



Clinic for  
Special Children®

# Newsletter

ISSUE #59

SUMMER 2023



## Transplanting Hope 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 heard about the Clinic for Special Children from friends in their community and reached out for help shortly after Raylon's diagnosis. "During the first call we made into the Clinic, my husband, Leon, spoke with Dr. Kevin Strauss for about 45 minutes. We learned more about SCID during that call than we ever had before," recounts Raylon's mother, Linda.

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 at the Clinic lab. "It was amazing how quickly the Clinic provided us with a diagnosis for Kendra. We received a diagnosis of SCID within just 12 hours of her birth," says Linda. After confirming Kendra's diagnosis, the Clinic sprang into action to get her on the path to effective treatment.

The next morning, Dr. Strauss drove two hours to meet the Hoovers in their home, where he collected 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. For several months thereafter, the Hoovers kept Kendra isolated to protect her from illness as her body built up a new, functional immune system. Then a setback: within five months, the first transplant was deemed unsuccessful.

Thankfully just a month later, Kendra was able to receive a second donation – called a "boost" – from her sister. This time Kendra received conditioning, which primed her body to accept the donor cells. 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. You would never know by looking at her that she had a transplant. We are so thankful to the Clinic for the help they gave us with Kendra. Our experience was so different than with our son. We trust the Clinic with caring for our child. They feel like family," says Linda.

At the Clinic, we are working on initiatives to better serve children facing severe immune or blood disorders. To help identify potential stem cell donors more quickly, the Clinic recently launched the Plain Marrow Donor Registry. This registry will include a list of potential stem cell donors to serve the Plain community. "Our family is excited about this new project," says Linda, "Our names are already in the registry. We would be excited to be called upon to donate and help another child and family." Read more about the Clinic's new registry on page 4 of the newsletter.



## SPECIAL DATES

### Missouri Benefit Auction Saturday, August 19

Ed Good Family Farm | Memphis, MO

### Labor Day | Office Closed Monday, September 4

All Day

### Blair County Benefit Auction Saturday, September 9

Morrison's Cove Produce | Roaring Spring, PA

### Clinic for Special Children 5k Saturday, September 16

At the Clinic

Registration form & details inside!

### Community Benefit Dinner Tuesday, September 26

Martindale Fellowship Center

A seafood and ham buffet dinner to benefit the Clinic!

### Finger Lakes Benefit Auction Saturday, October 7

Ontario Produce Auction | Stanley, NY

### The Extraordinary Give Friday, November 17

ExtraGive.org

Online Fundraiser – All Day

Help spread the word about the Clinic during this 24-hour online fundraising event!

### Thanksgiving | Office Closed November 23 & 24

All Day

*Events are subject to change due to severe weather conditions, restrictions, or unforeseen circumstances.*



## Staff News

### Kelly Cullen



Congratulations to Kelly Cullen, Communications Manager at the Clinic, for celebrating her 5<sup>th</sup> work anniversary!

Kelly joined our team on July 2, 2018. In her role, she manages the Clinic's communications and marketing through advertising, content creation, public relations, community outreach, social media, and supporting the development team's fundraising efforts.

### Ashlin Rodrigues, MS



Congratulations to Ashlin Rodrigues, MS, Laboratory Scientist at the Clinic, for recently obtaining her Master of Science degree in Bioinformatics from the

University of Delaware!

Ashlin joined the Clinic's team in 2017 as a Laboratory Technician and was promoted to Laboratory Scientist in 2019. In her role, she is responsible for running several clinical assays including amino acid quantification and DNA isolation from whole blood.

## Board of Directors News

### Welcome, Jonathan H. Salvin, MD!



We are elated to announce that Dr. Jonathan H. Salvin has joined our Board of Directors!

Dr. Salvin is likely a familiar face to many families at the Clinic, as he has been coming to our facility for over 10 years as a pediatric ophthalmology consultant. He was on staff for over 15 years in the Division of Ophthalmology at Nemours Children's Health. Currently, he works at Merck as a Senior Director in Clinical

Safety and Risk Management.

