2016

ANNUAL REPORT

Clinic *for*
Special Children

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"It is not enough to merely care for your patients, you must also care about them. When you start caring about them, they demand your time and effort; they begin to shape your future. The hours of worry are not a burden—they humble us, strengthen us, and make us mindful of the needs around us. They teach us compassion—which literally means "to suffer with."

- Dr. Kevin Strauss, Clinic for Special Children Medical Director

Our Mission

Provide comprehensive

LOCAL MEDICAL CARE,

integrate science and clinical medicine, and

SHARE KNOWLEDGE to improve

the HEALTH OF CHILDREN

who suffer from genetic disorders.

Advancing Science and Medicine,
One Child at a Time.

Thanks to you, we celebrate another year of innovative and life-saving therapies! Because of your care and support, children from our clinic community are living longer, healthier lives.

For the past 27 years, the Clinic for Special Children has been as a medical home to the most vulnerable and underserved children among us: children faced with genetic predispositions to disability, chronic disease, and untimely death. With your support, many of these children have reached adulthood and some have now been blessed with children of their own. We are grateful to walk alongside patients and families through life's greatest tribulations and blessings.

As we look toward the future, we remain steadfast in our mission to provide specialized and comprehensive medical care within our local community. In 2016, we welcomed a pediatric neurologist to our staff and expanded services to cover 13 sub-specialties including mental health support and counseling. We made changes to our building in response to the growing needs of the community, and created a large exam room to accommodate new specialists and adult-service providers.

Together, we have touched the lives of over 1,100 children and their families this year. We could not do it without your help! Over 67% of our funding comes from charitable sources, and 89% of all funds going directly to program services. We are grateful for your support! We look forward to the possibilities of 2017, as we continue our journey together on behalf of special children.

Kevin A. Strauss, MD
Medical Director

Adam D. Heaps, MS
Executive Director

Our Vision

We envision the Clinic for Special Children as a MEDICAL HOME

for predominately Amish and Mennonite children 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 children 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

1,083 *active patients*

16 *staff members*

Patient Care

Delivering effective and

AFFORDABLE CARE *for* CHILDREN

with genetic conditions.

PATIENT CARE STATS

3,897 *biochemical & genetic tests*

1,560 *patient visits*

Manage 225 *known variants that cause disease*

40 *states &* **17** *countries*

Patient Focus

CONOR WAS DIAGNOSED WITH MAPLE SYRUP URINE DISEASE (MSUD) at 4 days of age. MSUD is a genetic disorder in which the body is unable to process proteins properly. Without proper management, the disorder can cause severe brain damage and even untimely death. The most effective treatment for MSUD is a full liver transplant.

After learning of the diagnosis, Conor's parents, Daryl and Julia, were overwhelmed with shock and a myriad of questions, "Will he survive this? Will he ever be able to thrive?" The Martins sought help from the pediatricians at the Clinic for Special Children. Fortunately, the Clinic was able to help Conor.

Dr. Katie Williams and Dr. Kevin Strauss created a treatment plan for Conor with the ultimate goal of transplanting his liver. Though Conor's MSUD was well managed, he struggled with the impacts of MSUD on his daily life including a highly restricted diet and frequent hospitalizations. The Martins' prayers were answered on Julia's birthday, when they received a phone call with the news that a donor liver was available for Conor. Full of hope, faith, and anxiety, the Martin family rushed to the University of Virginia for Conor's transplant.

Since the surgery, Julia notices a marked difference in Conor's attention span and his improved ability to express himself. Most important to Conor, he is now able to eat protein-rich foods such as eggs, just like his brothers and friends. Today, anyone meeting 3-year-old Conor will experience his boundless energy and exuberance for life. He loves trains and is a fan of visiting the large Thomas the Tank Engine made of Mega Bloks at the Clinic. He loves reading, music and he has a savory tooth.

"We are truly grateful to the Clinic for being our medical home. CSC is a haven where we can receive not only the medical care Conor needs, but a place that focuses on the emotional needs of the whole family," says Julia. The Martin family hopes that their story may serve as an inspiration to others and a "testament to God's faithfulness."

