decade, Dr. Carson has provided exceptional care, advanced our understanding of rare genetic disorders, and offered compassionate support to hundreds of families who have found hope through his work.

Thank you, Dr. Carson, for your dedication and unwavering commitment to our mission.

Jonathan Deitrick, BSN, RN, MBA

We're excited to welcome Jonathan Deitrick, BSN, RN, MBA, to the Clinic! He joined our team in August as our Nursing Director.

Before coming to the Clinic, Jon worked as a Registered Nurse in pediatric and emergency nursing in both school health and acute care settings.

As the Clinic's Nursing Director, he oversees nursing programs, including clinical support for outpatient, outreach, and subspecialty encounters, as well as patient advocacy and home-based palliative care.

In his free time, Jon enjoys traveling with his family, hiking, exercising, and watching sports. He is a self-proclaimed huge Philadelphia sports fan!

Skye Gawn

Congratulations to Skye Gawn on five years with the Clinic!

Since joining the Clinic in August 2021, Skye has played an important role in supporting our fundraising efforts!

As a Development Associate, she manages our donor database, supports fundraising technology processes, maintains important institutional and donor data, and more.

Thank you, Skye, for your dedication and support of the Clinic's development efforts.

Brenda Yachasz, MSN, RN, CBC

We're excited to welcome Brenda Yachasz, MSN, RN, CBC, to the Clinic!

Brenda joins our team as a Nurse, bringing experience in postpartum and pediatric nursing to help care for our patients and families. She is passionate about working with both children and adults and helping each person receive the care they need.

Outside of the Clinic, Brenda enjoys traveling throughout the United States to visit her four adult children and seven grandchildren.

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 48 hours' 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.

Flu Shot & Measles Information

Flu Shot

We're approaching that time of year when seasonal viruses start going around! The best ways to protect yourself and your family during this time are to avoid exposure, practice good hand washing, and get your yearly flu shot. We recommend that everyone six months of age and older receive a flu shot each year.

Please call us at 717-687-9407 to schedule a flu shot for yourself or your child. We offer flu shots to anyone who does not have insurance or who has Medicaid.

Measles

As local measles cases continue to grow quickly, 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 to the Clinic.

The measles virus is highly contagious, and calling ahead allows us to take appropriate precautions to protect you, your family, and others in our Clinic.

Many of the children and adults that we care for at the Clinic are more vulnerable to serious complications from measles. We strongly encourage and recommend vaccination against measles, which has been proven to be safe and effective and provides long-lasting protection against the disease.

If you are unvaccinated and would like to learn more, please call us at 717-687-9407 or speak with a member of the Clinic staff during your next visit.

Thank you, Herman Bontrager!

Celebrating 16 years of dedicated service to the Clinic

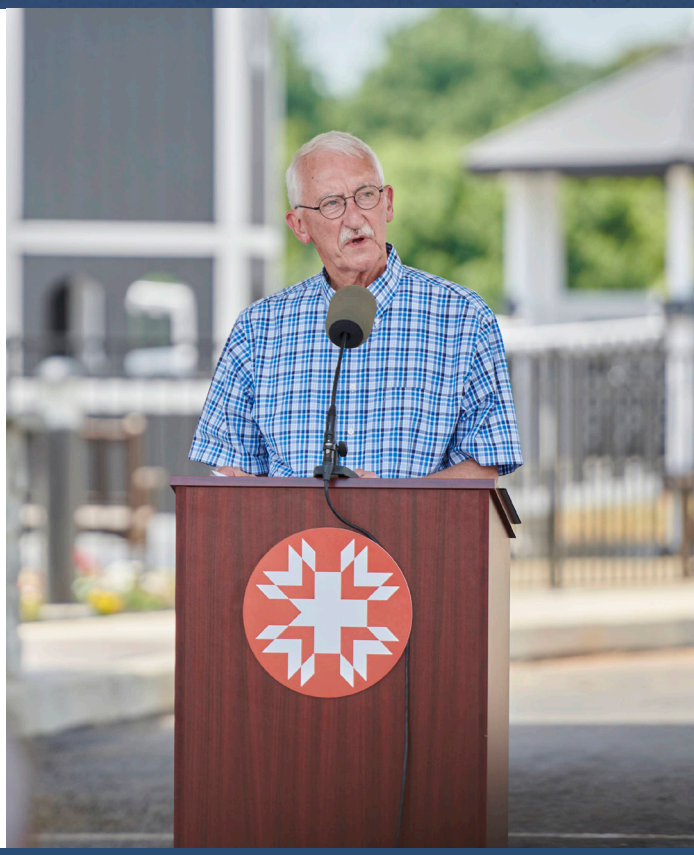
On behalf of the staff and Board of Directors of the Clinic for Special Children, we are deeply grateful to Herman Bontrager for 16 years of dedicated service and leadership. Herman will retire from the Board at the end of his term on September 30, 2026.

