Putting Down New Roots

2024 Annual Report

Clinic *for* Special Children®

Our Mission

TO SERVE CHILDREN AND ADULTS

who suffer from genetic and other complex medical disorders by providing comprehensive medical, laboratory, and consultative services, and by increasing and disseminating knowledge of science and medicine.

Our Vision

We envision the Clinic for Special Children as a

COMPREHENSIVE MEDICAL PRACTICE

for predominately Amish and Mennonite children and adults who are born with genetic predispositions to disability, chronic disease, or untimely death. We continually strive to integrate advanced scientific tools and concepts into clinical practice so that genetically vulnerable people have access to timely, affordable, and effective healthcare.

The Clinic represents an innovative and holistic approach to modern medical care that can inform the practice of genomic medicine in other settings. We seek opportunities for education and collaboration that promote the well-being of genetically disadvantaged, underserved people throughout the world, and are dedicated to training the young clinicians and scientists who will care for these individuals now and into the future.

GENERAL *STATS*

35 *years serving the community*

33 *staff members*

Ribbon cutting ceremony | June 2024

Putting Down **New Roots**

Friends,

At the groundbreaking ceremony of our new home in Gordonville, we continued a long-standing Clinic for Special Children tradition from our original founding. We planted a small, red Japanese maple tree at the entrance of our building. The tree stands as a symbol of the strength and resilience of all who pass through our doors in search of care, comfort, and answers for their complex genetic disorders and medical needs.

After many years of planning, building, and fundraising, we officially 'replanted' our operations to our new facility in Gordonville in April 2024. In June, we celebrated the generous support of thousands of companies, individuals, and foundations who made our new home a reality at our ribbon-cutting ceremony (pictured above).

Looking back on 2024, it was a year of great change for the Clinic. Not only did we manage the relocation without disruption of clinical or laboratory services, we also had an internal reorganization of staff and launched a strategic planning process.

As we look ahead, we continue to see increased, patient-driven demand in all areas of the Clinic: clinical care, in-house laboratory services, and patient-focused research. Our ongoing work of caring for families when they need us most, finding diagnostic answers, and searching for new treatments is only possible with the continued support of many people, like you. If you were introduced to us through our building project, we invite you to continue supporting our critical, ongoing mission.

With your steadfast support, the roots of our work at the Clinic will continue to grow deeper and our branches higher. On behalf of the staff, board of directors, and families at the Clinic for Special Children, we are deeply grateful to you for cherishing the lives of children and adults facing rare genetic disorders.

Adam D. Heaps, MS, MBA
Executive Director

Infusions at the Clinic

The Reiff Family's Story

"There's much more room and the new space makes it much easier to keep a toddler entertained for four hours," Rosene and Ivan Reiff share of their long infusion visits at the Clinic's new building. "At the old facility in Strasburg, there was just one hallway and smaller rooms, but now there's a loop we can walk and a kid's area in the waiting room for Kyler to play."

The Reiffs have three children, Angela (six years old), Jayna (three years old), and Kyler (22 months old, pictured on the right), who frequently visit the Clinic for infusion treatments. Each child has been diagnosed through the Clinic's laboratory with osteogenesis imperfecta (OI), a rare genetic disorder. OI causes brittle bones that can break easily, bones that do not form properly, and other problems. Angela, Jayna, and Kyler all receive medication for OI called pamidronate, which is delivered via intravenous (IV) infusion for up to four hours at a time, three days in a row. These IV treatments are typically only available in hospital settings, but seeing the need, the Clinic arranged to offer this service in-house.

The upgrades at our new facility make these marathon visits much more comfortable for families, like the Reiffs. "The Clinic has made such a big difference in the care of our children. Even though we travel about two hours each way to the Clinic, it's more affordable than getting the infusions done at larger hospitals," explains Rosene and Ivan.

The Clinic's new facility includes an IV prep room for staff, spacious family gathering rooms, larger exam rooms, and areas for children to play - all thoughtfully designed around the needs of families, like the Reiffs, who visit the Clinic for longer stretches of time.

