PRESS KIT

Clinic *for* Special Children®

Internationally recognized as an innovative MEDICAL & SCIENTIFIC organization

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.

ABOUT US

Since our founding in 1989, the Clinic for Special Children (CSC) has endeavored to bring compassionate clinical care to children and adults with complex medical disorders. While our focus is the treatment and research of disorders identified in Old Order Amish and Mennonite communities, the impact of our clinical and research work has been felt all over the world. We are envisioned as a comprehensive medical practice for patients, meaning they can see physicians knowledgable about their disorder for all their medical needs. We provide high-quality, affordable, and accessible care to those who need it most, children and adults with rare genetic disorders and complex medical needs.

2023 Quick Facts

Approximately **90%** of our patients are from the Plain community *(Mennonite/Amish)* and most do not have health insurance.

1,738 *active patients*

31 *staff members*

44 *states &* **17** *countries*

5,022 *patient encounters*

34 *years serving the community*

4 *peer reviewed publications*

4,530 *laboratory tests to help identify & manage genetic illnesses*

TRANSLATIONAL MEDICINE

As doctors, we are scientists, as well as caregivers. Our goal at the Clinic for Special Children is to ease the suffering of our patients.

We know that science can help shape medical care and achieve better results for our patients.

We use genomic research to provide early diagnosis, treatment, and counseling. Research, not only improves the quality of care, it is what makes the Clinic so unique in the medical world, as well as what allows us to be effective at identifying and treating complicated, often misunderstood genetic conditions.

This philosophy of translational medicine is essential to us fulfilling our mission to provide timely, affordable, and effective health care.

TRANSLATIONAL RESEARCH

Each year our team publishes scientific peer-reviewed articles to address research questions that are raised in our clinical setting. In over 35 years, we've established a deep understanding of the most common genetic conditions that affect members of the Plain communities (Amish or Mennonite). Many of our discoveries have been found in our in-house CLIA-certified laboratory.

Although we discover "new" genetic disorders each year in the Plain populations of Lancaster County, these disorders are typically not unique to the Plain community. Rather, they are found throughout the world's human population, although usually at lower frequencies.

This means that not only do we serve a unique population that falls through the cracks of the modern medical system, but we also pioneer innovative treatments and gain insights that are broadly applicable to genomic medical practice as a whole.

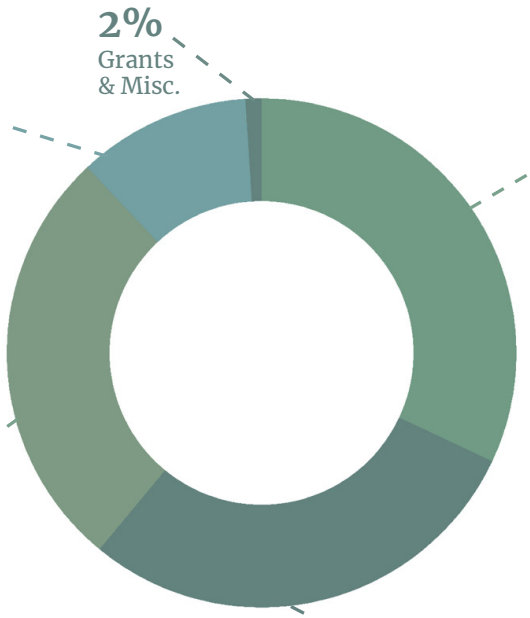
Philanthropy

HOW OUR WORK IS SUPPORTED

Donations to the Clinic for Special Children support our work in caring for those with rare genetic disorders. **We are a 501(c)(3) charitable organization** and philanthropy to our organization supports some of the most advanced genetic research in the world, while providing innovative treatment and prevention for children and adults at risk for rare illnesses.

Only 10% of our annual revenue is from clinical or laboratory fees. We aim to keep our patients fees low to provide the most vulnerable with our care. Over half of our annual revenue comes from philanthropic support which includes Plain community-led benefit auctions, fundraisers, individual giving, and grants.

2023 REVENUE SNAPSHOT



60%

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

Services

GENERAL SERVICES

- Amino acid quantification
- Consultation services
- Diagnostic genetic testing
- Dietary support
- Genetic carrier screening
- Genetic counseling and education
- Neurology
- Palliative Care | Cherished Lives program
- Routine immunizations
- Well care and sick visits

SPECIALTY MEDICINE

- Audiology
- Behavioral Therapy
- Cardiology
- Endocrinology
- ENT
- Nephrology
- Ophthalmology
- Orthopedics
- Psychology
- Psychiatry
- Pulmonology
- Wheelchair fittings

OUR LEADERSHIP

Karlla Brigatti, MS, CGC | *Research Operations Director*

Karlla joined the Clinic in 2014, bringing extensive experience in clinical genetics and research from across the lifespan. She has authored over 25 lay and scientific publications, mentored undergraduate, graduate, and medical students, and served on faculty at Sarah Lawrence College and Jefferson College of Biomedical Sciences.

Adam Heaps, MS, MBA | *Executive Director*

Adam joined the Clinic in 2010, starting as a laboratory technician until his appointment of Executive Director in 2014. He is responsible for financial management, strategic planning, collaborative relationships, facilities, and human resources at the Clinic.

Alexis McVey, BSN, RN, CPN | *Nursing Director*

Alexis joined the Clinic in 2021 and was promoted to Nursing Director in 2024. She works within our clinical team to provide exceptional patient care, oversees our nursing team, and organizes our nursing services. Before joining the Clinic, Alexis worked in nursing for adolescent medicine, acute care, primary care, skilled nursing care, and home care.

Laura Poskitt, DO | *Medical Director*

Dr. Poskitt joined the Clinic in 2019 and was promoted to Medical Director in 2024. She manages the clinical operations of the Clinic, oversees our physician team, and develops and implements strategic goals and objects to fulfill the clinical mission of the Clinic for Special Children.

Erik Puffenberger, PhD | *Laboratory Director*

Dr. Puffenberger joined the Clinic in 1998 and became Laboratory Director in 2000. He has built the genetic capabilities of the Clinic over his tenure. His work involves implementation of molecular techniques for routine diagnosis, research into genetics of isolated populations, and more.

Angela M. Sepela, MBA | *Development Director*

Angela joined the Clinic as the Development Director in 2022. She has extensive experience in nonprofit fundraising and management. She is responsible for all fundraising and development efforts at the Clinic. Her position includes planning and executing strategies for annual giving, major gifts, foundation grants, corporate giving, and more.

Digital Assets

Click the links below to access high-res, downloadable digital assets from the Clinic for Special Children

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