



2019

ANNUAL & INNOVATION REPORT



Clinic for
Special Children

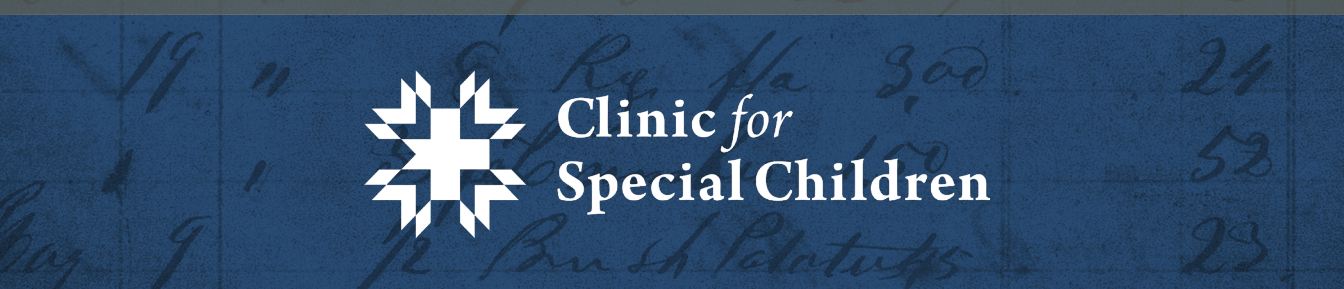


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Our Mission

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 **MEDICAL HOME**

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 the most timely, affordable, and effective healthcare. The Clinic for Special Children 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

1,091
active patients

22 *staff*
members



Advancing Science and Medicine, One Child at a Time.

Friends,

This past year the Clinic celebrated its 30th Anniversary – a feat that would have never been possible without your continued support. Over our 30-year history, we’ve served nearly 4,700 patients from 42 states and 17 countries, expanded our management of genetic conditions from a handful to over 300, and continue to grow in response to the needs of the community.

Next year promises to be even more dynamic. Many of the children that have come to the Clinic for Special Children are now adults who require complex medical care. To meet this growing need, we will take the first step in launching an adult service program with the hiring of Dr. Grace Loudon, a family practice physician who will join our staff

full-time this summer.

A few short years ago, we created a dedicated Research Operations department. The creation of this department and our dedication to translational research enabled the Clinic to serve as a clinical trial site for up to four separate gene therapy trials this year. We are humbled and excited to be a part of this innovative research that will allow our patients to have access to cutting-edge therapies.

On behalf of our entire staff and board, we are profoundly grateful for your support that allows for the vibrant success and growth of the Clinic for Special Children. It is because of you that we are able to do this life-changing work every day. Thank you for cherishing the lives of special children and adults.