"Having the dedicated space for infusion preparation, and storage of IV supplies and medications, makes it much easier to serve the families who visit us for IV treatments. It's been great to see families taking advantage of the kid-friendly spaces we have now during their long appointments. The new facility makes IV treatments easier for the families and our staff administering them," shares Donna Robinson, MSN, CRNP, Nurse Practitioner at the Clinic.

Due to the support of many donors and supporters, we offer our infusion services for just $200 - $1,200 per day at the Clinic. The cost for a similar service in a hospital setting can easily exceed $10,000 per day. The Reiff family's story is just one example of how donations to the Clinic have a deep impact on the families who visit us for specialized care and treatment.

PATIENT CARE *STATS*

1,688 *active patients*

from **46** *states &* **17** *countries*

5,854 *tests ordered through our laboratory to diagnose or manage genetic illnesses*

4,813 *patient encounters*

The Plain Insight Panel™

What have we learned in five years?

Since its launch in 2019, our Plain Insight Panel™ (PIP) genetic carrier screen has accelerated diagnostics and improved care for families facing rare genetic disorders in the Plain communities across North America. Developed by and performed only at our Clinic, the PIP identifies couples at risk of having children with recessive conditions. Proactive screening of young couples helps us ensure the best start for a baby after birth, especially when treatment is available.

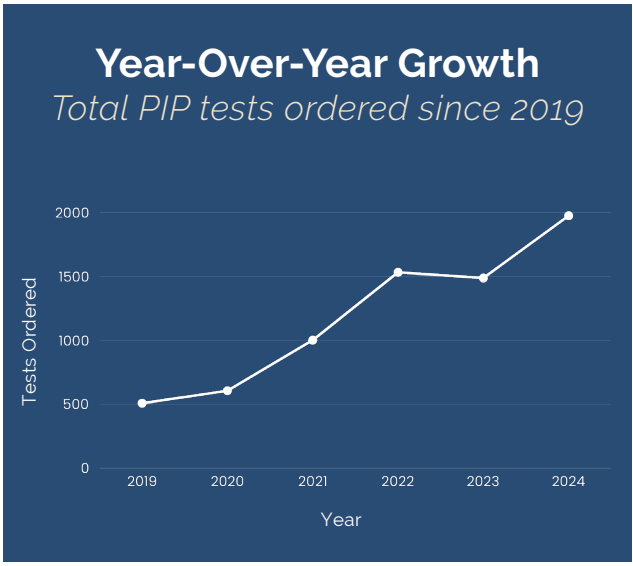
Over 6,500 individuals have gained insight into their carrier status through the PIP test, which screens for over 1,300 genetic variants identified in the Amish and Mennonite communities. What lessons have we learned from the PIP over the past five years?

Increasing demand for genetic insights

The demand for the PIP in the Plain community has increased at an average of 33.5% year-over-year since 2019. As of January 13, 2025, our in-house laboratory has completed 6,745 PIP tests. Of the individuals tested, 60% are Mennonite and 40% are Amish.

What have we learned?

The PIP provides invaluable knowledge about genetic susceptibility to disease for an individual and a couple. In an analysis of the first several thousand PIPs, 57% of participants found personally actionable results with implications for their health or the health of their offspring. On average, each person carried four to five disease-associated variants, and 25% of couples were mutual carriers for a variant in the same gene, putting them at risk of having a baby with a recessive genetic condition. Once we identify at-risk couples, cord blood testing on newborns can be performed in our laboratory for rapid diagnosis and treatment before the children become ill.



Ordering providers

The majority of PIP samples submitted to our laboratory (38%) are ordered by physicians and clinics serving the Plain communities throughout North America. These include our own Clinic physicians (11%) as well as providers at collaborating Plain clinics throughout the country (27%).

The second largest group of PIP samples (30%) is submitted by midwives, who form a critical network of care providers at the forefront of pregnancies and home births. Finally, the third largest group of PIP samples (28%) is submitted by the person being tested.

Advocacy by midwives and other healthcare organizations for the importance of the PIP has undoubtedly saved healthcare dollars and improved outcomes for affected children.