During his years of service, Herman has helped guide the Clinic through significant growth and change, including serving as Board Chair and Chair of the *Keeping the Promise: Building Hope* capital campaign that raised over $13 million for the Clinic's building in Gordonville. Through his leadership, he helped identify and marshal the resources needed to bring the Clinic's new building to completion.

Herman's commitment to the Clinic has always been rooted in a deep belief in its mission and the positive impact its services have on patients, families, communities, and beyond. His ability to bring people together and work thoughtfully with individuals from different communities, backgrounds, and beliefs, along with his dedication and countless hours of volunteer service, has made a lasting difference at the Clinic.

While we will miss his presence and the wisdom, friendships, and energy he brought to the Clinic, we are grateful for the many ways he has helped strengthen the Clinic and position it for a promising future.

Thank you, Herman, for your dedication and service!



EXTRA™ GIVE

Lancaster County Community Foundation · High Foundation · Murry Foundation

Friday, November 20

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 20th**! Help the Clinic **raise $50,000 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 20th 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. on Friday, November 20th 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. on Friday, November 20th 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 20th & share your page with friends and family!

A Dynamic Duo

The Plain Insight Panel™ & Newborn Screening

A question we commonly receive at the Clinic is: If I do the Plain Insight Panel (PIP), does my child still need newborn screening (NBS) (sometimes called the "PKU test" or the "heel prick test") when they are born? Our short answer is yes. NBS is still required, and the PIP is not a replacement for newborn screening. In this article, we'll explain how the two services serve different purposes and can work together to help identify genetic conditions as early as possible.

What is newborn screening (NBS)?

Every state has a newborn screening program. These programs test babies shortly after they're born for serious conditions that may not be visible at birth but can be life-threatening if not diagnosed and treated early. While the specific disorders screened for vary slightly by state, all programs focus on detecting severe metabolic, genetic, or hormonal disorders. NBS is designed to screen all babies for these serious conditions, no matter which genetic change may be causing the condition.

To complete NBS, a small amount of blood is collected from a baby's heel when they are around 24-48 hours old. The blood is placed on a special paper called a filter card to be sent to a lab for testing.

While the Clinic's lab does not run NBS testing, we do serve as an NBS follow-up center. This means that if a baby tests positive through NBS for a disorder we have expertise in, Pennsylvania's NBS team may refer the baby to us for care. Ideally, children with serious conditions are identified before they develop symptoms or other health problems. In 2025, we received 23 NBS referrals!

What is the Plain Insight Panel (PIP)?

The Plain Insight Panel (PIP) is a genetic test, developed by our laboratory, that includes more than 1,400 genetic changes, or "misspellings", that are known or suspected to cause disease within the Plain (Amish or Mennonite) communities. Many of these conditions affect a child only if both parents are "carriers" for the condition. Carriers do not have signs or symptoms of the conditions they carry, but can pass the condition to a child if both parents carry misspellings within the same gene. Several of the conditions on the PIP are also screened for with NBS. The PIP also includes some genetic changes that can provide information about a person's own health, including a mother's health before and during pregnancy. Instructions for ordering the PIP test and how to collect a blood sample are on our website, or you can call our team at 717-687-9407.

The PIP was designed specifically for people with Amish or Mennonite (Plain) ancestry and therefore isn't informative for people with other ancestry. The PIP also does not look at every possible change in a gene. Instead, it looks for specific genetic changes that are known or suspected to occur in Plain communities.

Why would I need to do both the PIP and NBS?

