



Fighting genetic illnesses with

# Cutting-Edge Research & Compassion



Clinic *for*  
Special Children<sup>®</sup>

# Our mission is 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 Goals


Deliver effective and affordable diagnosis and comprehensive care for children and adults with genetic conditions.

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Develop innovative laboratory methods that serve the needs of patients and families.

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Expand the capability for clinical studies, education, and training in genetic medicine.



# Our Services

Our unique model offers a pathway into the future of genomic medicine, where physicians, researchers, and scientists work hand-in-hand to solve ever-changing, complex problems. We explain the meaning of genomic data for the individual, providing the right treatment at the right time. By seamlessly integrating a CLIA-certified biochemical and molecular genetics laboratory into our primary care practice, we provide fast and affordable testing that continually drives better patient care. The focus of our research and laboratory centers on the needs of the families we serve.

## Our services include:

- Advanced Genomic Techniques
- Amino Acid Quantitation
- Genetic Counseling
- In-Hospital Care & Home Visits
- New Patient Evaluations
- Cherished Lives* Palliative Care Program
- Primary Care for Children & Adults
- Rapid Molecular Diagnostics





# By the Numbers

## DISCOVERY



**455**

known variants managed that can cause disease



**64,000+**

in-house laboratory tests & procedures since 2003



**141**

peer-reviewed publications

## TREATMENT



**73%**

of patients receive a specific, genetic diagnosis



**6,100**

total patients served since 1989



**18**

medical specialist services offered on-site

## ACCESS



**25,000+**

patient appointments since 2010



**\$112M**

annual community savings from CSC's services



**\$0**

cost to patients for doctor or nurse visits

## Research, Collaboration, & Discovery

We are a small practice by design, but a wide network of collaborators enhances our ability to provide comprehensive clinical care and conduct groundbreaking research, helping us to close the gap between scientific knowledge and the translation of knowledge into effective medical care. Our work has been published in over 140 peer-reviewed scientific journal articles and featured in news outlets both nationally and internationally. Clinical collaborations allow us to offer services typically only available at institutions in major cities.

### Our collaborative projects include:

- Cellular Research
- Clinical Trials
- Education
- Organ Transplantation
- Medical Food Design
- Scientific Publications
- Subspecialty Services
- Technology Development



## Meet a Family

# The Hoover Family

After four months of illness, hospitalizations, and countless tests, Leon and Linda Hoover finally received a diagnosis for their son, Raylon. The answer – severe

combined immunodeficiency (SCID) – is a rare and devastating disorder that renders an infant without a working immune system.

The Hoover family reached out to the Clinic for help shortly after Raylon's diagnosis. The Clinic quickly connected the Hoover family with the stem-cell transplantation team at the Children's Hospital of Philadelphia (CHOP). For children with SCID, the most effective treatment is bone marrow or stem cell transplantation, which restores their immune system using healthy donor cells. Sadly, Raylon's treatment came too late. He died at six months of age.

Eight years later, the Hoovers welcomed a daughter, Kendra, into their family. Within hours after her birth, she tested positive for SCID through the Clinic's lab. After confirming Kendra's diagnosis, the Clinic sprang into action to get her on the path to effective treatment. The next morning, the Clinic team visited the family to collect blood samples in the hopes of finding a perfect stem cell match. Kendra's 11-year-old sister, Esther Mae, was that perfect match.

At just 16 days of age, Kendra was transplanted with Esther Mae's cells. A month later, Kendra was able to receive a second donation – called a “boost” – from her sister. After more months of isolation and checkups, Kendra's second transplant worked, just in time for her first birthday.

“We were so thankful Kendra didn't experience any major complications after her transplant. Today, Kendra is doing great. We are so thankful to the Clinic for the help they gave us with Kendra. We trust the Clinic with caring for our child. They feel like family,” says Linda.

## CSC STATS

**1,738**

Active patients

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

**33** Staff members

**35** Years in operation



# Ways to Support

## Give

- Make a gift online or mail us your gift – gifts of all sizes make a difference
- Make a gift in honor or memory of a loved one
- Give to the Clinic through your will, trust, or gifts of stock



Scan the QR code to visit our giving page!

## Attend or Volunteer

- Join us at one of our annual benefit auctions
- Attend a fundraising or educational event organized by the Clinic
- Sign up to help volunteer at a Clinic event



## Fundraise & Share

- Plan your own fundraising event with proceeds benefiting the Clinic
- Create a fundraising page for the Clinic and share with your friends and family
- Follow us on one of our social media channels



## Connect with us!



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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.