Building Hope

2022 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 individuals 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*

33 *years serving the community*

30 *staff members*

CSC Staff Spring 2022

Building Hope

We have welcomed thousands of families to our clinic in Strasburg over our 33-year history. While the challenges facing each family vary, they all seek answers, comfort, and relief in the face of complex medical threats. Through compassionate care and innovative research, we have walked alongside them as they navigate this journey.

It is only because of your unwavering support that we are able to ***build hope*** for families. Our main focus is to improve quality of life, and this informs every aspect of the clinical care, laboratory services, and research that form the Clinic's mission. We are deeply grateful for all our empathetic and skilled staff members who carry out that mission.

Thanks to the work of many volunteers and supporters through annual benefit auctions, fundraisers, grants, collaborations, and donations, we can provide high-quality services at a minimal cost. In 2022, only 11% of total revenue originated from fees for medical or laboratory services while 62% came from philanthropic sources. Reducing financial barriers ensures access to care, and remains a core component of our work.

Due to increasing demand for our services, we now provide medical care for adults as well as children. In parallel, we continue to expand cutting-edge genetic testing capabilities and push forward complex research projects. This has pushed our facility's capacity to its maximum, leaving inadequate space for parking, offices, exam rooms, meeting rooms, and storage.

To address this challenge, we recently announced our new building project – the *Keeping the Promise: Building Hope* capital campaign. The campaign launch was the culmination of years of work in evaluating site options, developing building plans, and raising initial funds. The project represents our commitment and promise to continue providing innovative services to the community for many years to come (learn more on pages 10 and 11.) We are grateful to 1,500 donors who have already contributed funds, materials, and time to the project. There is still much work to do to bring the new facility to life, and we invite anyone interested to contribute in the ways they are able.

As we close our 33rd year, we are reminded of the promises of our mission: to tend to the most vulnerable, continually innovate to improve their lives, and humbly serve all who seek our care.

Herman Bontrager
Chair of the Board

Adam D. Heaps, MS, MBA
Executive Director

Kevin A. Strauss, MD
Medical Director

Navigating Seizures
A DEPDC5 Diagnosis

JARED'S STORY

Jared Zimmerman was a typical active child for the first three years of his life. Shortly before his 4th birthday, he started to mention to his family that he "felt dizzy" when playing with his siblings and friends. When a dizzy episode would hit, he learned to lay down and it would pass in time.

The infrequent dizzy episodes soon increased to about twice per week. He kept having episodes for several months until he suddenly was experiencing two to three episodes per day. His parents, Ella and Timothy Zimmerman, knew something wasn't quite right and took Jared to the Compassion Parochial Clinic in Mifflinburg, PA for examination.

Stacy Chubb, CRNP immediately ordered an MRI for the next day, which did not show anything unusual. Around this time, Jared was now having six to seven episodes a day and started displaying more prominent seizures with stiffening and shaking. Stacy referred the family to the Clinic for Special Children where he was seen by Dr. Vincent Carson, Pediatric Neurologist.

Dr. Carson started Jared on a seizure medication called oxcarbazepine. Within the first days of starting the medication, the Zimmerman family noticed Jared was experiencing shorter seizures. Dr. Carson met with the family a month later at an outreach clinic in Mifflinburg organized by the Clinic. "We definitely appreciate that the Clinic does outreach in Mifflinburg. It's much easier to access for us," explains Ella.

By that time, Jared was already completely seizure-free. "Our time meeting with Dr. Carson was very positive," says Ella. Dr. Carson ordered genetic testing to determine that Jared had a misspelling in the *DEPDC5* gene, which was causing his seizures.

The *DEPDC5* gene provides instructions for making the DEPDC5 protein which is important for regulating the mTOR pathway. The mTOR pathway is important for the growth and development of nerve cells. Therefore, changes in *DEPDC5* can lead to brain malformations and seizures. Interestingly, people with changes in *DEPDC5* only sometimes experience seizures.

"When we received the diagnosis of *DEPDC5*-related epilepsy, we were glad to know what we were dealing with. We have extended family that have the *DEPDC5* genetic variant, so the diagnosis made sense," explains Ella. Today, Jared has been seizure-free for almost a year. He loves to draw and play outside in the woods.