PIP testing and newborn screening are both important tools, but they answer slightly different questions and are used at different times. The PIP test should be completed just once per couple, while NBS should be completed for each baby. The PIP can be very helpful for adults with Plain ancestry who want to understand their risk of having a child with certain known genetic conditions, some of which are also detected by NBS. NBS tests babies directly and indicates which children may be affected by a condition.

If parents are found to be carriers for a condition through PIP testing, whenever one of their babies is born, an umbilical cord blood sample can be collected and sent to our lab for rapid genetic testing. Our lab team will check the baby for the specific genetic change of concern and, depending on the genetic change and urgency of results, can have an answer within a couple of hours to several days. In some cases, we can have the genetic test completed before the baby's NBS sample is even collected.

PIP testing looks for more conditions than only those severe, early-onset conditions detected by NBS. Couples who wish to know carrier status for conditions which are more common within the Plain community should consider PIP testing.

The PIP does not replace NBS. NBS can detect diseases in babies regardless of the underlying genetic cause. For example, a baby may have a genetic change that is different from the specific changes tested for on the PIP. This can occur if a genetic change developed brand new in the baby. In that case, the PIP would not identify the risk for the condition.

NBS can also help identify new conditions that are not yet known to us. For example, in recent years a positive NBS result alerted our staff to a previously unknown rare immune disorder in the Plain community. This prompted further investigation and research that helped us better understand the disorder and improve care. This immune disorder is now on the PIP and is an example of how NBS can help to keep babies safe.

The PIP and NBS have different strengths. The PIP can help adults with Amish or Mennonite ancestry understand their risk of having children with certain known genetic disorders before their children are even born. If a risk is identified, a baby can often be tested quickly after birth, which can improve outcomes and save families and communities significant expenses. NBS provides a broader screen for serious conditions in every baby, regardless of the specific genetic change that may be causing the condition. When used together, the PIP and NBS give babies with Amish or Mennonite heritage the best opportunity for early diagnosis, leading to earlier treatment, better outcomes, and less cost and stress for families.

How do other community providers use our Plain Insight Panel™ test?

We asked, they answered!

Stacy Chubb, MSN, CRNP, FNP-C
Certified Registered Nurse Practitioner
Compassion Parochial Clinic
Mifflinburg, PA

"The Plain Insight Panel (PIP) has become an integral part of my daily clinical practice. PIP testing provides valuable reassurance to expectant families by identifying inherited genetic and metabolic conditions through preconception screening. Early identification allows for timely education, counseling, and care planning, significantly reducing time to diagnosis and initiation of appropriate treatment when needed.

In addition, PIP screening helps guide the management of inherited conditions such as familial hypercholesterolemia and identifies genetic variants associated with statin-induced myopathy, supporting more personalized treatment decisions."

"The PIP is one of the most useful tools that I have in providing genetic counseling to the Plain community. I've witnessed PIP results provide reassurance to families as well as answers for puzzling symptoms or the reason for the death of a loved one. The PIP has many conditions unique to or more common in the Plain community that are not included on carrier screening panels available at commercial genetic testing laboratories, so the PIP truly does live up to its name in providing invaluable genetic insights for the Plain community.

I enjoy collaborating with the Clinic for Special Children in developing future versions of the PIP by providing phenotypic information on certain variants and suggesting variants to add based on new conditions CHC discovers in our local community."

Nicole Bertsch, MS, CGC
Certified Genetic Counselor
The Community Health Clinic (CHC)
Shipshewana, IN

Rose Fisher, CNM
Certified Nurse Midwife
Rose Fisher Midwifery, LLC
Mifflin, PA

"As a homebirth midwife, I love it if my clients are willing to do the PIP. When we understand what a child is at risk for, we can develop an appropriate treatment plan and, in some cases, take steps that can be lifesaving.

PIP results can help provide clarity for families, usually showing that couples are not carriers for any of the same disorders. Sometimes when parents are identified as mutual carriers, it helps us plan. For metabolic conditions that affect how a baby can use breast milk, we send cord blood to the Clinic after birth, and within a few hours the baby can start a special formula to prevent lifelong damage. For heart defects, an ultrasound can help them choose the safest location for delivery and prepare for the care their baby may need.

With clear information, families can make wise decisions with greater confidence and peace of mind."