Education and Community Empowerment

COMMUNITY

To date, nearly 100 of our patients at the Clinic for Special Children have undergone a life-saving organ transplant by the surgeons of CHP (Children's Hospital of Pittsburgh). This July we had the honor of hosting our annual Transplant Day in partnership with CHP. Much of the day was devoted to family education about research and updates to the treatment and maintenance associated with this specialized transplant process. We are very thankful to every one of our collaborators who make days like this possible and to every person involved in helping to change the lives of our patients and families.

EDUCATION

Midwives provide a critical connection between the Clinic and many of the special children we serve. Midwifery Pearls, our 2016 CME accredited educational conference, presented a comprehensive review of disease screening and management for commonly encountered diseases in our patient population. Midwives, clinicians, and many others who help care for newborns met to discuss newborn screening, management of neonatal group B strep, eye exams, and pulse oximeter testing. Last year, with the education provided on pulse oximeter screening, midwives were able to screen over 1,200 babies. From these early screenings, 3 children were identified with heart or lung conditions, enabling treatment within hours of birth and before they became critically ill.

EDUCATION & COMMUNITY STATS

10 *family days in 2016*

4 *research students*

Research

This year, the Clinic received national recognition by GENOME MAGAZINE

The Clinic for Special Children was featured in the January 2016 issue of *Genome Magazine*, detailing how a clinic in a cornfield, nestled among the rural back roads of Strasburg, Pa., blends simplicity with cutting-edge science. Highlighted is an inspiring personal account of one family's difficult journey with Pretzel Syndrome and the Clinic's remarkable impact through their diagnosis, treatment and personal influence on both this family and a genetically vulnerable community predisposed to rare genetic diseases.

READ THE ARTICLE ONLINE AT:

http://genomemag.com/clinic-in-a-cornfield/

RESEARCH & DEVELOPMENT STATS

33 NEW *disease-causing genetic variants*

5 *peer-reviewed publications in 2016*

2016 | FINANCIALS

STATEMENT OF FINANCIAL POSITION
As of 9/30/2016

ASSETS

Cash and Equivalents	$860,274
Accounts Receivable	$103,689
Promises to Give	$25,000
Prepaid Expenses	$20,815
Property and Equipment	$670,429
Investments	$2,948,701
Investments Restricted	$770,744
Total Assets	$5,399,652

LIABILITIES & NET ASSETS

LIABILITIES	
Accounts Payable	$155,335
Accrued Expenses	$22,881
Accrued Wages	$26,153
Deferred Revenue	$5,000
Total Liabilities	$209,369
NET ASSETS	
Undesignated	$1,360,812
Board Designated	$2,885,383
Temporarily Restricted	$664,578
Permanently Restricted	$279,510
Total Net Assets	$5,190,283
Total Liabilities and Net Assets	$5,399,652

STATEMENT OF ACTIVITIES
10/1/2015-9/30/2016

REVENUE

Contributions	$940,954
Grants	$90,000
Collaboration Funds	$481,248
Special Events	$885,910
Clinic Fees	$226,015
Investment Income	$396,185
Laboratory Fees	$156,992
In-Kind Donations	$288,349
Miscellaneous income	$18,020
Total Revenue	$3,483,673

EXPENSES & PROGRAM INVESTMENTS

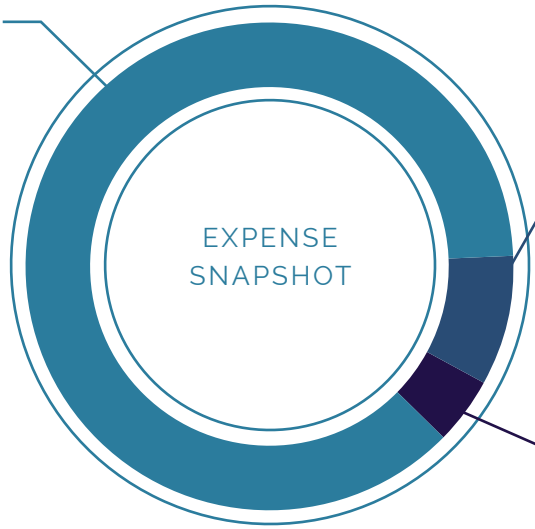
Program Services	$2,750,475
Management	$233.411
Fundraising	$95,464
Total Expenses	$3,079,350