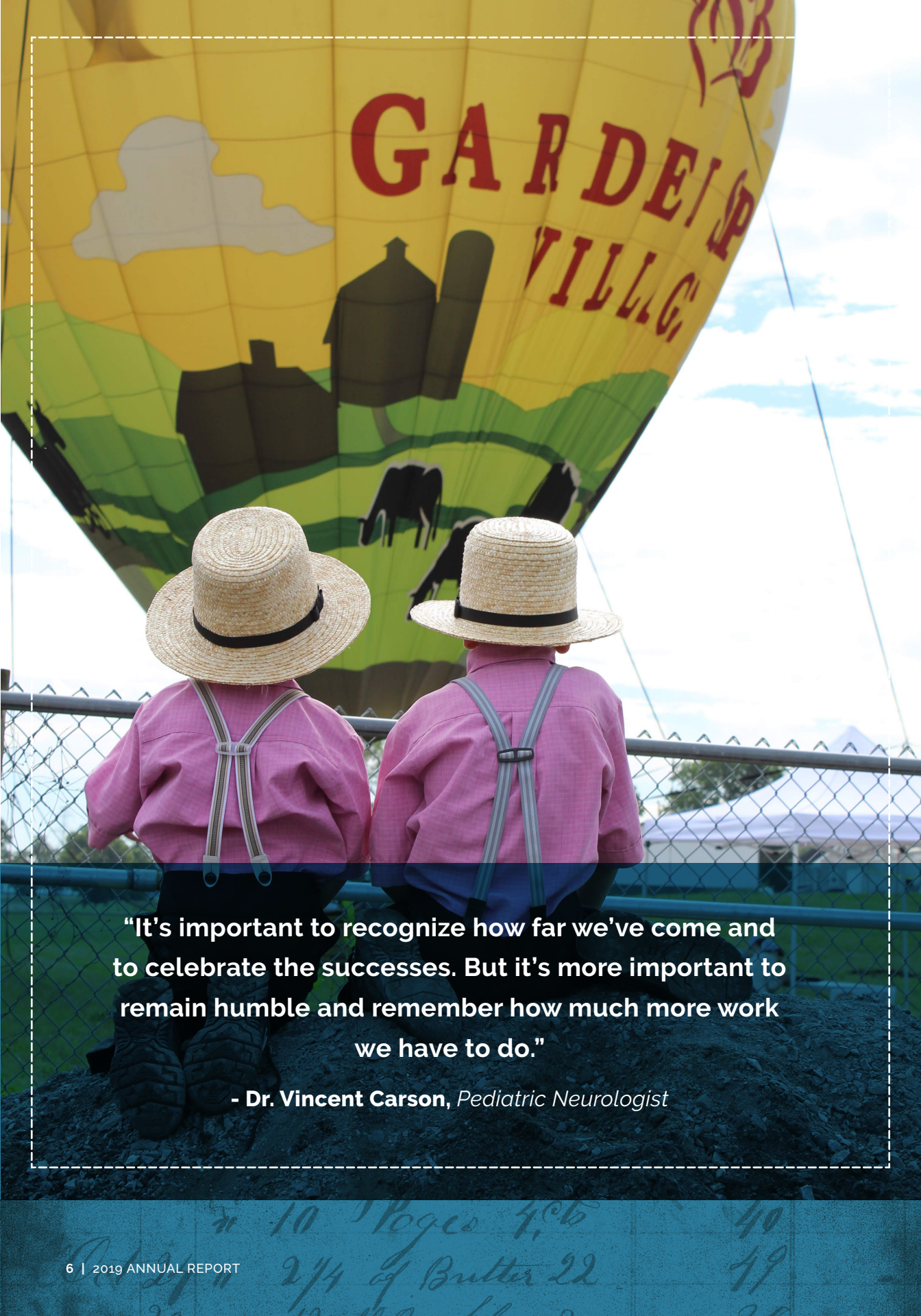
Karlla W. Brigatti, MS, LCGC
Research Operations Director

Adam D. Heaps, MS, MBA
Executive Director

Erik G. Puffenberger, PhD
Laboratory Director

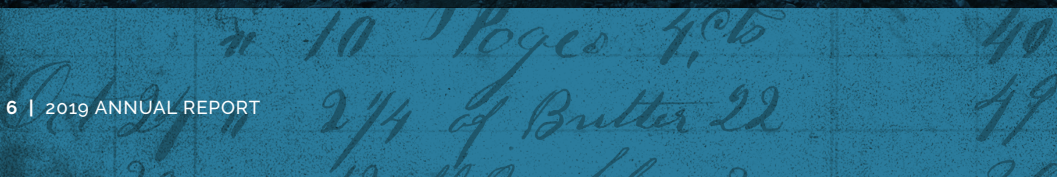
Emily Seitz
Development Director

Kevin A. Strauss, MD
Medical Director



“It’s important to recognize how far we’ve come and to celebrate the successes. But it’s more important to remain humble and remember how much more work we have to do.”

- Dr. Vincent Carson, *Pediatric Neurologist*



Delivering effective and

AFFORDABLE
CARE *for* INDIVIDUALS

with genetic conditions.

PATIENT CARE STATS

5,937 biochemical
& genetic tests

1,764
patient visits

Manage **382** known
variants that cause disease

42 states &
17 countries



Patient Story

Kris and Maureen Newkirk experienced an easy pregnancy and delivery with their third son, Charlie, in December of 2015. They never expected that several days after Charlie was born his state newborn screen test would come back positive for a disorder they had never heard of - Glutaric Acidemia Type 1 (GA-1). The Newkirk family soon learned that only four other people had been diagnosed with GA-1 in their home state of Arizona. GA-1 is a genetic disorder in which the body is unable to break down essential amino acids, which can lead to irreversible brain damage.

