



Keeping <sup>THE</sup>  
**Promise**

A Campaign for  
the Clinic for  
Special Children

**BUILDING HOPE**



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

# Keeping the Promise.

The **Clinic for Special Children** was founded in 1989 to provide families, primarily from the local Amish and Mennonite (Plain) communities, with compassionate care for their children with complex, sometimes fatal, genetic disorders.

Since then, children with once life-limiting disorders are growing into adults, new treatments are on the horizon for many disorders, and the Plain community continues to grow. This campaign is about keeping our promise to care for children as they age, seeking the promise of life-giving therapies, and **keeping the promise** to be here for families when they need us.



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**Our unique approach  
combines specialized treatment  
with cutting-edge research.**

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## **Innovative Model for Patient Care**

The Clinic is a comprehensive medical practice for children and adults with complicated genetic disorders, providing all of their healthcare needs in one location. Our unique approach combines specialized treatment with cutting-edge research to meet each patient's individual needs. The on-site laboratory provides biochemical and genetic tests normally only available at major healthcare centers. The testing services are offered at a fraction of the cost and rapidly enough to influence the patient's treatment and outcome. Our goal is to translate genetic research into effective, affordable medical care for the most vulnerable among us.

# Building Hope.

Dear Friend,

The Clinic for Special Children has a wonderful problem.

Thanks to the Clinic's major advances in both diagnosis and treatment, many genetic disorders that used to be fatal in childhood are now survivable or preventable. Accordingly, 30 percent of patients served by the Clinic today are 14 or older. Their complex conditions require ongoing monitoring and specialty care.

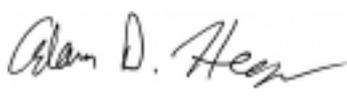
The Clinic was not originally designed to serve children and adults, and is too small to accommodate current demand. The waiting room is often standing room only. Former conference rooms now house cubicles for our growing staff. The Clinic needs a larger facility so we can treat patients into adulthood and serve an ever-increasing number of children and their families.

In recognition of our growing facility requirements, we searched for a new location. We established three essential criteria: proximity to the Clinic's patients, accessibility to the broader Plain community, and to be within a 30-minute drive of Penn Medicine Lancaster General Hospital.

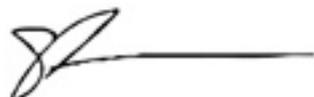
We are excited to announce that the Clinic has purchased a site in Leacock Township that meets all our criteria! Generous assistance from a few friends funded the land purchase.

Now we must raise the funds to build a new Clinic. We hope you will join us to make this vision a reality. It represents the vital next step in keeping our long-standing promise to provide optimal, compassionate care for vulnerable people living with genetic diseases.

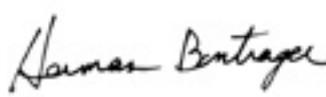
With hope and gratitude,



**Adam D. Heaps, MS, MBA**  
Executive Director



**Kevin A. Strauss, MD**  
Medical Director



**Herman Bontrager**  
Chair, Board of Directors

## CSC BY THE NUMBERS

**1,200**  
Active  
Patients

Patients from  
**44** States &  
**17** Countries



From L to R: Adam D. Heaps, MS, MBA, Kevin A. Strauss, MD, and Herman Bontrager



# Ideally Situated

**The Clinic's new site** places us squarely in the middle of Lancaster County's Plain communities, just east of Intercourse on Old Philadelphia Pike at Hatville Road. It will be easily accessible by horse and buggy while providing the Clinic with 10.27 acres on which to grow.



**44%**  
of Patients  
Reside in  
Lancaster County

The Clinic's exterior will reflect Lancaster's agricultural character. A covered entry portico and an inclusive, accessible playground will make visits more comfortable and enjoyable for all families.

## A Familiar Experience

Arriving at the Clinic will be similar to the current experience. A short lane will take families from the entrance on Old Philadelphia Pike to the Clinic, which will be set back from Hatville Road and Old Philadelphia Pike. The new building will feel familiar and welcoming amidst the surrounding farmland. New family-friendly amenities will include comfortable indoor and outdoor waiting areas, a nature path, and a garden area.