"We appreciate the research on genetic disorders that the Clinic does. It's why we chose to go to the Clinic because we trusted that they knew a lot about *DEPDC5*," says Ella. "If you have epilepsy in your family, it would be a good idea to get genetic testing so you know if your children may have it."

Thank you to the Zimmerman family for sharing their story and we are inspired by Jared's progress!

PATIENT CARE *STATS*

1,492 *active patients*

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

4,232 *laboratory tests to help identify & manage genetic illnesses*

4,433 *patient encounters*

Living with Ellis-van Creveld Syndrome

An interview with CSC's Community Liaison, Lavina King

As a close neighbor to the Clinic for Special Children, a member of the Old Order Amish community, and a person living with a rare genetic disorder, Lavina King knows all too well the impact that the Clinic has had on many families over the years. After learning about the Clinic's mission several years ago, Lavina joined the Clinic staff part-time as a Community Liaison. Lavina has lived with Ellis-van Creveld Syndrome (EVC) for decades, and shared her experiences with us through an interview.

What was your early childhood like living with EVC?

My parents knew right away when I was born that I had EVC. However, I didn't realize that something was really different with me until I started school and started riding the bus. Naturally, my mother was worried about me keeping up and being able to do things that the other kids would do. I was very bashful as a child and my sister, who also has EVC, didn't go to the same school as me. For the most part, the teachers and other students were very good and kind and accepting of who I was - which was a huge blessing.

What are some challenges that you've faced and how have you dealt with them?

My sister and I had healthy years growing up, which we are very thankful for as many EVC children have heart issues and/or orthopedic issues. We didn't have the Clinic for Special Children back then, and it would have been such a blessing to have at the time.

While I had great school years, and it wasn't until I grew older, about 16 years old, that it was a harder time for me to face and a huge milestone of my life. It was an intimidating time to start going out with the youth, however, most people were accepting and I ended up meeting my husband, Phares, and had a son named Leroy (who is now a grown young man!). After I had Leroy, I ended up getting heart surgery and in more recent years, have had some challenging orthopedic surgeries.

Overall, I really didn't think much about having EVC growing up. It wasn't until I was older that I came to accept it very well, got married, and had a child - a normal life like most other people. At times when I go into a crowd of people I can hear children or people say things, but it impacted me a lot more as a child. Now when I see someone staring in my direction, I'll look back at them and give them a smile.

What advice would you give to families with children with EVC?

For parents, I would say to just accept your children as they are as much as possible and to not make a big deal out of it. It's fine to talk to your children about what they have and what they are facing, but always treat them like everyone else. You can show your child that they can do anything that they put their mind to. The feelings that they experience are real when someone looks at them as different or looks down on them. Listen to your children when they share their feelings and know that what they are feeling is real to them.

In my role as a Community Liaison at the Clinic, I feel blessed to reach out to the younger generation and feel led to help and support the next generation of children with EVC. Honestly, I'm drawn to little people like a magnet.

What is a common misunderstanding people have about EVC or rare genetic disorders in general?

Often people would look at others with a rare genetic disorder, or in a wheelchair, and would not realize that the person is just like us. I've learned so much myself by working at the Clinic that many of our patients may have physical disabilities that do not affect their mental state. They're just like everyone else and want you to talk to them as a person or adult.

After speaking with one mom whose daughter goes to the Clinic, she mentioned that her daughter does not appreciate when people walk in the room and start talking to her like she's a toddler. She's an adult and just wants to have a conversation just like any other adult. Overall, say hello to everyone you meet and accept them for who they are.

What do you wish for the future? Specifically for EVC?

One of my life lessons has been to be content and accept where God plants you in life. I know some people with EVC are married and some are not, but be content with God's life plan for you. I always think to myself about how I never thought that I'd get married and have a family of my own when I was growing up. I actually had dreamed of a life on my own and having my own house until I met my husband Phares.

