2021

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 service*s, and by *increasing and disseminating knowledge* of science and medicine.

OUR HISTORY

For over 30 years, the non-profit Clinic for Special Children (CSC) has provided a medical home for children and adults with rare genetic disorders. Starting as a simple partnership between our founders, Dr. Holmes and Caroline Morton, and the Amish and Mennonite communities they served, the clinic has stayed true to its mission from the beginning. We work tirelessly to advance effective treatment of genetic illnesses that would otherwise cause great suffering, through the integrations of genomic research and practical, affordable, medical treatment.

2020 Quick Facts

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

1,153 *active patients*	**25** *staff members*	**42** *states &* **17** *countries*
1,310 *patient visits*	**31** *years serving the community*	
9 *peer reviewed publications*	**3,632** *laboratory tests completed*	

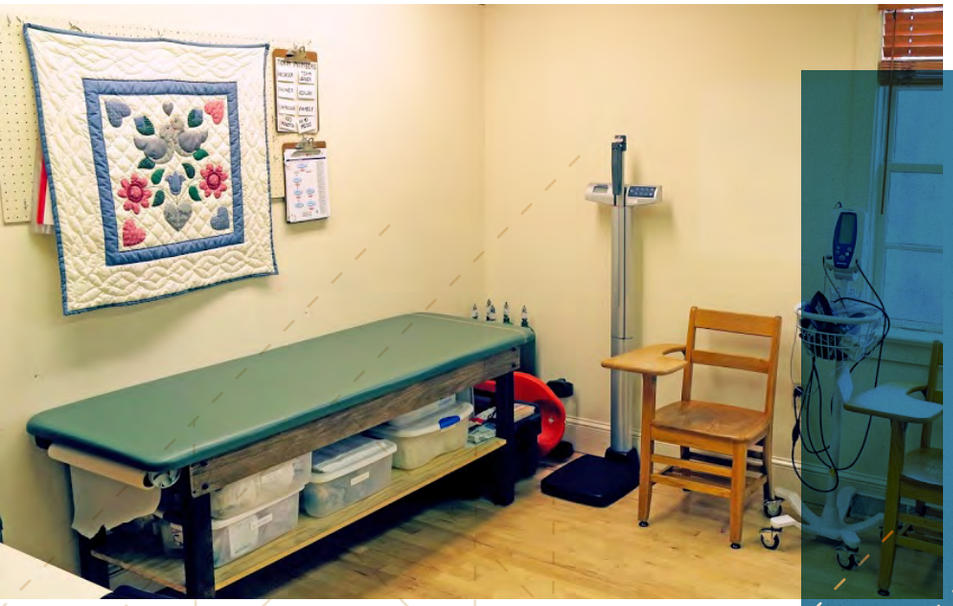
Clinical

TRANSLATIONAL MEDICINE

As doctors, we are scientists, as well as care-givers. 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.



Research & Laboratory

TRANSLATIONAL RESEARCH

Each year our team publishes scientific peer-reviewed articles to address research questions that are raised in our clinical setting. In over 30 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 laboratories.

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 at usually 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.

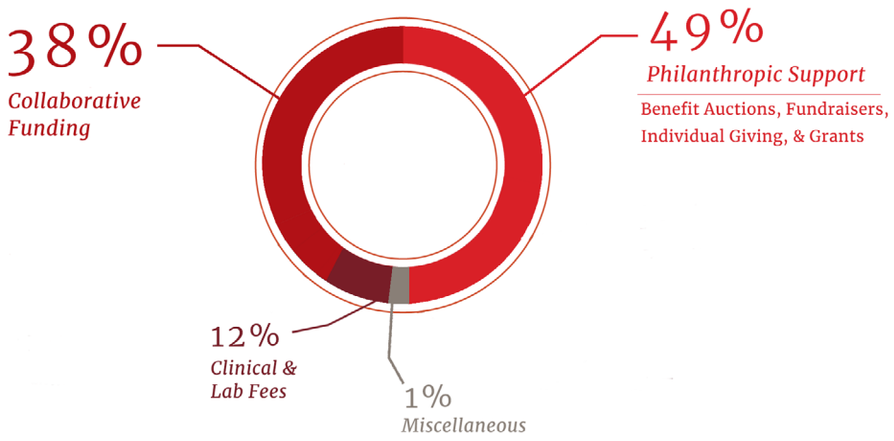
Philanthropy

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 12% 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. About half of our annual revenue comes from philanthropic support which includes Plain community led benefit auctions, fundraisers, individual giving, and grants.