Outside of work, he lives in Kennett Square, PA with his wife, Karen, and daughter, Laurel. He enjoys traveling, reading, and photography.

We're grateful to Dr. Salvin for his continued support of the Clinic and look forward to working with him as a member of our Board of Directors.

## Finance Committee

### Volunteers Needed!

We are looking for one or two volunteers to serve on the Clinic's finance committee. The finance committee meets every other month and provides guidance on financial matters to the Clinic's Board of Directors including reviewing budgets, financial statements, and investments.

The committee also ensures proper controls are in place, audits are completed, the investment strategy is implemented, and reviews all detailed financial statements.

We are looking for volunteers to commit to a two-year term. If you have a professional background in finance, accounting, or business management and are interested in learning more, please contact Adam Heaps, MS, MBA, Executive Director at [aheaps@clinicforspecialchildren.org](mailto:aheaps@clinicforspecialchildren.org) or call 717-687-9407.

## Join us!

### Community Benefit Dinner

**Tuesday, September 26<sup>th</sup>**

**4:00 p.m. – 7:30 p.m.**

**at the Martindale Fellowship Center**

The annual Community Benefit Dinner is slated for Tuesday, September 26<sup>th</sup> from 4:00 p.m. until 7:30 p.m. at the Martindale Fellowship Center (352 Martindale Road, Ephrata, PA, 17522)!

Meals will include a variety of delicious food like oysters, shrimp, ham, cole slaw, green beans, fresh fruit cup, rolls, and a whoopie pie! The cost of the dinner is by donation only. All proceeds will benefit the Clinic for Special Children's mission.

We hope to see you there for a fun night of

delicious food and great fellowship all in support of the Clinic!

## Matching Gift Opportunity!

We are excited to share that the Clinic currently has a 1-for-1 giving match up to \$10,000. The match is available thanks to the continued generosity of a local family foundation and is for wherever the funds are needed the most.

To help us fulfill the matching funds, please give via the included giving envelope in this newsletter. The first \$10,000 in funds received will be matched dollar-for-dollar. We thank you for your support of the Clinic's mission!

## Remaining 2023 Family Days

We're looking forward to the remaining family educational days for 2023! One family day (EVC) has changed the date since our last newsletter. Please see below for the date marked with "date change" below.

If you receive an invite for a family day this year, we hope that you can join us! All of our 2023 family days will be held at Strasburg Menonite Church (1514 Village Road, Strasburg, PA, 17579). If you have any questions about our family days, please contact Kelly Woodson, Events Manager, at 717-687-9407 or [kwoodson@clinicforspecialchildren.org](mailto:kwoodson@clinicforspecialchildren.org).

### Ellis-van Creveld syndrome

(EVC)

**Tuesday, July 25<sup>th</sup>**

**\*Date Change\***

### Spinal muscular atrophy

(SMA)

**Friday, August 25<sup>th</sup>**

### TNNT1 myopathy

(Chicken Breast Disease)

**Tuesday, September 26<sup>th</sup>**

### Glutaric acidemia type 1

(GA-1)

**Tuesday, October 31<sup>st</sup>**





6<sup>th</sup> Annual



Clinic for  
Special Children®

5K

Saturday,  
September 16, 2023  
9:00 a.m. – 11:00 a.m.

at the Clinic for Special Children

Presented by:



NEMOURS  
CHILDREN'S HEALTH

**\$30** (by Aug. 21<sup>st</sup>, includes t-shirt)

**\$35** (after Aug. 21<sup>st</sup>, t-shirt while supplies last)

**\$10** Kid's color fun run (ages 10 & under)

KID'S COLOR FUN RUN  
BAKE SALE  
RUNNER'S SNACKS

Register for the Clinic for Special Children 5k!  
You can sign-up by:

- 1) Filling out the application included in this newsletter  
OR
- 2) Visiting [www.ClinicforSpecialChildren.org/events/5k](http://www.ClinicforSpecialChildren.org/events/5k)  
OR
- 3) Calling the Clinic at 717-687-9407  
OR
- 4) Scanning the QR code

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



## Remaining 2023 Benefit Auctions



Most auctions will feature  
CSC remarks and quilts midday.