For the medical side of EVC, I've already seen so

much progress in my lifetime with the heart surgeries that are performed now and the orthopedic help that patients get. I would say for the future of taking care of EVC patients, to keep them as healthy as possible and to be there for them. Even if there is the possibility to have therapies that can reduce suffering for more severe cases of EVC, it would be a blessing.

The Clinic has done so much for EVC patients over the years. Especially with connecting families to speciality care on-site like cardiology services or orthopedic surgery.

I also think that continuing to connect EVC families together so that they can support each other. It's huge for young adults with EVC to have friends that also have EVC - it can be such a therapeutic relationship to have. I'm part of a group of women with EVC and we have such a strong bond. Even though we live in different areas, we get together once in a while and will write to each other consistently. Even if it's at a distance, keep connecting with others that are facing the same things that you are.

What is Ellis-van Creveld Syndrome?

Ellis-van Creveld Syndrome (EVC) is a rare genetic condition that affects development of the heart, lungs, ribs, limb bones, nails, and teeth. EVC is caused by a misspelling in the *EVC* gene, which appears to play important roles in the normal shaping of many body parts. People affected with EVC generally have short stature (dwarfism; short arms and legs) and short ribs, which in turn causes a narrowing of the chest that restricts air movement. About half of all babies with EVC syndrome are born with a life-threatening heart malformation that requires surgical repair. Other signs and symptoms include polydactyly (extra fingers or toes), missing or malformed nails, and dental abnormalities. The condition is inherited in an autosomal recessive pattern, meaning that a child diagnosed with EVC inherited two mutated copies of the *EVC* gene; one from each healthy carrier parent.

Information from NIH and GARD

RESEARCH *STATS*

23 **NEW** *disease-causing genetic variants identified*

9 *peer-reviewed publications*

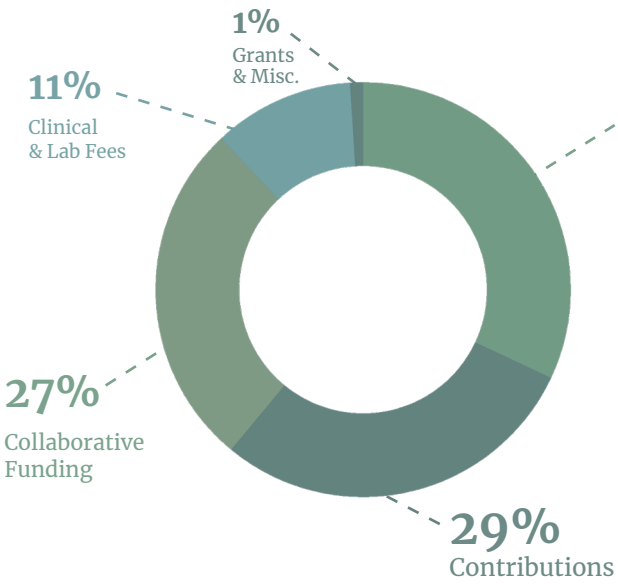
Financials Overview

A fiscal year in review

Only 11% of the Clinic's 2022 annual operating budget was derived from patient and laboratory fees. In order to provide accessible care, our clinical and laboratory fees have not been raised in over a decade. The remaining 89% of the funds needed to provide timely, affordable, and effective care come from philanthropic sources like benefit auctions, fundraisers, contributions, and grants, as well as collaborative relationships.

As a 501(c)3 non-profit organization, philanthropy and support from the community is vital to achieving our mission. Your support enables us to continue caring for special children and adults.