Accessibility

One of our goals is to reduce barriers faced by people in the Plain community when accessing healthcare. In addition to offering PIP testing in our clinical setting, we host testing drives each year at benefit auctions and fundraising dinners throughout the Plain communities —from Lan-

"The **Plain Insight Panel helps prevent children from possibly suffering in multiple ways**, not only from the condition itself but also **from unnecessary testing**. The PIP has helped us provide early diagnoses for many of our patients, allowing us to connect families with specialized care teams earlier than we could before, **sending children home from the hospital much sooner.**"

Katie A. Preedy, APRN-BC
Nemours Children's Hospital Delaware

caster County to northern Missouri—in order to further our reach.

The current cost to the Clinic for each PIP test is over $550, which includes materials and labor. Thanks to donations and grants, we currently offer the PIP to families at a subsidized price of $150 per person. The widespread success of the PIP is only possible due to the generous support of many donors who enable us to offer this testing at an affordable price.

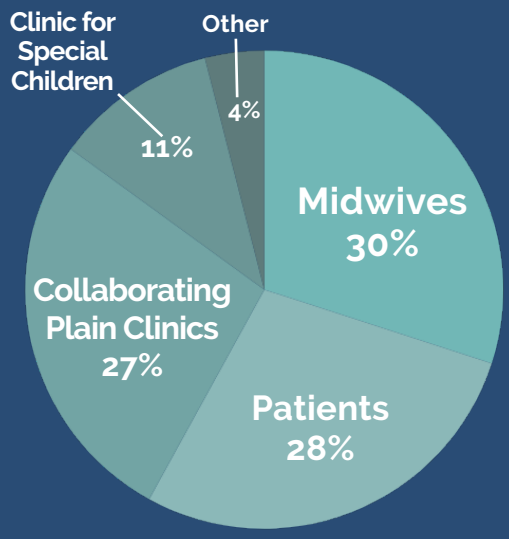
Version 3.0 and ongoing learnings

Our laboratory is launching an updated, third version of the PIP in early 2025! This version will include additional, new genetic variants identified through research and patient care that might impact the health of individuals in the Plain community.

We will continue to improve the PIP as we learn more about the relationship between genetics and health in the Plain communities.

Who's Using the PIP?