*Events are subject to change due to severe weather conditions, restrictions, or unforeseen circumstances.*

### Saturday, August 19 Missouri Auction

Airplane Candy Drop at 9:30 a.m.  
Auction at 10:15 a.m.

Aug. 18 | 5:00 p.m.  
Food & Fellowship

Ed Good Family Farm  
10507 County Road 813  
Memphis, MO 63555

Contact: Harlan Burkholder | 660-341-4113

### Saturday, September 9 Blair County Auction

Breakfast at 7:00 a.m., auction at 8:30 a.m.

Sept. 8 | 4:30 p.m.  
Rib Dinner & Auction Preview

Morrison's Cove Produce  
4826 Woodbury Pike  
Roaring Spring, PA 16673

Contact: Mervin Martin | 814-793-3529

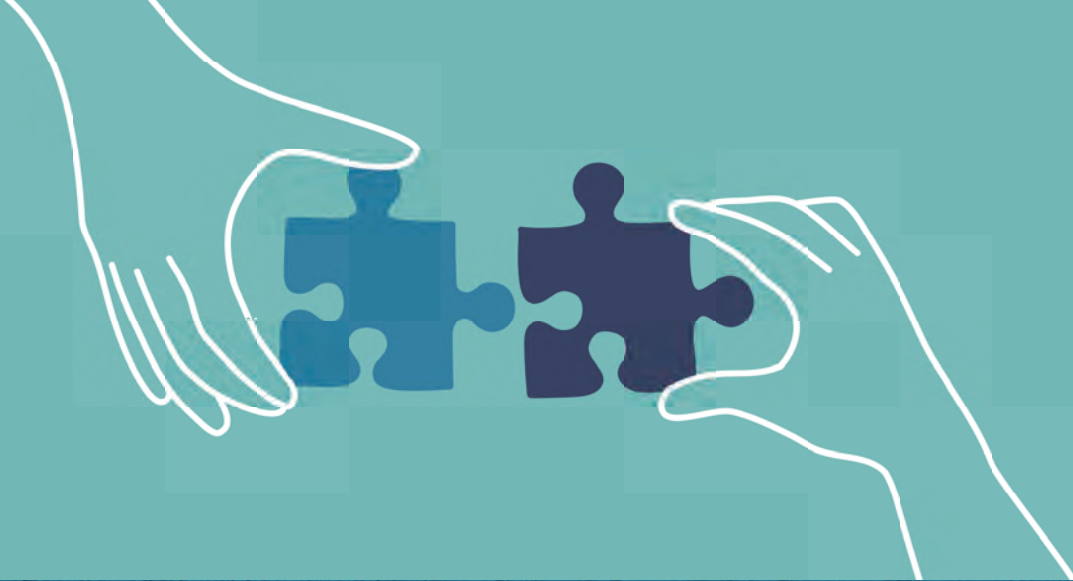
### Saturday, October 7 Finger Lakes Auction

Country style breakfast at 6:30 a.m.  
Auction at 8:00 a.m.

Ontario Produce Auction  
4860 Yautzy Road  
Stanley, NY 14561  
Contact: David Fox | 585-526-5913

### Carrier Testing at the Auctions!

The Clinic will be on-site at each auction to offer carrier testing! The Plain Insight Panel™ (PIP) will be available from 10 a.m. – 2 p.m. at the auctions. Cost is \$99 per person for the PIP.