At four-days-old, Charlie started treatment at Phoenix Children's Hospital with a strict diet of a special formula just for GA-1 patients in order to prevent brain damage. Over the next year and a half, Kris and Maureen conducted a great amount of research on GA-1 and quickly realized limited information was available. During their research efforts they kept finding the name of Dr. Kevin A. Strauss and the Clinic for Special Children.

The Newkirk family decided to take a leap of faith and travel to Pennsylvania to meet with Dr. Strauss to learn more about GA-1. Their first appointment at

the Clinic included a three hour meeting with Dr. Strauss where he explained the Clinic's research and many years of experience with GA-1. Maureen and Kris said of that first meeting, "We walked away with the feeling that Charlie was going to be okay. There's something magical about coming down the lane to the Clinic with its reassuring feeling - it's so different than anything out there."

The Newkirk family says that each year gets easier as Charlie is allowed more protein and stress the importance of the newborn screen test. Unlike when Charlie was younger, they are able to treat him at home when he is sick, and don't have to visit the hospital. Today, Charlie is a happy four-year-old and enjoys playing with his older brothers, who are always looking out for their little brother.

In addition to being a patient family, Kris and Maureen Newkirk have been amazing supporters of CSC along with the Crain Family Foundation and are advocates for giving back to the rare disease community.

We look forward to seeing the Newkirk family each summer when they visit the Clinic!

29	"	2 lb Butter	22	44
30	"	Cash		75
31	10	lb Rice	pl	30
Nov 1		Cash	159	159



31	"	1 Chicken		11
	"	2 lb Butter	22	44
30	"	Cash		75
31	10	lb Rice	pl	30
Nov 1		Cash	159	159

Outreach and New Programs

INTERNATIONAL OUTREACH | *BRAZIL*

In mid-November, Dr. Kevin A. Strauss and Karlla W. Brigatti, MS, LCGC, visited São Paulo, Brazil at the invitation of the Sociedade Brasileira de Neurologia Infantil Congress. Dr. Strauss gave numerous talks throughout the week on the Clinic's treatment innovations with disorders like Glutaric Aciduria Type 1 (GA-1) and Maple Syrup Urine Disease (MSUD).

The CSC team also had the opportunity to consult on a number of GA-1 and MSUD patients along with residents in Pediatric Neurology and Genetics. Dr. Clarissa Bueno and Dr. Flavia Piazzon made the agenda possible and will be sharing the cases in a master presentation with their Neurology residents that we not able to attend.

One evening the CSC team met with members of government, private enterprise, NGO's, medical experts and parents of children with rare disorders to talk about ways to advance diagnosis and treatment for rare metabolic and genetic conditions in Brazil. Dr. Strauss presented the Clinic's approach to early diagnosis and innovative therapies and a discussion with a resulting working plan followed. The meeting was organized by a Brazilian mother whose child with GA-1 was successfully treated at the Clinic for Special Children.

We look forward to more collaborative partnerships in Brazil and improving the care of GA-1 and MSUD patients in the country.





CHERISHED LIVES PALLIATIVE CARE PROGRAM

BY: KETURAH BEILER, RN

Although CSC has informally provided palliative care (care for families with life-limiting disorders) for many years, we recently formalized the program. We now call it “Cherished Lives”. This name reflects our view that every life, even a short one, should be cherished. We all have much to learn from every patient we treat.

At CSC, it is our desire to provide supportive care for these babies and to walk alongside the family by providing support during a life-changing and difficult time. As a nurse, I am drawn to work with families as they prepare to part with their little one. When a family reaches out to CSC about a baby with a condition that indicates a lethal diagnosis, like Amish Lethal Microcephaly, our team will often see them in their home to establish a care plan. Most often this plan arranges for them to be seen in their home once a month or as needs arise.

