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“Each office visit is like a teaching seminar for us. The doctors explain every detail very thoroughly and help us understand why our children’s special needs affect them the way they do.”

- LM, Mother of a patient
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.
We are thankful to all of you for another year of service at the Clinic for Special Children promoting healing, community, and medical discovery.

In 2015, the Clinic discovered 32 new known genetic variants that cause disease, and 10 peer reviewed articles in prestigious scientific journals. The work of the Clinic, and the power of genetics, also received national recognition in the November 2015 issue of Scientific American; a testament to the power of science to improve health. Most importantly, however, 2015 marked another year where your faith and support enabled us to leave an indelible mark upon the lives of genetically disadvantaged and underserved children and their families.

The vibrant growth and success of the Clinic for Special Children is a testament to the precious covenant formed between people who need special care and those professionals who are called to serve them. With your continued support, the work of many hands and hearts will safeguard this promise for generations to come.

Kevin A. Strauss, MD
Medical Director

Adam D. Heaps, MS
Administrative Director
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**

<table>
<thead>
<tr>
<th>1,182</th>
<th>16</th>
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<tr>
<td><strong>active patients</strong></td>
<td><strong>staff members</strong></td>
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Delivering effective and affordable care for children with genetic conditions.

### Patient Care Stats

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<td><strong>4,213</strong> biochemical &amp; genetic tests</td>
<td><strong>1,575</strong> patient visits</td>
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<tr>
<td>Manage <strong>225</strong> known variants that cause disease</td>
<td><strong>40</strong> states &amp; <strong>17</strong> countries</td>
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JULIA WAS DIAGNOSED WITH GLUTARIC ACIDEMIA TYPE I (GA-1) at 5 days of age. GA-1 is a genetic disorder in which the body is unable to process proteins properly. Without proper management, the disorder can cause physical and intellectual disability.

After learning of the diagnosis, Julia’s mother was devastated to learn that many children with GA-1 suffer from debilitating effects of the disorder. Unable to find anyone with experience in the disorder locally, Julia’s mother began an international search to find a service that could help her daughter. Julia’s mother learned of the Clinic for Special Children by searching online. The only problem was Julia’s family lived in Hawaii and CSC was located in rural Pennsylvania.

Wanting to ensure the best possible care for Julia, her family moved to Strasburg for what ended up being four years. Fortunately, the Clinic was able to help Julia. “I can’t put in words what Dr. Strauss means to us... he helped us in ways you cannot even imagine,” says Julia’s mother. After Julia grew to an age where a devastating brain injury was much less likely, she and her family were able to move back to Hawaii. Today, Julia is an active, beautiful and vibrant 5 year old who enjoys dancing, swimming, and wants to learn to surf.

“I can’t put in words what Dr. Strauss means to us... helped us in ways you cannot even imagine.”

Julia’s family, originally from Brazil, set up a Facebook page in Portuguese to help connect other families with the services offered by CSC. As a result, patients from Brazil, Portugal, and Spain have been helped by CSC’s services.
COMMUNITY

The Clinic for Special Children hosts “Family Days” special events where the families of children affected with similar disorders can come together and learn more about the biology of a disorder and the medical treatments in a warm and compassionate environment of fellowship and mutual support. Families from around the country who traveled to Strasburg for the Clinic’s Family Day for girls with the DDX3X gene mutation. The families learned about genetic sequencing, the biology behind genetic mutations and more. DDX3X is a genetic mutation that causes a range of intellectual disabilities and in some cases seizures, poor muscle tone or behavioral issues. An estimated 1 to 3% of girls with undiagnosed intellectual disabilities may have this mutation, affecting as many as 1 in 5,000 girls.
EDUCATION

The Clinic, jointly with Franklin & Marshall College, hosted the 3rd Annual conference on Translational Medicine the Plain Populations. The Conference was sponsored by The Children’s Hospital of Pittsburgh, Lancaster General Health and Nemours Children’s Health System. The conference brought together clinicians, scientists, administrator and other interested individuals to discuss topics related to the Plain populations of North America including: GA-1, MSUD, mental health conditions, therapeutic tissue transplant, cardiac disease and disorders, and early diagnosis and treatment using pulse-ox screening.

EDUCATION & COMMUNITY STATS

10 family days in 2015

4 research interns
This fall, the Clinic received national recognition by **SCIENTIFIC AMERICAN** who featured an article on our own medical director, Kevin Strauss, MD and how genetics can be used to inform medical treatment. Like so many disorders treated at the Clinic, early diagnosis and treatment is essential and may mean the difference between life and death. For one family treated at the Clinic, a SCID diagnosis was made at 4 hours of age and resulted in a life-saving bone marrow transplant at 1 month of age.

**READ THE ARTICLE ONLINE AT:**
scientificamerican.com/article/clinic-genomics-can-improve-health-care-right-now/

**RESEARCH & DEVELOPMENT STATS**

32 NEW variants found that cause disease  

10 peer-reviewed publications in 2015


2015 FINANCES

EXPENSE SNAPSHOT

- **86%** Program Services: $2,423,597
- **9%** management: $259,779
- **5%** fundraising: $128,791

**TOTAL EXPENSES**

$2,812,167
2015 REVENUE SNAPSHOT

29.5%
Contributions

28.5%
Benefits Auctions

16%
Collaborative Funding

16%
Clinical & Lab Fees

4%
Endowment Draw

4%
Grants

2%
Miscellaneous
Clinic for Special Children

Our Staff
Karlla Brigatti, MS
Genetic Counselor
Kim Calderwood, MA
Communications Manager
Vincent Carson, MD
Pediatric Neurologist
Adam D. Heaps, MS
Administrative Director
Christine Hendrickson, RNC
Nurse
Yalonda L. Kosek
Receptionist
Mindy Kuebler, MS
Laboratory Technician
Stephanie Kulp, RN
Nurse
Caroline S. Morton, EdM
Co-founder
Erik G. Puffenberger, PhD
Laboratory Director
Kendra Poirier
Avery Fellow
Donna L. Robinson, CRNP
Nurse Practitioner
Kevin A. Strauss, MD
Medical Director
Christine Stickler, JD
Development Director
Carolyn K. Williams
Laboratory Technician
Katie B. Williams, MD, PhD
Pediatrician
Millie Young, RNC
Nurse

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The Clinic for Special Children is a non-profit 501(c)(3) tax-exempt organization and a registered charitable organization in Pennsylvania (Tax ID # 23-2555373). PA law requires us to advise that a copy of our official registration and financial information may be obtained from the PA Department of State by calling toll free, 1-800-732-0999. Registration does not imply endorsement.