Our Staff

MEDICAL

Vincent J. Carson, MD | *Pediatric Neurologist*
Julia A. Goroff, DO | *Pediatrician*
Grace L. Meier, MD | *Family Medicine Physician*
Kurestin Miller, MD
Internal Medicine and Pediatrics Physician
Laura Poskitt, DO | *Medical Director*

FRONT OFFICE

Jennifer Giacoio, CMAA | *Patient Navigator*
Candace Kendig, RMA | *Practice Manager*
Peggy Riehl | *Medical Receptionist*
Dawn Sheets, GCA, CMAA
Medical Receptionist and Genetic Counseling Assistant

GENETIC COUNSELING

Amy Albright, MS, CGC | *Genetic Counseling Manager*
Samuel Miller, MS, CGC | *Genetic Counselor*
Susan Walther, MS, CGC | *Genetic Counselor*

NURSING

Keturah Beiler, BSN, RN, CHPPN
Cherished Lives Program Manager
Jonathan Deitrick, BSN, RN, MBA
Nursing Director
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*
Brenda Yachasz, MSN, RN, CBC | *Nurse*

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

Karlla W. Brigatti, MS, CGC | *Research Director*
Joelle Williamson Clark, MPH
Clinical Research Manager
Justin Hersh | *Research Associate*
Ashlin Rodrigues, MS | *Clinical Research Analyst*

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 Manager
William Van Ess, MS, CFE | *Accounting Manager*

Board of Directors

Cindy Bo, MBA | *Secretary*
Elam Esh
Meg Frizzola, DO, FAAP
Leon Hoover | *Chair of the Board*
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 | *Vice Chair*

Make the Most of Your 2026 Giving

by Renny Magill, Development Director

The Clinic's mission depends on the generosity of donors. In fact, 70% of the Clinic's operating revenue comes from charitable donations from benefit auctions, individuals, businesses, and foundations. Your support directly funds clinical services, patient assistance, laboratory services, and research! Here are a few tips to make sure that you maximize the benefit of your contribution to the Clinic, and to yourself:

2026 Tax Season

When you file your 2026 taxes, you will have an opportunity to deduct up to $1,000 if filing singly, or $2,000 if filing jointly, of your charitable contributions. You will be eligible for this, even if you do not itemize any other deductions. If you contributed in 2026 to the Clinic and want to use your contribution for this deduction, make sure you keep your thank-you letter, which is a receipt of your gift. Misplace yours? Please feel free to call or email, and we'll be glad to issue you a duplicate copy!

One easy way to take advantage of this new tax benefit is to contribute to the Clinic's year-end appeal. This mailing will be in your mailbox in late November/early December, and after you contribute, you will receive a thank-you letter that you may be able to use for a deduction.

IRA Distributions

If you are required to take a distribution from your IRA, did you know that you can make a gift from a portion (up to $100,000) of your required minimum distribution to a charitable organization like the Clinic? Please note that you will need to contact the company that manages your IRA, and the distribution must come directly from them. When you make a qualified charitable distribution (QCD) from your retirement account, the amount you contribute will not be subject to income tax.

"Since I have been taking required minimum distributions (RMD) from my IRA, I have found that giving a portion to the Clinic has been a win-win situation. It is tax-free, but even more importantly, it is an excellent way to support an organization that I truly believe is providing unparalleled medical care to our community," shares Stephen Tifft, MD, retired pediatrician and member of the Clinic's Board of Directors.

Estate Gifts

Have you considered including a gift from your estate to the Clinic for Special Children? Estate giving is a way to make a lasting gift to the Clinic by designating the Clinic for Special Children as a beneficiary in your Will, estate plan, IRA, or life insurance policy. It is always good to check with your trusted financial advisor to see if this option is right for you.

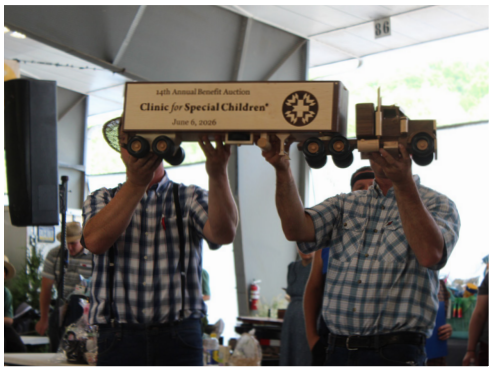
If you have any questions regarding giving to the Clinic, please contact Renny Magill, CFRE, Development Director, at 717-687-9407 or rmagill@clinicforspecialchildren.org.