The Clinic is also committed to providing support and comfort to families who have children with severe, life-limiting diseases. These diseases are those in which we know the diagnosis but do not have a cure, and the disorder will most likely shorten their life span. Families choosing comfort care, primarily at home, is part of a model of care known as palliative care. This type of care makes patients as comfortable as possible without using extreme interventions in the hospital.

As part of the Cherished Lives program at CSC, we have begun to make memory gifts for the families that lose little ones to rare genetic disease. At one of our first visits, we stamp the baby’s feet onto paper to record their footprints. After their passing, we make small quilts with their footprints printed on the fabric as a token of remembrance and comfort for the families. Log Cabin Quilt Shop & Fabrics in Bird-in-Hand, PA has graciously donated supplies for the project. Priscilla Beiler, the mother of Lavina King, Community Liaison at CSC, pieces the wall hangings and quilts to make a finished product. Since the start of the quilt project, families have expressed their gratitude for this gift to remember their cherished baby.

The main objective of our Cherished Lives program is to clearly learn what parents’ goals are for their children related to their care. This is a discussion that families can have with the doctors here at CSC. Our long-term goal for our new Cherished Lives program is to expand the services for these families to include home visits by a nurse, care packages, and other ways to reduce the suffering of these children and their families.

Thank you to WellSpan Health and the Anabaptist Foundation for their support of the Cherished Lives program.

EDUCATION & COMMUNITY STATS

6 family days in 2019

13 research students



Innovation at the Clinic

CLINICAL STUDIES AND TRIALS AT THE CLINIC FOR SPECIAL CHILDREN

NEUROGRO STUDY

Together with Dr. Linda Lowes and her team from Nationwide Children's Hospital, we are working to collect information on how healthy children, from birth to 18 years old, develop their motor skills over time. This information will be used in studies of new treatments for conditions that affect motor development (such as spinal muscular atrophy). We hope to develop and refine better tools to capture small changes and allow for better comparisons to what is in the normal range for children across all ages. This study is funded by Biogen, Inc.

SPR1NT STUDY | SMA

SPR1NT, a phase 3 clinical trial, focuses on treating presymptomatic infants with SMA types 1 and 2 who are six weeks of age, or younger. In this study, we aim to treat infants as early in life as possible via a one-time IV infusion of Zolgensma®. We then closely monitor their progress and development throughout the first 18 months of life and beyond. This study is sponsored by AveXis.

PKU STUDIES

The Clinic for Special Children expects to enroll teenage and adult patients with PKU in an observational natural history study called PHENOM, beginning in spring/summer 2020. PHENOM will measure various disease markers and clinical outcomes. Following PHENOM will be a phase 1/2 clinical trial called PHEARLESS. Sponsored by BioMarin, this trial will evaluate safety, efficacy, and tolerability of gene therapy in patients with PKU. The gene therapy will be delivered via a one-time IV infusion. The hope is that this therapy will normalize phenylalanine (Phe) levels in the blood and enable patients to consume a normal diet.

GENE THERAPY STUDIES

The Clinic for Special Children is a site for the AveXis-sponsored trial of Zolgensma administered as a one-time IV infusion in infants with SMA less than 6 weeks of age (known as SPR1NT). Enrollment is now complete across all sites, and CSC enrolled the most patients of any site in the study. We will continue to follow these children for many years as part of a long-term study with AveXis to determine the long-term effects and safety of Zolgensma.

SPINRAZA® STUDIES

The Clinic for Special Children has enrolled 17 participants in the SPINTASTIC study, administering Spinraza (nusinersen) through an indwelling intrathecal catheter system. This study is in collaboration with the Nemours/A.I. duPont Hospital for Children and funded by Biogen, the company that makes Spinraza. Most patients have completed the initial one year study and all continue to receive Spinraza through the port.

GENE THERAPY DEVELOPMENTS

At the Clinic for Special Children, we have been working diligently to design a number of prospective studies for certain disorders that we think could be amendable to gene therapy treatments. These are conditions that we have seen clinically for a long time, including Maple Syrup Urine Disease (MSUD), which is most commonly caused by variants in the gene *BCKDHA* and Amish Nemaline Rod Myopathy (also called Chicken Breast Disease), which is caused by variants in the gene *TNNT1*. Researchers and clinicians at CSC have already conducted natural history studies for the two disorders, which are important because that information can be used as a “control” group when testing a new treatment and to determine if the treatment is actually making a beneficial and meaningful difference.

