

Reaching New Heights



2025
Annual Report



Clinic for
Special Children[®]

Our Mission

IMPROVING THE QUALITY OF LIFE

for those with **genetic or other complex medical conditions** through innovative **research**, accessible **laboratory services**, and compassionate **care**.

Our Values

COMPASSION

We practice empathy and understanding.

CURIOSITY

We approach situations with humility and a desire to learn.

INNOVATION

We seek creative and meaningful solutions.

RESPECT

We build trust through consistent and ethical behavior.

TRANSPARENCY

We communicate clearly and openly.

GENERAL STATS

36 *years serving the community*

35 *staff members*



Alex enjoying our playground

Reaching New Heights

Friends,

The inspiring image of a young patient, Alex, featured on the cover, sets the theme for this year's annual report: *Reaching New Heights*.

In 2025, we completed a comprehensive strategic planning process, setting an ambitious course for the Clinic through 2029. This process was guided by how we can collectively ascend to new heights by focusing on three essential pillars: *Expanding Accessible Care*, *Engaging in Impactful Research*, and *Sharing Knowledge*. This annual report will detail the impactful work we accomplished in 2025 and outline how these strategic areas will guide our journey toward 2029 and beyond.

Beyond defining our strategy, we refreshed our mission statement and formalized our organizational values (detailed on page 2). These will serve as unwavering core principles, guiding actions we take to fulfill our mission in the coming years.

One thing remains constant each year: we continue to experience an increase in the patient-driven demand for our comprehensive services. This continuous growth spans all critical areas of the Clinic: compassionate clinical care, specialized in-house laboratory testing, and innovative research.

Our essential work of providing families with accessible medical care, diagnostic answers, and the hope of new treatments for rare genetic disorders is made possible solely through the continued support of generous people like you.

As we look ahead to achieving the goals outlined in our strategic plan, we are filled with optimism and purpose. We pursue our path to reaching new heights in care accessibility, research innovation, and knowledge dissemination, knowing that your partnership is what makes this work possible.



Adam D. Heaps, MS, MBA
Executive Director

Expanding Accessible Care

at the Clinic for Special Children & beyond

Affordable, accessible care is at the heart of our mission.

Learn how our compassionate outreach supported families across the United States. Discover the impact we've made in 2025 and see how we're expanding our reach in 2026.



The Hoover Family

"After traveling **250 miles to Lancaster for almost 19 years** with our daughter, Lavina, it is **VERY** nice to have the outreach clinic here in Penn Yan. As everyone with experience realizes, **it is a lot less stressful for everyone involved. THANK YOU very much for making it happen.**"

Penn Yan, New York



Memphis, Missouri



The Fox Family

"Being seen by Dr. Vincent Carson from the outreach clinic **within 10 miles from home saved us many miles of travel.** We are excited about the future of clinic outreach here in Missouri."



PATIENT CARE STATS

1,624 *active patients*

5,171 *patient encounters*

Updates from

Laura Poskitt, DO
Medical Director

Alexis McVey, BSN, RN, CPN
Nursing Director



Expanding Outreach

Our outreach program is growing! In 2025, we added new outreach clinic sites in Newville, PA, Penn Yan, NY, and Memphis, MO. Christine Hendrickson, RN, BSN, PED-BC, a longtime nurse at the Clinic, stepped into the new role of Outreach Program Manager. In 2026, we will continue to prioritize bringing care closer to families.

Specialty Care

We offer access to over 18 on-site specialty services, like cardiology, ophthalmology, and audiology. Through strategic planning in 2025, we identified new specialties to add to serve families better. We're currently working with collaborators to offer physical therapy and maternal fetal medicine at the Clinic in 2026.

More Enjoyable Visits

We understand that doctor visits can be stressful for our patients. In 2025, thanks to a local foundation, we introduced therapeutic play support to help ease that anxiety. We now offer sensory tools, music, games, and specialized medical training dolls to make visits more comfortable. In fact, some families have shared that their children now look forward to their appointments!



46 states & **17** countries

where our patients have lived & traveled from to visit us for care

189 outreach patients

Engaging in Impactful Research

to improve quality of life with new therapies and strategies



Our impactful research allows us to translate knowledge into actionable ways to improve health.