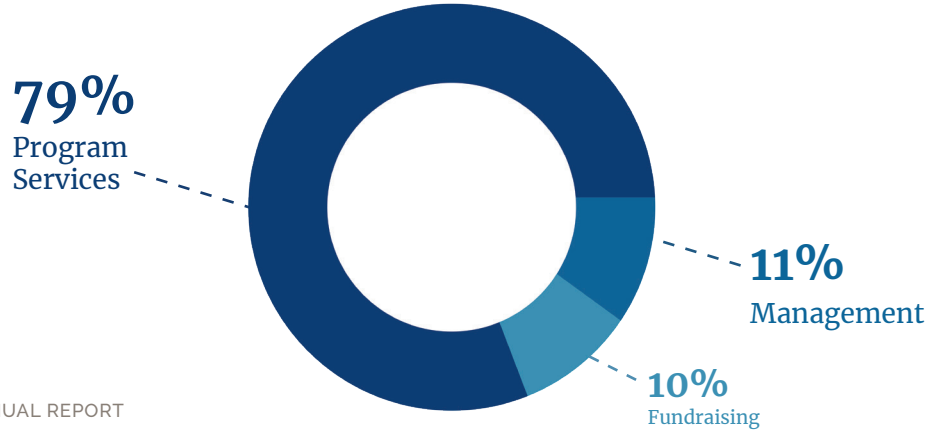
2022 REVENUE SNAPSHOT



62%

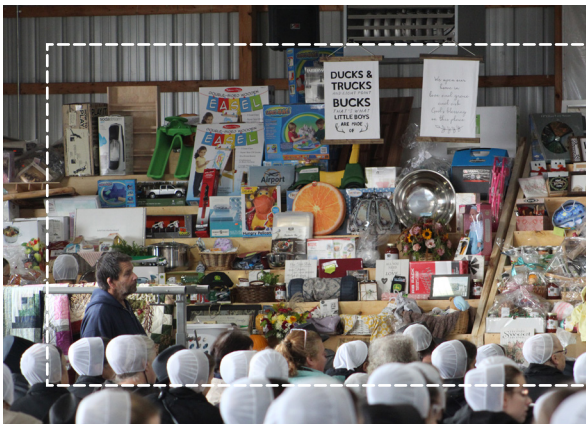
of CSC's revenue came from philanthropic sources like benefit auctions, fundraisers, contributions, and grants.

2022 EXPENSES SNAPSHOT



2022 Benefit Auction Season

For the community, by the community



If you've ever joined us at a benefit auction supporting the Clinic for Special Children, you've experienced the unique atmosphere abuzz with the rapid fire bid calling of auctioneers, greeting of friends, pitter-patter of running children, and clip-clop sounds of horse and buggies arriving. The seven annual benefit auctions, across central Pennsylvania, Ohio, Missouri, and New York, all provide support to the Clinic for Special Children and help us realize our mission of caring for children and adults with rare genetic disorders.

Each benefit auction is organized by a committee of devoted volunteers from the Plain communities that dedicate their time to hold these large scale events every year. Many of the volunteers on the auction committees have family members that have been served by the Clinic. The benefit auctions are a living example of the support of the Clinic being "for the community, by the community."

The 2022 auction season was a record-breaking one! The seven auctions cumulatively raised almost $1.8 million to help support the Clinic - a truly remarkable feat and testament to the power of community! The auctions, along with other fundraisers, contributions, and grants made up **62%** of the Clinic's 2022 revenue. Not only did the 2022 benefit auction season reach new heights in total funds raised, it expanded with the addition of a new auction in the Finger Lakes region of New York. The local community there banded together and organized the inaugural auction in just several months!

We invite you to join us at one of our 2023 benefit auctions for a day of fellowship, fundraising, and fun! A schedule detailing our benefit auction season is available on our Clinic auction website at www.ClinicAuctions.org.

FINANCIAL *STATS*

11%
of revenue came from patient & lab fees

$5 million
2022 operating budget

Keeping THE Promise

A Campaign for the Clinic for Special Children

For more than 30 years, we've been able to provide comprehensive medical care and laboratory services, conduct cutting-edge translational research, and advocate for vulnerable members of the community at our location in Strasburg, Pennsylvania. Nestled in between fertile farmland the current Clinic facility is a warm home for our patients and staff alike.

Exam Room Rendering

However, as each year passes, the operations of our Strasburg location become more challenging as we've outgrown the space due to a 'happy problem.' Many of the children served by the Clinic are now growing and thriving into adulthood, thanks to many advancements by the Clinic, and our services are more in-demand than ever. Today, over 30% of patients served by the Clinic are 14 or older. On a normal day at the Clinic, our parking spaces are full and the waiting and exam rooms are at capacity. Since the current Clinic is surrounded by land protected by a farmland trust, we started the process of identifying a new site for the Clinic. For more than four years, we've been working diligently to identify and purchase land, secure township approvals, and develop building plans.