## A Community Project

The Leacock Township site will be easy to find for families traveling from long distances for care. Nearby hotels and restaurants will offer convenient accommodations for their stay.

The Clinic will sit behind our neighbor, the Community Care Center, a care facility for Plain adults with special needs, well away from the hustle and bustle of Old Philadelphia Pike. Our two organizations are collaborating and sharing land development costs to reduce the overall costs of our projects.

The Clinic for Special Children and Community Care Center will both partner with Hoover Building Specialists, EK3 Design Architects, and ML Saxinger & Associates for their respective projects.



## Larger Lab for New Life-Saving Discoveries

The lower level will provide increased space for the Clinic's state-of-the-art laboratory. For the first time, all our biochemical and genetic testing equipment will be consolidated in one area, improving efficiency and collaboration. Investments in new technology will grow our capacity to serve our patients while conducting advanced genetic research.



Our research has identified more than 1,300 known or suspected pathogenic variants, or changes in a gene that can cause disease. This knowledge base enables the Clinic to provide a diagnosis 75% of the time—a rate 2–3 times more accurate than major academic medical centers.



# 408

Genetic Disorders  
Identified and  
Treated



The larger laboratory will increase the Clinic's capacity to do carrier screening. The Plain Insight Panel™, developed by Clinic scientists, enables Plain couples in North America to find out if they carry changes to their genes that put their babies at risk for known genetic disorders. To date, there has been a large demand from the community for the Panel. The new facility includes family discussion rooms for genetic counseling to accommodate this increased demand.





## A Living Miracle

If **Alayna Wenger** had been born 30 years ago, before the Clinic began, she probably would not have survived beyond her first birthday. But according to her parents, Lucinda and Lydell Wenger, she is now “a very normal, very active toddler.”

Alayna was born with the genetic change that can cause Spinal Muscular Atrophy Type 1, a genetic disorder that causes muscles to become increasingly weak. Her condition was detected by newborn screening, the blood test given to every baby born in Pennsylvania. The Wengers’ midwife notified them of the results when Alayna was 11 days old; Clinic staff met with them that afternoon.

“We learned a lot at that first appointment,” remembers Lucinda, “especially how much they cared.”

A few days later, Alayna received gene replacement therapy at Penn Medicine Lancaster General Hospital, one of the Clinic’s collaborators. An intravenous infusion gave Alayna’s cells a working copy of the faulty gene. According to the Clinic’s Dr. Vincent Carson, Alayna’s physician, “This is one of the most dramatic treatments we can provide. It’s almost miraculous.”

Alayna is also receiving a second drug therapy. “We still don’t know what a normal treatment plan is for her,” says Dr. Carson, “so we’re doing research and clinical care simultaneously. It’s patient-centered research. We make a decision with the family and then study it.”

With years of Clinic visits ahead, Lucinda and Lydell like the idea of the new facility off Old Philadelphia Pike. “It’s well thought-out,” notes Lydell, “and it’s ten minutes closer to our house.”

In the meantime, the incredible advancements in diagnosis and treatment that the Clinic has helped pioneer will enable Alayna to live and grow almost normally. As Lydell says, “If you didn’t know it, you wouldn’t notice it.”



## Patient-centered Design

The new three-floor center will be a larger, more spacious, and more accessible version of our current facility. It will retain the comfortable environment our families value while accommodating the needs of children and adults with special needs and providing room for growth.



The genetic disorders we treat require ongoing monitoring as our patients grow into adulthood. The new clinic will have more exam rooms for children and several designed for adults. All rooms will be designed to be both accessible and comfortable for everyone.



### CURRENT VS. NEW FACILITY

	Current	New
Exam rooms	5	11
Family discussion lounges	0	2
Infusion room	0	1
Community meeting room (capacity: 90)	0	1
Small group meeting rooms	1	4
Total square feet	8,839	25,535

Many of our patients need regular physical therapy. A fully equipped space on the lower level will enable Clinic patients to get physical therapy treatment on-site.