Ordering providers since 2019



2024 LABORATORY *STATS*

1,974 *PIP samples ordered*

5,457 *total samples received*

30
NEW *disease-related genetic variants discovered*

281
cord blood samples tested

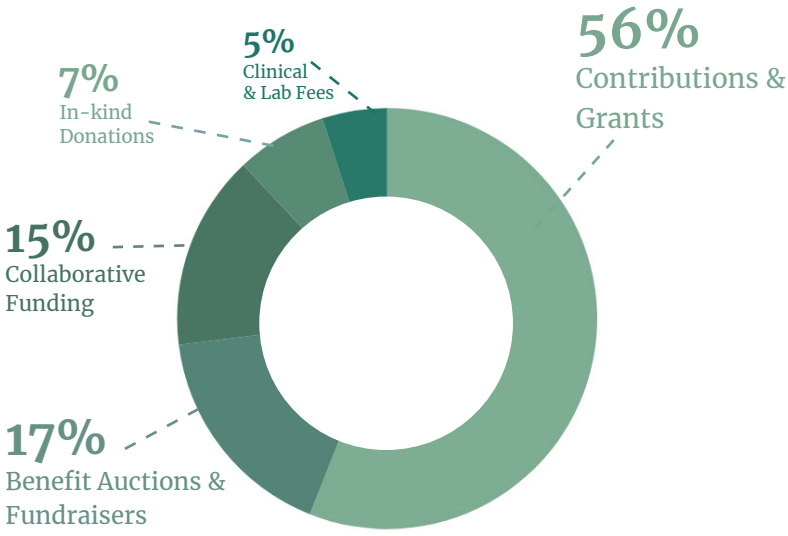
Financials Overview

Our fiscal year in review

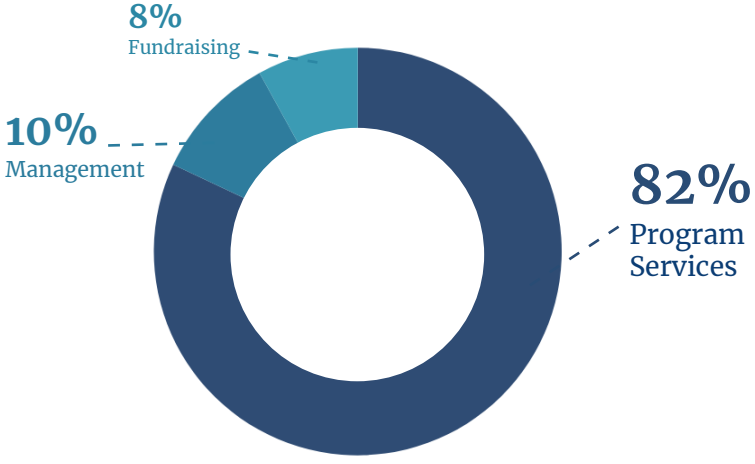
As a private, independent non-profit organization, philanthropy and support from the community is vital to achieving our mission. In 2024, our financials show a larger percentage for contributions, grants, and in-kind donations than in past years, largely due to our *Keeping the Promise: Building Hope* capital campaign fundraising. Each year the large majority of our budget, over 90%, comes from philanthropic sources like benefit auctions, fundraisers, contributions, and grants, as well as collaborative relationships. We hope our financials show just how critically important the support of many people is to allow us to accomplish our mission.

2024 REVENUE SNAPSHOT

73%
of CSC's 2024 revenue came from philanthropic sources like benefit auctions, fundraisers, contributions, and grants.



2024 EXPENSES SNAPSHOT



The Impact of Your Support

How your donations help us care for families

Our everyday work at the Clinic for Special Children of caring for vulnerable families, finding genetic answers, and searching for new treatments is only possible through the philanthropic support of many people. Below are several examples of how, in 2024, your support helped families facing rare genetic disorders find accessible, comprehensive, and innovative care at the Clinic for Special Children.

2,139 hours

Time spent with families in new or routine patient appointments caring for their complex medical needs in 2024

30 variants

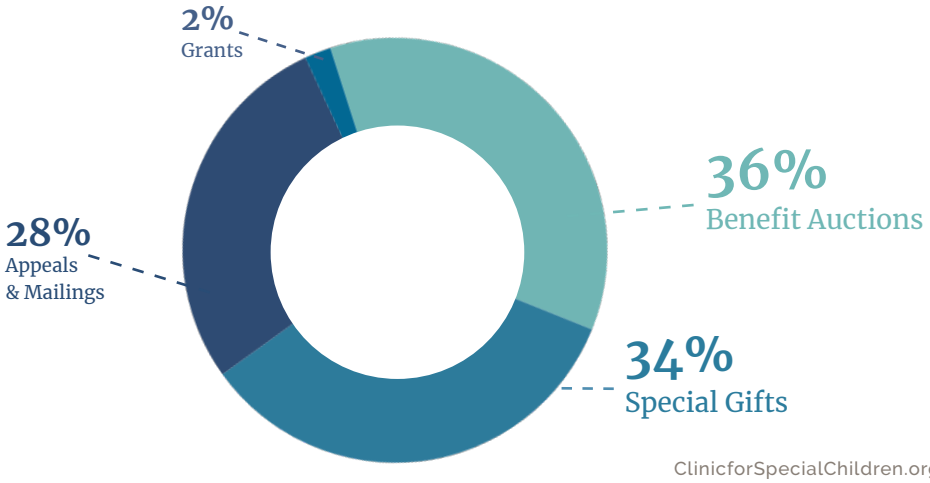
New disease-related genetic variants discovered in our on-site, CLIA-certified laboratory

15%

On average, the cost of our services covered by patient or laboratory fees. Philanthropic support allows us to charge only nominal fees for our innovative services.

SUPPORT FOR THE CLINIC IN 2024

Thanks to the generosity of individuals, groups, businesses, and foundations, over $5 million in operating support was provided to the Clinic in 2024. As you can see in the graph below, it takes contributions in a variety of ways to support our mission of providing world-class medical care, research, and laboratory services cost-effectively. We are grateful for your generosity!