After the recent introductions of gene therapy treatments for conditions like spinal muscular atrophy (SMA), the CSC team felt the need for similar treatments for MSUD and Amish Nemaline Rod Myopathy, both rare genetic disorders commonly found in the Plain populations. Since MSUD and Amish Nemaline Rod Myopathy are rare disorders, they are unlikely to be pursued for gene therapy treatment innovations by larger pharmaceutical development companies without CSC’s involvement. Since the application of recent gene therapy treatments look promising and with the devastating disease course of these disorders, we felt that we needed

to start working on our own studies for gene therapy treatments from the ground up.

We are currently working on early stage proof of concept studies with the University of Massachusetts Medical School Horae Gene Therapy Center and the Cummings School of Veterinary Medicine at Tufts University. For MSUD, we are planning a trial for the safety and efficacy of gene therapy vectors in Hereford cattle.

In 2018, CSC researchers identified Hereford cows that had naturally occurring MSUD. Somewhat mimicking the human course of MSUD, when an MSUD calf was

born, they would die within hours of birth from brain swelling. Our hope is to use Hereford cows with MSUD to test the safety and efficacy of the potential gene therapy treatments. We have received partial support for this project from the MSUD family support group, whose members have family that have been diagnosed with MSUD.

While we are at the early stages of the development of gene therapy treatments for MSUD and *TNNT1*, and while there is no guarantee the studies will be successful, we are hopeful that by working with enthusiastic partners we can bring innovative solutions to families diagnosed with these devastating disorders!



Development at the Clinic

2019 CLINIC FOR SPECIAL CHILDREN 5K

On Saturday, September 21, 2019 we welcomed over 350 runners, joggers, and walkers to the Clinic for our 2nd annual Clinic for Special Children 5k. Together we raised \$40,000 to support the Clinic's mission! We'd like to thank all of our sponsors, especially our presenting sponsor, Nemours Children's Health System, for their support!

New this past year were our whoopie pie medals – edible whoopie pies in gold, silver, and bronze awarded to each of the winners from our male and female age groups. We also hosted our first free kid's fun run after the 5k race and enjoyed seeing all of the little ones participating in this great day!

Save the date for our 2020 Clinic for Special Children 5k to be held this year on Saturday, September 19, 2020. Registration details will be available in the late Spring/Summer and we hope to see you there!



COMMUNITY BENEFIT DINNER

Members from the Plain community organized the first Community Benefit Dinner for the Clinic on Wednesday, September 25, 2019 at the Martindale Fellowship Center in Ephrata, PA. The night featured a buffet-style ham and oyster supper, as well as informational talks from CSC staff members.

The event raised over \$20,000 for the Clinic, and we are so thankful to the community for their continued support! We look forward to this year's dinner on Wednesday, October 14, 2020 in Lancaster County.





Donor Spotlight

Sweet Odyssey by Idario Santos

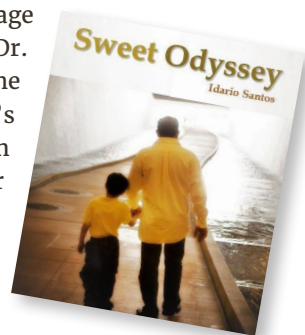
Idario Santos and Soraya Carvalho were overjoyed at the birth of their second son, Artur, in 2002. However, within several days of Artur's birth, his parents noticed that something was not right. After a brief stay at a local hospital, they moved Artur to a bigger city that had better medical resources. Thirty-one days and a couple misdiagnoses later, they found out their newborn son had Maple Syrup Urine Disease (MSUD).