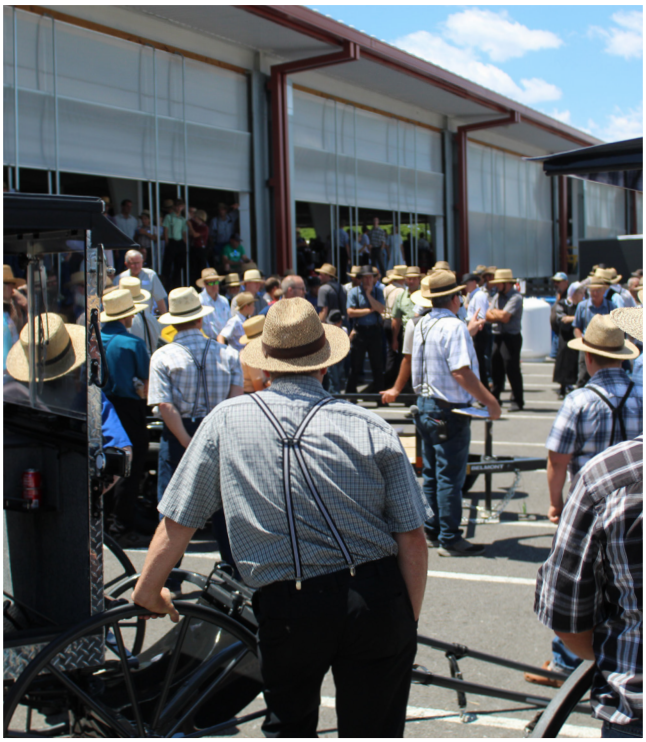
2026 Benefit Auction Season

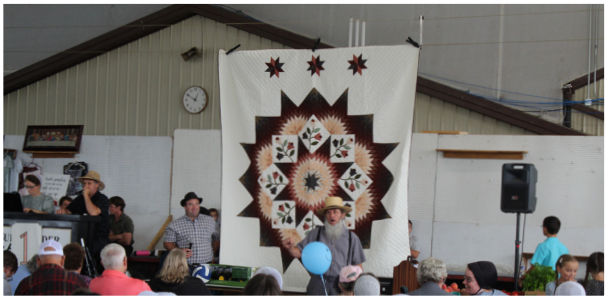
Fun, Food, Fellowship, & Fundraising

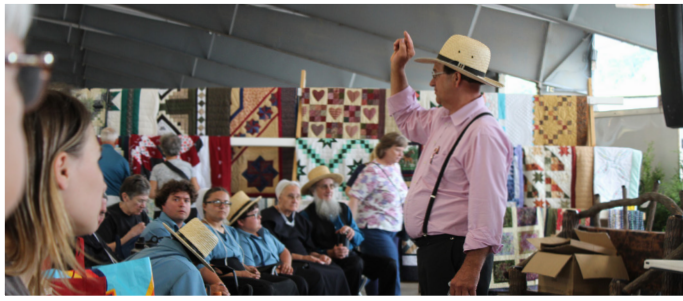
Our 2026 benefit auction season has brought together communities across the country in support of the Clinic for Special Children. We are deeply grateful to everyone who volunteered, attended, donated, sponsored, purchased, and helped make each auction a success.

Auction proceeds make up a substantial part of the Clinic's annual budget, helping us provide care, genetic testing, research, and support to families facing rare genetic disorders. Thank you for making our work possible! Enjoy a few photos from this year's auctions.









Clinic for Special Children®

PO Box 500
Intercourse, PA 17534

tel (717) 687-9407
fax (717) 687-9237

ClinicforSpecialChildren.org

Using Genetic Insight to Guide Care

This issue features how genetic testing, specifically our Plain Insight Panel™ test, can provide answers, guide care, and, in some cases, save lives.

2026 ExtraGive

On Friday, November 20th, we have just 24 hours to raise $50,000 for the Clinic! Find out how you can help us reach our goal and join hundreds of other supporters in making a difference for the Clinic!

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.