2016 | FINANCES

89%

Program Services

$2,461,801



8%

Management

$226,421

3%

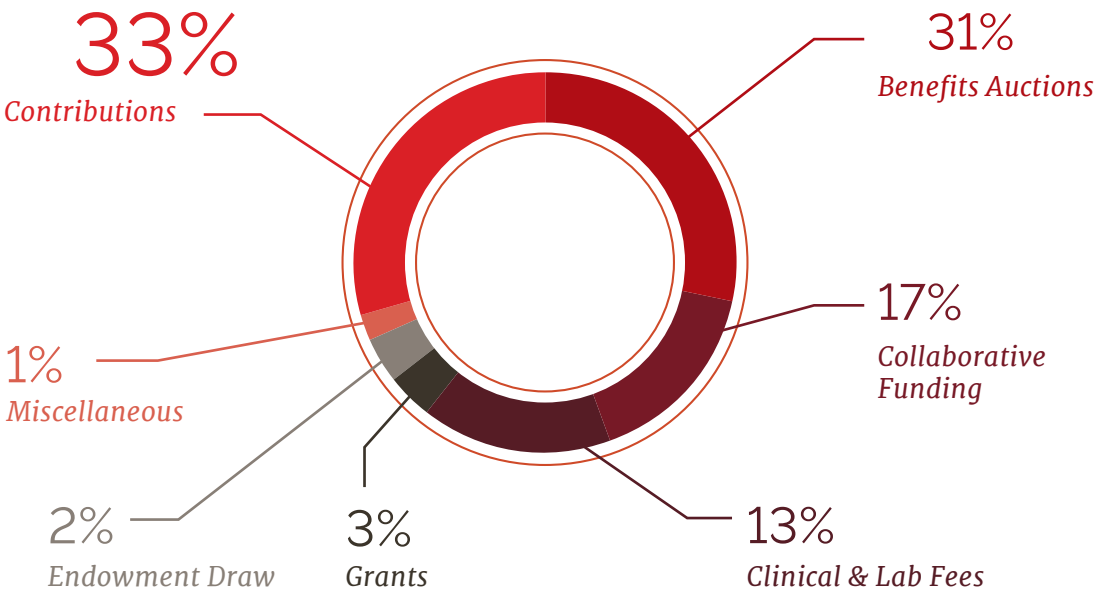
Fundraising

$92,863

TOTAL BUDGET EXPENSES

$2,781,085

2016 REVENUE SNAPSHOT



Front (L-R): Christine Stickler, Christine Hendrickson, Kevin Strauss, Katie Williams, Karlla Brigatti, Kim Calderwood
Back (L-R): Erik Puffenberger, Mindy Kuebler, Millie Young, Vincent Carson, Donna Robinson, Yalonda Kosek, Adam Heaps
Not Pictured: Keturah Beiler, Lavina King

Clinic *for* Special Children

Our Staff

Keturah Beiler, RN
Nurse

Karlla Brigatti, MS, LCGC
Genetic Counselor

Kim Calderwood, MA
Communications Manager

Vincent Carson, MD
Pediatric Neurologist

Adam D. Heaps, MS
Executive Director

Christine Hendrickson, RNC
Nurse

Lavina King
Community Liaison

Yalonda L. Kosek
Medical Receptionist

Mindy Kuebler, MS
Laboratory Technician

Erik G. Puffenberger, PhD
Laboratory Director

Donna L. Robinson, CRNP
Nurse Practitioner

Kevin A. Strauss, MD
Medical Director

Christine Stickler, JD
Development Director & General Counsel

Katie B. Williams, MD, PhD
Pediatrician

Millie Young, RNC
Nurse

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Secretary

Leon Hoover

Leonard Hurst

Mark Martin
Treasurer

Stephen D. Ratcliffe, MD, MSPH

Jacob Zook
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