Shortly after Artur's MSUD diagnosis, Idario met Dr. Strauss in 2003 in Natal, Rio Grande Do Norte, Brazil. The next year Idario and Soraya visited the USA to attend a MSUD support group and biannual MSUD symposium. Idario was shocked to see the children with MSUD that were Artur's age and how they were thriving. It was in that moment that Idario decided to meet with Dr. Strauss again at the Clinic for Special Children. After consulting with Dr. Strauss, the family decided the best solution for Artur would be a liver transplant at the Children's Hospital of Pittsburgh. The family moved to Pittsburgh from Brazil permanently in 2005. Artur became the first Brazilian to receive a liver transplant as treatment for MSUD, effectively curing him of the disease.

Since his son's treatment, Idario is dedicated to supporting the Clinic. He's written a book about his journey called, *A Sweet Odyssey*. The book is available for purchase on Amazon and 50% of its proceeds benefit the Clinic. When asked why he supports the Clinic, Idario says, "I'm passionate about the meaningful work that you're giving a chance to a family like mine. It's important for me to keep the work up and try to be a great supporter and advocate for the Clinic." Since writing the book, Idario and his eldest son, Vinicius, have spoken at events all over the world including a symposium in Finland hosted by Perkin Elmer. Numerous games were held throughout the event in Finland and all proceeds were donated to the Clinic at Idario's request.

Today Artur is doing great and is in 11th grade. He speaks three languages: English, Portuguese and Spanish. When asked if he'd like to share anything with other Clinic supporters, Idario said, "I really wish that our story would become a movie because it would bring awareness to the whole world. Most people in the USA have no clue that people are dying for no reason." Idario wrote a bill in Artur's name to establish proper newborn screening, protocols and proper treatments around MSUD in Brazil.

All of us at the Clinic thank Idario and his family for their tireless work in support of the Clinic for Special Children.

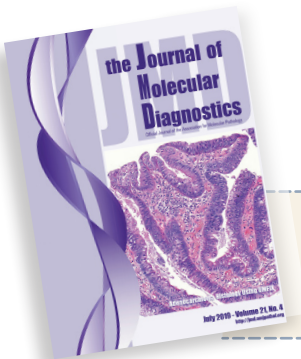


Research

This year, Clinic staff contributed
to original research published in

THE JOURNAL OF MOLECULAR DIAGNOSTICS

The report identified a novel next generation sequencing assay to carrier test for autosomal recessive disorders found in the Old Order Amish and Old Order Mennonite (Plain) populations. The study included 48 samples based on prior whole exome sequencing (WES) results. In order to assess the accuracy of the panel, 168 unique genes were targeted, with a focus on 202 genetic variants associated with 162 different syndromes found in the Plain communities. Collectively, the panel detected 273 pathogenic (single nucleotide or small insertion/deletion) variants, 35 copy number variants (CNVs), and one chromosomal abnormality (Klinefelter syndrome). The panel matched 100% with the previous WES analyses. The researchers utilized Anchored Multiplex PCR (AMP™) technology, with its use of a unique molecular index created by ArcherDX, to target numerous classes of variants with a wide range of allele frequencies. The study was conducted by clinicians and researchers at the Clinic for Special Children in Strasburg, PA, Nemours/A.I. duPont Hospital for Children in Wilmington DE, and ArcherDX, Inc. in Boulder, CO. This expanded carrier screening method has allowed the successful creation of Plain population-wide carrier testing and has the potential to drastically reduce overall medical costs and improve patient outcomes by identifying at-risk couples and informing them of their carrier status before affected children are born. This also allows the opportunity for presymptomatic treatment, a tantalizing prospect in the age of gene therapy. This panel is available for clinical samples at the Clinic for Special Children, and is aptly named the Plain Insight Panel™.



READ THE ARTICLE ONLINE AT:

<https://bit.ly/319kidS>

RESEARCH STATS

76 NEW disease-causing
genetic variants

8 peer-reviewed
publications

Collaborator Spotlight

University of Georgia | *Complex Carbohydrate Research Center*

When Dr. Michael Tiemeyer was completing his undergraduate work at Johns Hopkins University, he was exposed to an emerging field that would come to be known as Glycobiology (the study of carbohydrate function and structure). His PhD graduate work at Johns Hopkins School of Medicine provided him with “a deep appreciation of glycolipid biochemistry and glycolipid function in neural tissue.” After obtaining his PhD, Dr. Tiemeyer joined the Complex Carbohydrate Research Center (CCRC) at the University of Georgia and currently works as the Co-Director of the CCRC.

