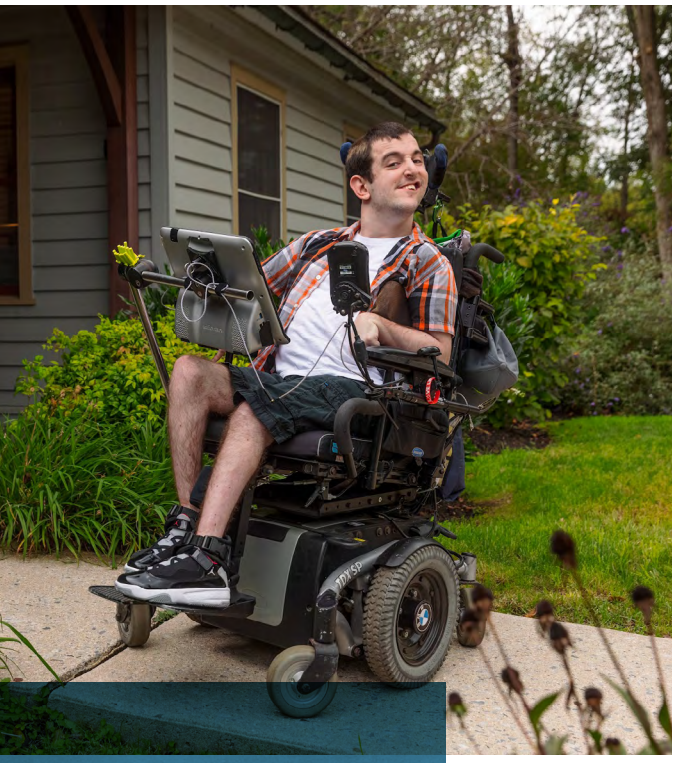
# 2022

# 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) we have 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.

# 2021 Quick Facts

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

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|---|---|---|
| **1,252** *active patients* | **26** *staff members* | **44** *states &* **17** *countries* |
| **1,260** *patient visits* | **32** *years serving the community* | |
| **11** *peer reviewed publications* | **5,652** *laboratory tests completed* | |

# 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.

# 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 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.

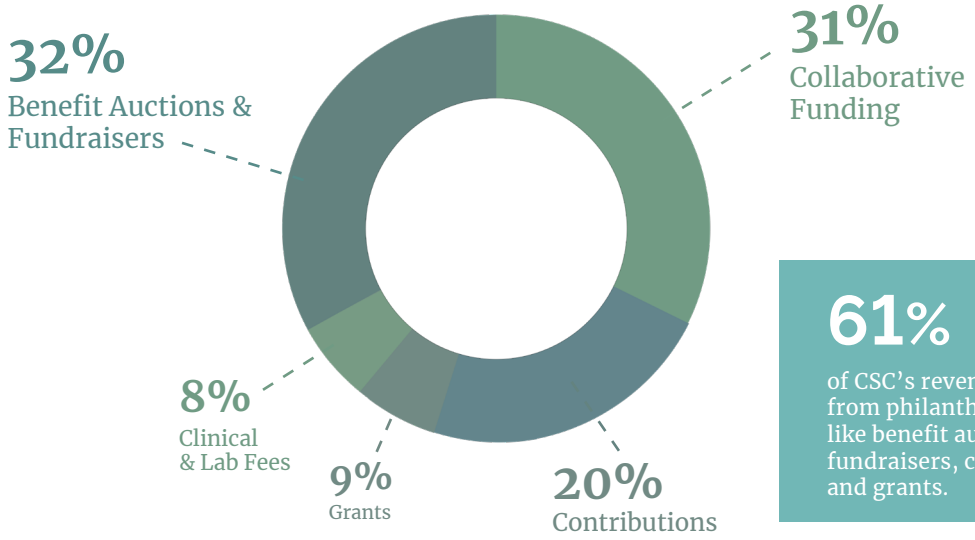
# Philanthropy

## 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 8% 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.

## 2021 REVENUE SNAPSHOT




**61%**

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

# 2022 *AMBASSADORS*

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

## **Jevon & Josiah King** | 2 years old & 1 year old

*CODAS Syndrome*

Jevon and Josiah King are adorable and cheerful brothers that have a special bond as they both were diagnosed with CODAS Syndrome. The King family visits the Clinic for monthly check-ins and CSC serves as their primary care physician by providing and coordinating compassionate care. Jevon loves books and music and communicates by signing. Last year he "sang" a song at his church's Christmas service. Josiah loves to play peek-a-boo and is almost ready to crawl!

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## **Rose Snyder** | 5 years old

*Down Syndrome*

Rose is a joyful little girl whose special qualities endear her to all that come to know her. Shortly after birth, Rose was diagnosed with Down Syndrome. From her first visits as a newborn to undergoing cardiac, hearing, and eye examinations with visiting specialists, Rose has been comprehensively cared for by the Clinic. She is an enthusiastic lover of music, and especially enjoys playing her little guitar or her sister's violin. She greets everyone that she sees in church or school with equal joy, which reminds us all to do the same.

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## **Estelle Weaver** | 2 years old

*Phenylketonuria (PKU)*

Estelle is a cheerful and happy-go-lucky toddler who loves playing in the snow! Shortly after her birth, Estelle was diagnosed with the rare metabolic disorder Phenylketonuria (PKU) via the state newborn "heel stick" test. Estelle visits the Clinic regularly for check-in appointments and ongoing management of her PKU levels. Some of Estelle's favorite things are when her brothers read stories to her and sitting beside her big sister when she plays the piano!

# 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, PhD | *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 two Development Associates.

## 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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