## Fighting genetic illnesses with Cutting-Edge Research & Compassion

Special Children



# Meet a Family The Zimmermans

Martha and Malvern Zimmerman couldn't find answers to the health challenges faced by their son, Oakley. Despite a flurry of visits to local physicians and emergency rooms in Oakley's first year of life,

the Zimmermans still didn't have answers for how to provide relief for their son. Martha called the Clinic and her concerns for her son's health were met with compassion and action.

Dr. Grace Loudon Meier, Oakley's physician, spent time researching Oakley's symptoms before his family even began their two-hour trek to the Clinic. Genetic testing for Martha and Malvern revealed that Oakley had mevalonate kinase deficiency (MKD), a rare condition that causes Oakley's immune system to flare and his temperature to quickly spike. Dr. Meier learned that the condition can be easily managed with monthly anti-inflammatory injections, and this treatment worked well for Oakley. Within a few months, Oakley's health improved dramatically thanks to the collaboration between Dr. Meier and the Clinic's laboratory team.

The care that Oakley receives every month embodies the core values of the Clinic for Special Children: compassion coupled with personalized, cutting-edge clinical care supported by genetic research and testing. Finding answers for tricky diagnoses like Oakley's requires a team of nurses, doctors, genetic counselors, and scientists committed to working together. At the center of this equation is a person who needs care and compassion. At the Clinic, relationships are just as important as knowledge.



## 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 Goals**

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

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

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

## **Our Impact**

#### DISCOVERY

408

known variants managed that cause disease

> 55,000 in-house laboratory tests & procedures since 2003

**130** peer-reviewed

### 73%

of patients receive a specific, genetic diagnosis

**5,000** total patients served since 1989

18

medical specialist services offered on-site

## \$20 million

ACCESS

annual community savings from CSC's services

14,000 patient appointments since 2010 **2 hours** length of all new patient

## Collaboration, Research & Discovery

The Clinic is a small practice by design, but a wide network of collaborators enhances our ability to provide clinical care and conduct research, helping us to close the gap between increased scientific knowledge and the translation of knowledge into effective medical care. Our work has been published in over 130 peer-reviewed scientific journal articles and featured in major 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
- o Organ Transplantation
- Medical Food Design
- Scientific Publications
- Subspecialty Services
- Technology Development

#### TREATMENT

## **Our Services**

The Clinic's unique model offers a pathway into the future of genomic medicine, where physicians 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 genetic laboratory into our primary care practice, we provide fast and affordable testing that continually drives better patient care. The laboratory's focus is on the needs of the patients 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



## **Support Our Work**

#### Only about 10% of the Clinic's budget

of \$5,000,000 comes from patient fees and philanthropy is critical to our ability to offer cutting-edge clinical care at an affordable rate for patients and families. We invite you to join us in fulfilling this vital mission.



#### Make a monetary donation You can make your gift online at www.ClinicforSpecialChildren.org/give by scanning the QR code or mail your donation to: Clinic for Special Children, Attn: Development Team, P.O. Box 128, Strasburg, PA 17579. We also accept in-kind gifts and gifts of stock.

#### You're invited

to join us at one of our six annual summer benefit auctions and the Clinic's yearly 5k race in September. Sponsorship and volunteer opportunities are available.





Make a legacy gift by joining the Clinic's planned giving society, the Quilter's Circle, and include the Clinic in your estate plans.

#### Contact us

Please contact the Clinic's development team at 717-687-9407 or giving@clinicforspecialchildren.org for additional information. We welcome the opportunity to assist you.



535 Bunker Hill Road PO Box 128 Strasburg, PA 17579 tel (717) 687-9407 fax (717) 687-9237 ClinicforSpecialChildren.org

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.