We share how our innovative, patient-driven research has made a difference in 2025 and the new therapies and strategies we're pursuing in 2026.

Updates from

Karla Brigatti, MS, CGC
Research Director

Erik Puffenberger, PhD
Laboratory Director



Non-invasive Prenatal Testing

Throughout 2025, our team worked to develop an in-house Non-Invasive Prenatal Test (NIPT) for 11 genetic disorders prevalent in Plain communities. By analyzing fetal DNA fragments from a simple maternal blood draw, we can identify conditions that require early medical intervention to provide the best outcomes.

Expected to launch in 2026, this screening gives families and doctors the information they need sooner, ensuring every baby receives the best possible care the moment they need it most.

Published Papers

This year, we published seven peer-reviewed research papers. Our research spanned a broad spectrum, including novel gene discovery, the natural history of specific disorders, and population genetics within the Plain community.

LABORATORY & RESEARCH STATS

6,107

tests ordered through our laboratory to diagnose or manage genetic illnesses

32

collaborators we worked with in 2025

Plain Insight Panel™

Demand for our Plain Insight Panel carrier screening test continues to grow annually. This panel screens individuals from Plain communities (Amish or Mennonite) for over 1,400 genetic variants known or suspected to cause disease.

As of December 2025, we have screened nearly 9,000 individuals across 40 states and two Canadian provinces. Notably, 57% of participants received results with actionable implications for their own health or that of their children. To ensure the program remains accessible, we currently offer the test at a heavily subsidized price and are exploring ways to sustain this vital service for years to come.

Prenatal Intervention

As the Brubaker family's story demonstrates, many genetic disorders seen at the Clinic manifest in utero. The success of our Plain Insight Panel, paired with our upcoming Non-Invasive Prenatal Testing (NIPT), will allow us to provide crucial diagnoses before birth—especially for conditions where immediate access to specialized care is lifesaving.

Pursuing prenatal interventions is a core component of our strategic plan. By identifying these conditions early, we can modify birth plans and facilitate emerging in utero therapies that offer the best possible start for children facing these disorders.

To support this mission, our research team is actively studying the natural history of these specific disorders and collaborating with experts in prenatal treatment modalities to ensure we are ready to deliver the next generation of care.

The Brubaker Family

"We're grateful to everyone at the Clinic for the dedicated service we have received. Three of our sons, Tristan, Tyrell, and Trenton, were diagnosed with spinal muscular atrophy (SMA), a rare progressive muscular disease. Sadly, our firstborn son, Tristan, passed away before treatments became available.

Tyrell was diagnosed at birth and treated with gene therapy on day eight of life. **Even though he was treated quickly after birth, we noticed some weakness.** He was started on a second therapy, and regained some strength. Today, he is over four years old, and despite muscle weakness, it's a miracle what he can do.

In 2023, **knowing how critical time is in treating these babies, we decided to induce the delivery of our son, Trenton, at 37 weeks after discovering during prenatal testing that he had a high chance of having SMA.** We immediately started on an oral medication, and he received gene therapy at a week old. **The difference in early intervention is clear:** Trenton never showed signs of weakness and has amazed us with his strong muscles. At almost two years old, he has reached every milestone at a normal age."



Pictured above: Tyrell & Trenton Brubaker

27 *in-progress research studies throughout 2025*

26 *NEW disease-related genetic variants discovered*

Sharing Knowledge

to enhance the care of rare genetic disorders

At the Clinic, our work extends beyond our exam rooms.

We view knowledge-sharing as a vital responsibility, translating our specialized research and clinical findings into training for healthcare providers and community members alike.

See how we are sharing our expertise to create lasting change in the treatment and care of rare genetic disorders.



Lizzie Sensenig

Midwife

“One of the first midwife conferences I attended at the Clinic had a talk by Dr. Chowdhury on how the newborn heart works & offering pulse ox meters have been a real asset in detecting early serious heart defects for quite a few of my babies. Now with the Plain Insight Panel™ test, I feel as a midwife we have a lot more tools and knowledge to catch babies before a crisis.”

Janet Selman, CNM

Certified Nurse-Midwife

“The Plain Community trusts the Clinic. So when I talk about what I’ve learned at a conference run by the Clinic, they trust that information. And by disseminating what I learn, they can start hearing about new treatments, new therapies, things that might sound really scary, especially to folks who haven’t had a basis in science education. Because the information is coming from sources they trust, it can start to feel a little more familiar, a little safer, and they are more likely to be receptive to it.”