## Space for Specialists

The Clinic for Special Children's care model includes a broad range of on-staff expertise, including pediatrics, pediatric neurology, adult medicine, and genetics. When a patient requires specialty services beyond this scope, we collaborate with specialists from places like Nemours Children's Hospital in Delaware, Cardiology Care for Children, and WellSpan Health to bring specialists to the Clinic.

The increased number of exam rooms, a separate workspace for visiting clinicians, and dedicated areas for specialists, such as audiologists, will make it easier for these providers to see families at the Clinic.



## Family-centered Design

The facility will include many family-friendly features: discussion rooms for clinicians and families to meet, small family waiting areas outside exam rooms, a lactation room, and a telephone room for Plain families to call their drivers.



# Keeping the Promise

## From Infant to Young Adult

**Crystal Martin** has been coming to the Clinic since she was two days old. That was 24 years ago.

Born with Maple Syrup Urine Disease (MSUD), Crystal benefitted from the Clinic's groundbreaking discoveries into this devastating condition. Previously, one in three people with MSUD died in childhood. The condition left many others with severe neurological and physical disabilities.

Not Crystal.

Clinic physicians immediately started her on a special formula they developed and later transitioned her to a diet that prevented brain damage. Growing up with a severe metabolic disease was not easy, as her condition could change quickly. Yet she has good memories of her frequent visits to the Clinic.

"All three doctors were trying to figure me out, not just one," she recalls. "Dr. Strauss would draw things out so I could understand them." She also remembers that after having blood drawn, "I would run my blood samples down the hall to Erik" (Dr. Puffenberger, the Lab Director). Stickers, Band-Aids, and Beanie Babies remain part of her Clinic memories.



A liver transplant at age 15 changed her life. The Clinic's close collaborative relationship with UPMC Children's Hospital of Pittsburgh helped make the transplant possible. For Crystal, a properly functioning liver meant the end of her many dietary restrictions. Her first request? Mint chocolate chip ice cream. "It was creamier than I expected."

Crystal is now a teacher at the Millway School. She returns to the Clinic for quarterly checkups and has monthly blood tests to monitor her condition. "Being able to continue to meet with my doctors will be a great benefit," she says. "The new location will be 15 minutes closer for me, too."





## Beyond the Chair

On his website, **Michael Fondacaro** describes himself as “a young adult with many interests and hobbies: motivational speaker, avid skier with multiple medals, competitive chess player, college graduate with a 3.8 GPA, passionate video gamer.”

“Oh yeah,” he adds, “I also use a wheelchair to get around and a communication device to speak.”

Michael has been coming to the Clinic every year for most of his 24 years. He receives treatment for Glutaric Acidemia Type 1, an enzyme deficiency that doesn’t let the body break down certain amino acids. When these amino acids build up, they become toxic to the body.

“The Clinic has impacted my life immensely,” Michael says. “When I was a baby, the Clinic staff gave us hope that I would be okay when other doctors said I would not make it past the age of 3. When we had any questions, the doctors at the Clinic answered them with care and immediacy. If I had to go to the hospital, they would call to make sure I got the right fluids to prevent further damage. As I got older, they helped us adjust my diet so I would remain healthy.”

Michael is now running the business he founded, Beyond the Chair. “My mission is to enlighten people to treat people with a disability the same as everyone else,” he explains. “We don’t want to be treated differently.”

As for a new clinic designed to serve both children and adults, Michael says, “Not having to worry about aging out would mean the world to me. Plus, with the new facility, we can learn more about how Glutaric Acidemia affects adults.”



# Keeping the Promise



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**The Clinic has  
saved hundreds  
of lives ...**  
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## A Unique Perspective

As a long-time Elizabethtown College teacher, researcher, and writer about Lancaster’s Plain communities, **Donald B. Kraybill** has witnessed the Clinic’s relationship with the Amish and Mennonite communities from the start.

The Clinic practices personalized medicine, customizing diagnosis, treatment, and prevention to match each patient’s genetic blueprint. I think a large chunk of the Clinic’s success can be explained by its commitment to culturalized medicine. The staff infuse cultural practices into their medical practices. The current building has Old Order soul, right alongside the precision tools for DNA testing. There’s an embodiment of the culture in the building—the chairs, the toys for kids, the art on the walls, the colors. It speaks the language of home, and it reflects the values of the Old Order community.