The CCRC is unique as it has the highest concentration of research scientists with expertise in understanding the function and structure of complex carbohydrates, a class of molecules that regulate almost every aspect of cell survival and function. Dr. Tiemeyer explains, “by being in a center filled with scientists that share common research goals and complementary expertise, we are able to make rapid progress in novel research areas.”

During Dr. Tiemeyer’s early years at CCRC, on the other side of the globe, Dr. Kazuhiro Aoki was obtaining his PhD degree in life science at Kyoto University in Japan. His thesis focused on studying the role and structure of glycoconjugates in pathogenic fungi, explaining the mechanisms of host-pathogen interaction via glycoconjugates. After completing his PhD, he joined Dr. Tiemeyer’s team at CCRC as it’s known as one of the best institutes in the world to study function and structure of complex glycans. Dr. Aoki currently works as a Senior Research Scientist at the CCRC.

The CCRC, CSC, and the Plain Community Health Consortium (PCHC) published the largest clinical description of *ST3GAL5* (GM3 synthase) deficiency. The study examined objective measures of biochemistry, auditory function, brain development, and caregiver burden of GM3 synthase deficiency. Throughout this study, the CCRC “provided analytic assistance by measuring blood levels of glycolipids in PCHC patients and unaffected individuals using advanced mass spectrometric methods that the CCRC developed and published with PCHC collaborators. We are also investigating the basic cell biology of neuronal survival using cultured cells that have the same biosynthetic defect as a patient with GM3 deficiency”, explains Dr. Tiemeyer.

The CCRC and CSC published a paper describing an accurate method of measuring the amount of GM3 and other gangliosides in various samples. This method was used to generate data for the clinical description paper and can be used to measure the effectiveness of future treatments.

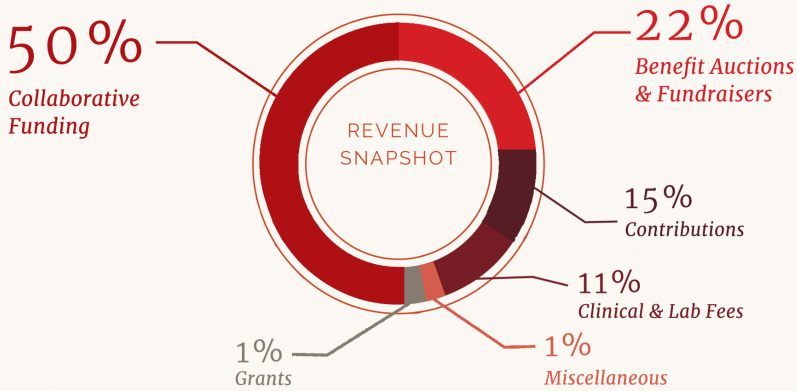
Dr. Aoki describes the CCRC & CSC’s collaboration, “I have been studying glycomic consequences of human disorders in cancer, rare genetic disorders and one of the projects targets on a rare mutation in *ST3GAL5*, GM3 synthase which causes ‘Salt and Pepper Syndrome’ (S&PS) in African American siblings. The S&PS is allelic to the Amish GM3 deficiency.” When approached about partnering with CSC and PCHC, Dr. Aoki said, “I am always wondering if my research contributions support people suffering from health problems. By taking the chance to work with CSC and PCHC, now I have obtained the great opportunity to interact with patients, doctors, clinicians, and other scientists through the project by providing my scientific expertise which may contribute in the development of new therapies for patients with GM3 deficiency.