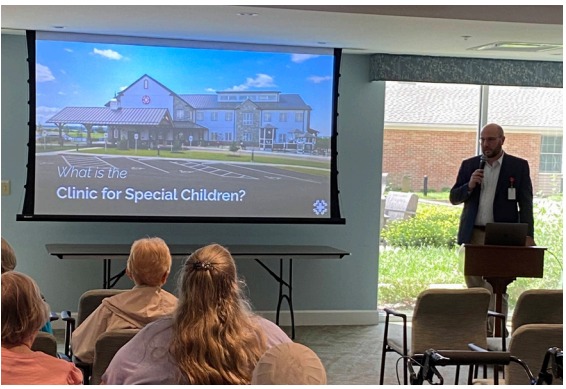


Community Outreach

Sharing about our mission and work

Family Educational Days

For the first time in many years, we hosted three of our educational 'family days' on-site at our Clinic! Each family day brought together patient families facing a specific rare genetic disorder and experts to learn about new treatments, updates in research, and more.

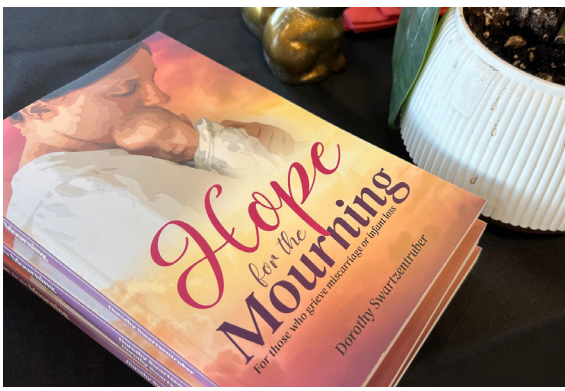


Community Talks

Our team visited local retirement communities, healthcare systems, community centers, and churches this past year to share about our work in caring for families facing rare genetic disorders. Thank you to everyone who attended one of our informational talks in 2024!

Bereavement Gatherings

As part of our Cherished Lives palliative care program, we organized monthly mother's groups and an annual dinner to gather families who have faced the loss of a child due to a genetic illness at the Clinic. We cherish this time of helping families remember their loved ones.



FINANCIAL *STATS*

73%

of 2024 revenue came from philanthropic sources

$6.8 million

2024 operating budget

Keeping THE Promise

A Campaign for the Clinic for Special Children

We are deeply grateful

We launched the *Keeping the Promise: Building Hope* capital campaign in June 2022 filled with cautious hope and optimism. The **new building project represented the goal to 'keep our promise'** to care for children as they age, seek the promise of life-saving therapies, and be here for families when they need us for generations to come.

Because of over 2,800 generous supporters, we were able to build our new facility and we closed active outreach for our capital campaign at the end of 2024. In April 2024, we moved operations to our new, 28,000-square-foot home in Gordonville, PA. At the end of the year, we were elated to receive an innovative and generous partnership gift of $250,000 from Ephrata National Bank to seed the Sustainability Fund. Through this partnership, donors can participate in a match, which will significantly impact the Clinic's funds for ongoing sustainability.

It's been inspiring to see the real differences the building is making for families - a fully accessible playground greeting children at our entrance, more space and resources to provide compassionate care, and an integrated laboratory to find answers more quickly, to name a few.

With the overwhelming support we received, even as costs ran higher than expected, we were able to fully fund the entire cost of purchasing the land and building the clinic. **Our deepest gratitude to everyone who helped us achieve this milestone in the Clinic's history** - as always, we cannot do our vital work without you.

Waiting Room

Adult Exam Room

Clinic *for* Special Children®

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
Office 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
Nurse

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

Karlla 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

Leon Hoover
Vice Chair

Mark Martin
Treasurer
Chair- Finance Committee

Jacob Petersheim

Jonathan H. Salvin, MD

Stephen Tifft, MD

Glen Zimmerman
Chair- Development Committee

Glenn Zimmerman

P.O. Box 500
Intercourse, PA 17534

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

ClinicforSpecialChildren.org