2020 Revenue Snapshot



Services

GENERAL SERVICES

- Amino acid quantification
- Consultation services
- Dietary support
- Genetic counseling and education
- Molecular diagnostic testing
- Next generation sequencing (NGS)
- Palliative Care | Cherished Lives program
- Routine immunizations
- Molecular cytogenetic analysis
- Well care and sick visits

SPECIALTY MEDICINE

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

2021 *AMBASSADORS*

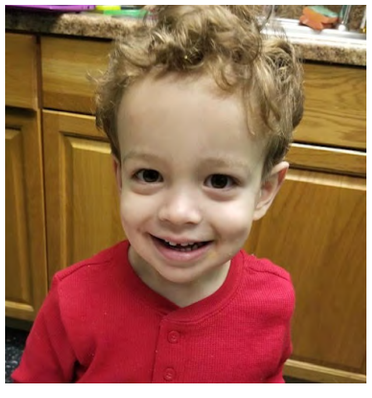
If you're interested in interviewing one of our ambassador families, please contact us!

Michael Fondacaro | 23 years old
Glutaric aciduria type 1 (GA-1)

A motivational speaker and entrepreneur, Michael is an inspiring young adult. He was diagnosed with Glutaric Acidemia type 1 (GA-1) at eight months old by a doctor who hadn't previously seen children with GA-1 survive past age three. Michael's family did their own research and found the Clinic. Michael now visits the Clinic about once a year where we monitor his condition. He has even participated in on-going research for GA-1. In his free time, Michael is busy running his motivational speaking business called 'Beyond the Chair'.

Kyreece Martin | 2 years old
Maple Syrup Urine Disease (MSUD)

Kyreece is an adorable and outgoing toddler who loves to give smiles to everyone he meets! He was diagnosed on his first day of life with Maple Syrup Urine Disease (MSUD). He recently underwent liver transplantation at the UPMC Children's Hospital of Pittsburgh and is doing well. Kyreece visits the Clinic about every month or so for ongoing management of his MSUD. Our entire team enjoys seeing Kyreece and his family when they visit us!



Eric Rodriguez | 2 years old
Glutaric aciduria type 1 (GA-1)

Eric is a "force of nature" as described by his parents. Born premature at 31 weeks, Eric received his diagnosis of GA-1 within days after his birth. After researching about GA-1, his family learned of the Clinic and had their first consultation when he was six months old. The rest is history! The Rodriguez family visits the Clinic now every three months to monitor Eric's progress. Eric recently started day care where "he is learning to share (in theory)."

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.

Vincent Carson, MD | *Clinical Operations Director*

Dr. Carson joined in Clinic in 2016. He has a special interest in the genetics of brain disease and specializes in disorders of the brain, spinal cord, nerves, and muscles. Dr. Carson is a co-investigator on clinical trials for spinal muscular atrophy (SMA).

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.

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.

Emily Seitz | *Development Director*

Emily joined in the Clinic in 2018, starting as part-time Scientific Grant Writer until her promotion to Development Director in 2019. Emily is responsible for all fundraising and development efforts at the Clinic, and manages a team that includes a Development Associate and Development Operations and Grants Strategist.

Kevin Strauss, MD | *Medical Director*

Dr. Strauss joined the Clinic in 2001, and became the Clinic's Medical Director in 2008. He has co-authored over 60 peer reviewed journal articles and given many lectures about medical, scientific, and cultural issues all over the globe. He is responsible for managing the Clinic's clinical and research programs.

"We provide a medical home for some of the world's most vulnerable children. These children are vulnerable in every sense of the word"

- Dr. Kevin A. Strauss, Medical Director

Digital Assets

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

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