Pictured (L to R): Kazuhiro Aoki, PhD and Michael Tiemeyer, PhD

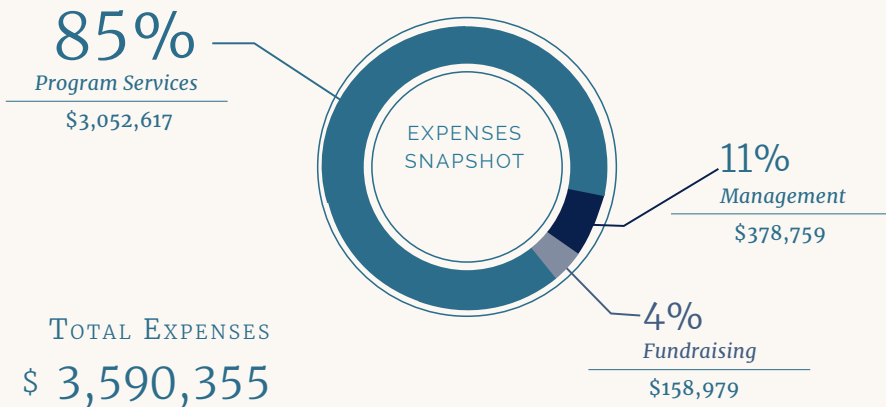
2019 | FINANCIALS

2019 REVENUE SNAPSHOT



The Clinic is funded from four major sources of revenue—annual benefit auctions, philanthropic donations, collaborative relationships, and patient fees.

Your support enables CSC to continue to provide patients with timely, affordable, and effective care! We work hard to keep clinic fees to a minimum and effectively utilize funds to fulfill CSC's mission.



STATEMENT OF FINANCIAL POSITION
As of 9/30/2019

ASSETS	
Cash and Equivalents	\$1,961,362
Accounts Receivable	\$316,551
Promises to Give	\$98,394
Prepaid Expenses	\$48,052
Property and Equipment	\$645,435
Investments	\$4,054,794
Loans Receivable	\$150,000
Investments Restricted	\$1,036,790
Total Assets	\$8,311,378

LIABILITIES & NET ASSETS

LIABILITIES	
Accounts Payable	\$177,465
Accrued Expenses	\$59,507
Accrued Wages	\$48,522
Deferred Revenue	\$7,909
Total Liabilities	\$293,403

NET ASSETS

<i>Without donor restrictions</i>	
Undesignated	\$2,889,338
Board Designated	\$4,028,166
<i>With donor restrictions</i>	
	\$1,100,471
Total Net Assets	\$8,017,975

Total Liabilities and Net Assets	\$8,311,378
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STATEMENT OF ACTIVITIES
10/1/2018-9/30/2019

REVENUE	
Contributions	\$704,562
Grants	\$34,893
Collaboration Funds	\$2,373,424
Special Events	\$1,044,917
Clinic Fees	\$297,366
Investment Income	\$407,210
Laboratory Fees	\$242,252
In-Kind Donations	\$51,513
Miscellaneous income	\$32,137
Total Revenue	\$5,188,274

**EXPENSES & PROGRAM
INVESTMENTS**

Program Services	\$3,052,617
Management	\$378,759
Fundraising	\$158,979
Total Expenses	\$3,590,355



Front (L-R): Donna Robinson, Ashlin Rodrigues, Emily Seitz, Caitlin Russell, Kevin Strauss, Candace Kendig, Vincent Carson, Lauren Bowser, and William Van Ess

Back (L-R): Erik Puffenberger, Keturah Beiler, Laura Poskitt, Yalonda Kosek, Karlla Brigatti, Christine Hendrickson, Kelly Cullen, and Adam Heaps (Not Pictured: Lavina King, KaLynn Loeven, Julia Martin, Stephen Ratcliffe, Millie Young)

*Charles Hantrop Dr
To 30 B Rn Harris 300 90*



Clinic for Special Children

Our Staff

Keturah Beiler, RN
Nurse

Lauren E. Bowser
Research Fellow

Karlla Brigatti, MS, LCGC
Research Operations Director

Vincent Carson, MD
Pediatric Neurologist

Kelly Cullen
Communications Manager

Adam D. Heaps, MS, MBA
Executive Director

Christine Hendrickson, RNC
Nurse

Candace Kendig
Medical Receptionist

Lavina King
Community Liaison

Yalonda Kosek
Office Coordinator

KaLynn Loeven
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Development Assistant

Laura Poskitt, DO
Pediatrician

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Kevin A. Strauss, MD
Medical Director

William Van Ess, MS, CFE
Accountant

Millie Young, RNC
Research Nurse

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