The Clinic clearly needs a new space. The community understands that. The Clinic has selected an excellent location that will be more easily accessible to more families. I believe Lancaster’s Plain communities will welcome the new facility. A larger exam room with space for more family members signals it’s for them. The Clinic will continue to feel like a medical and cultural home if it embodies an Old Order ethos.

The Clinic has saved hundreds of lives. Lancaster’s Plain communities are grateful for that and recognize the need for this new phase.



### Designed for Community

The upper level of the new facility will include a community meeting room for up to 90 people, where the Clinic can host future events, such as our Family Days. The top floor will also provide office space for Clinic staff.



Each new discovery builds hope for a better life for people living with genetic disease both here in Lancaster County and around the globe. You can help us keep our promise to continue making life-changing discoveries.



# Building Hope

A new Clinic will require a community investment of \$12,500,000. The Plain community has already demonstrated enthusiasm for this campaign through early investments in the project. They know the Clinic’s facility requirements are changing rapidly because they see it first-hand as their children grow into adulthood. We look forward to continued, broad community support of this vital project so that we can continue keeping the promise of caring for those living with rare genetic illnesses.

## PROJECT BUDGET

Land	\$1,000,000
Professional Fees	\$775,000
Site Work	\$1,450,000
Construction	\$6,200,000
Furnishings and Equipment	\$725,000
Project Contingencies	\$850,000
Innovation Fund	\$500,000
Sustainability Fund	\$1,000,000
<b>Total</b>	<b>\$12,500,000</b>

As shown below, gifts, grants, and multi-year pledges of all sizes are needed, and every contribution will make a difference in this \$12.5 million fundraising campaign. Gifts can be made in many forms, including cash, gifts of stock/bonds/mutual funds, personal property, in-kind donations of materials and labor, and real estate. Commitments may be paid over a period of up to five years. Gifts in support of future programs, benevolence funds, innovation, and technology may also be made through one’s estate. Please contact the Clinic Development Department staff for details.

## TABLE OF GIFTS NEEDED TO REACH GOAL

Gift Range	Number Needed	Total in Range	Cumulative
\$1,000,000+	1	\$1,000,000	\$1,000,000
\$750,000	1	\$750,000	\$1,750,000
\$500,000+	4	\$2,000,000	\$3,750,000
\$250,000+	6	\$1,500,000	\$5,250,000
\$100,000+	20	\$2,000,000	\$7,250,000
\$50,000	30	\$1,500,000	\$8,750,000
\$25,000	60	\$1,500,000	\$10,250,000
\$10,000	80	\$800,000	\$11,050,000
\$5,000	90	\$450,000	\$11,500,000
\$2,500	100	\$250,000	\$11,750,000
\$1,000	500	\$500,000	\$12,250,000
\$500 and under	Many	\$250,000	<b>\$12,500,000</b>

Donors may take up to five years to pay their pledge

## SUSTAINABILITY FUND

While designed to be highly efficient, the new Clinic building is much larger and therefore will require more annual operational funds to maintain. The Sustainability Fund will create permanent future funds that tackle this challenge by providing a bedrock of financial support that allows Clinic staff to focus on developing innovative services.

## INNOVATION FUND

Campaign proceeds for the Innovation Fund will be used where the needs are greatest to respond to new research, programmatic needs, and technology opportunities. The fields of medicine, science, and technology change quickly and we strive to keep pace in order to provide state of the art services and programs.

### Gifts-in-kind

To make a gift of in-kind materials or labor towards the project, please contact the Development Team at the Clinic at 717-687-9407 or [giving@clinicforspecialchildren.org](mailto:giving@clinicforspecialchildren.org).



Clinic for  
Special Children®



## A Campaign for the Clinic for Special Children

### Our Mission

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.



For more information, contact:

Development Team

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[ClinicforSpecialChildren.org](http://ClinicforSpecialChildren.org)