Updates from Across the Clinic



Grand Rounds & Talks

Sharing the Clinic's knowledge is a collective responsibility. Our physicians frequently present at local and national healthcare systems, and international conferences to discuss our research and community care models. Beyond clinical settings, we engage with local retirement communities, rotary clubs, and schools to raise awareness of our groundbreaking work.

Midwife Conference

In 2025, we hosted our biennial midwives conference, welcoming over 60 attendees for a day of learning at the Clinic. Our *Birth & Beyond: Tools & Advances in Maternal & Newborn Care* conference featured experts from the Clinic, providers from local children's hospitals and healthcare systems, representatives from the Pennsylvania Department of Health, and more.

Specialized Trainings

In 2025, we introduced S.T.A.B.L.E., a specialized neonatal education program led by a Clinic nurse. Focused on post-resuscitation and pre-transport stabilization for sick infants, the program launched with two full sessions attended by practicing community midwives.

Family Days

We hosted three family days in 2025, focusing on immune deficiencies, properdin & CFI deficiencies, and myotonic dystrophy. Each family day brings together clinicians, researchers, care providers, and families to share updates on specific disorders.



Financials Overview

of our fiscal year

Charitable giving is critical to accomplishing our work as an independent nonprofit.

In 2025, consistent with previous years, close to 70% of our operating budget was powered by charitable sources, including benefit auctions, grants, and individual contributions. These financials underscore a vital reality: our impact is made possible only through the collective generosity of our supporters and partners.

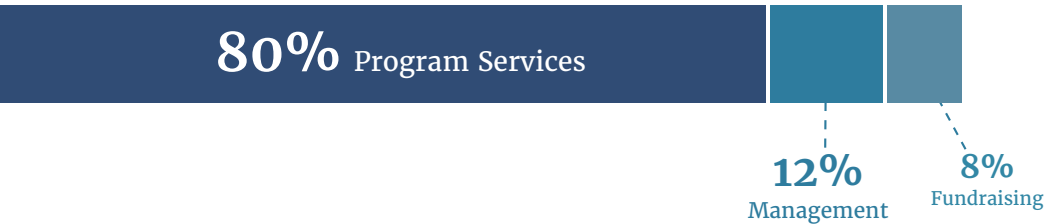
2025

REVENUE SNAPSHOT



2025

EXPENSES SNAPSHOT



FINANCIAL STATS

68% *of our 2025 revenue came from charitable sources*

\$7.4 million
2025-2026 operating budget

Generous Giving

throughout 2025



2025 CSC 5k

Saturday, May 17, 2025

Following a brief hiatus, our 5K race returned in 2025 with a fresh Leola location and a new May date! The response was incredible: over 445 participants joined us to raise more than \$70,000 for our mission. This record-breaking event also featured a Kids' Color Fun Run, where 80+ children sprinted through clouds of color. We are deeply grateful to the runners, sponsors, and volunteers who made this return a success.

Updates from

Renny Magill, CFRE

Development Director



New HPLC Machine

Thanks to the generosity of 21 donors, last year we replaced a vital High-Performance Liquid Chromatography (HPLC) machine that was nearing the end of its lifespan. This essential equipment is used daily in our on-site laboratory to monitor amino acid levels in patients with metabolic disorders, providing the critical data we need to adjust diets and prevent serious complications.



SUPPORT FOR THE CLINIC IN 2025

While financial uncertainty gripped the headlines in 2025, generous donors ensured the Clinic's continued success. Individuals, groups, businesses and foundations contributed nearly \$4 million in operating support in fiscal year 2025, which was 68% of our overall revenue. In the chart below you will see the ways that donors supported the Clinic's mission of improving the quality of life for those with genetic or complex medical conditions. Thank you for your generosity!

46% Benefit Auctions

26%
Appeals & Mailings

25%
Special Gifts

3%
Grants



Staff Photo | May 2025



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
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

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

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 Manager

William Van Ess, MS, CFE
Accounting Manager

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Stephen Tifft, MD

Glen Zimmerman
Chair- Development Committee

Glenn Zimmerman

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