In order to keep our promise of caring for the most vulnerable, we formally launched the *Keeping the Promise: Building Hope* capital campaign in Summer 2022 to build a new facility near Intercourse in Lancaster County, Pennsylvania. Since then we've been holding meetings with our capital campaign and gifts-in-kind committees, both comprised of dedicated volunteers that are tasked with fundraising and soliciting a variety of gifts including the in-kind donations of ma-

Front View Rendering

terials and labor. The campaign will be publicly announced in April after many years of quiet but diligent work.

The new Clinic will be a larger, more spacious, and more accessible version of the current Clinic. Highlights include twelve exam rooms designed to accommodate whole families, discussion rooms where patients and their physicians can speak comfortably, a community room to host patient-focused educational events, and a small fully accessible playground.

Laboratory Rendering

The project will require a community investment of $12.5 million in materials, labor, and funds. In addition to the building costs, our total $12.5 million budget includes land costs, site work, furnishings and equipment, contingencies, and two funds to support the Clinic's sustainability and growth - the Sustainability and Innovation Funds. While the new Clinic is designed to be highly efficient, it will be much larger and therefore will require more annual operational funds to maintain. The Sustainability Fund will create permanent future funds that tackle this challenge by providing a bedrock of financial support that allows the Clinic staff to focus on developing innovative services. The Innovation Fund will be used where needs are greatest to respond to new research, programmatic needs, and technology opportunities. The fields of medicine, science, and technology change quickly and we strive to keep pace in order to provide state-of-the-art services and programs.

Map of Lancaster Co.

As of February 2023 we have raised over $7.4 million (or 59%) of our $12.5 million goal, thanks to nearly 1,500 supporters of the project. We look forward to sharing many exciting campaign updates in 2023 as this transformational project progresses. We continue to be inspired by the support of many for a campaign that will enable us to keep our promise to provide care and cures for the special children and adults we serve.

Waiting Room Rendering

Clinic *for* Special Children®

Our Staff

Clinical Services

Amy Albright, MS, CGC
Genetic Counselor

Keturah Beiler, BSN, RN, CHPPN
Nurse & Cherished Lives Program Manager

Vincent Carson, MD
Managing Physician

Christine Hendrickson, RNC
Nurse

Alexis McVey, BSN, RN, CPN
Nurse Manager

Grace Meier, MD
Family Medicine Physician

Laura Poskitt, DO
Pediatrician

Stephen D. Ratcliffe, MD, MSPH
Senior Consulting Physician

Donna L. Robinson, MSN, CRNP
Nurse Practitioner

Kevin A. Strauss, MD
Medical Director

Susan Walther, MS, CGC
Genetic Counselor

Research Operations

Karlla W. Brigatti, MS, CGC
Research Operations Director

Ashton Bollinger
Research Associate

Millie Young, BSN, RNC
Research Nurse

Laboratory

Alanna Koehler, PhD
Assistant Laboratory Director

KaLynn Loeven
Laboratory Scientist

Erik G. Puffenberger, PhD
Laboratory Director

Ashlin Rodrigues
Laboratory Scientist

Development

Skye Gawn
Development Associate - Operations

Julia Martin
Development Associate

Angela M. Sepela, MBA
Development Director

Administration

Kelly Cullen
Communications Manager

Jennifer Giacoio
Medical Receptionist

Adam D. Heaps, MS, MBA
Executive Director

Candace Kendig, RMA
Office Manager

Lavina King
Community Liaison

Dawn Sheets
Medical Receptionist

Jessica Snyder, PHR, SHRM-CP
Human Resources Generalist

William Van Ess, MS, CFE
Accounting Manager

Kelly Woodson
Event and Volunteer Manager

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Jan L. Bergen

Cindy Bo, MBA
Secretary

Herman Bontrager
Chair of the Board

Elam Esh

Leon Hoover
Vice Chair

Leonard Hurst

Mark Martin
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Chair- Finance Committee

Jacob Petersheim

Stephen Tifft, MD

Glen Zimmerman
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