# Be a Child's Cure

## Introducing our new Plain Marrow Donor Registry

The Clinic for Special Children has developed a new community-wide service to help patients with severe immune or blood disorders in need of bone marrow or stem cell transplantation. *Be a Child's Cure: Plain Marrow Donor Registry* is a marrow donor registry created to match Plain patients at the Clinic who need these life-saving therapies with bone marrow donors of similar genetic heritage. With a quick genetic test, our laboratory staff can screen healthy adults from the Plain community to find a donor for patients needing a transplant, provided at no-cost to either the patient or donor.

### Immune disorders in the Plain community

Our immune system prevents viruses, bacteria, and other germs from making us sick while also helping us recover from infection. No one's immune system is 100% protective all the time, but in people with a primary immune disorder, their immune system may be too weak to fight off infection or it may even wrongly attack the body's own tissues. In either case, this can be obvious and life-threatening soon after birth.

The primary immune disorders we see at the Clinic, like severe combined immunodeficiency (SCID), have genetic causes, meaning that one of several genes that direct production of the many different parts of the immune system has an error that affects that process. In most cases, these immune disorders are recessive, following the same inheritance pattern as maple syrup urine disease (MSUD) and spinal muscular atrophy (SMA). This means children with an immune deficiency are born to healthy carrier parents. When both parents are carriers for the same genetic immune disorder, each one of their children has a 25% chance (1 in 4) of being affected with that condition. At the Clinic, we use advanced carrier screening methods like the Plain Insight Panel™ to identify carrier couples before a baby is even born. At birth, we can rapidly perform targeted testing on cord blood to make a genetic diagnosis on the first or second day of life – days to weeks before the return of the state newborn heel-prick test, which screens all babies for immune dysfunction soon after they are born. The sooner affected children are found, the faster and better we can treat them.

### Treatment: Bone marrow or stem cell transplantation

In serious cases, we need to build the patient's immune system through transplantation of healthy cells. Some hospitals can transplant blood stem cells or bone marrow (spongy tissue inside bones where blood stem cells are found) taken from a healthy donor and given to a patient with an immune disorder ("the recipient"). Those cells then create new white blood cells of the immune system that respond to infec-

tion, reconstructing the patient's immunity to healthier levels.

### Finding the best donor

Patients with an immune disorder cannot receive bone marrow or blood stem cells from just anyone willing to donate to them. Instead, they need to find a donor who has the same or very similar HLA (human leukocyte antigens) profile. HLA proteins help your immune system recognize which cells are part of your body ("self") and which are invaders that need to be destroyed. Finding an HLA-matched bone marrow donor increases success rates of transplantation by limiting the likelihood that the recipient's body will reject the transplanted cells or that the donor cells will attack the recipient's tissues.

The genes that encode HLA proteins are inherited, so individuals within families or from similar genetic backgrounds have the highest chance of being a suitable match to one another. This inspired us to create a registry of potential bone marrow donors from the Plain community serving the Plain community.

### Be a Child's Cure – sign up today!

ALL Plain adults (18 years and older) are invited to participate in our Plain Marrow Donor Registry to help connect recipient patients with their donor. Participation in the registry is fully voluntary and does not mean you consent to be a donor, just that you are open to that possibility should you be a match for someone in need. Full counseling and consenting will be provided to any participant found to be a match about what that means for the donor. Even those who are ineligible to donate marrow or stem cells (ex: due to older age) are encouraged to participate, as their genetic information may be useful in tracking down potential matches and understanding the genetic makeup of the community.

To join the registry, we require a simple blood draw to get the genetic material needed for HLA testing. If you have already had genetic testing with the Clinic for Special Children, that sample may often be used so you do not need another blood draw.

## To learn more or to join the registry:

Please contact the Clinic at 717-687-9407 (Monday – Friday, 9:00 a.m. to 5:00 p.m.) or email [queries@clinicforspecialchildren.org](mailto:queries@clinicforspecialchildren.org) for more information on how to submit a sample and join the registry.





## Collaborator Spotlight

Jolan E. Walter, MD, PhD

*Robert A. Good Endowed Chair, Division of Pediatric Allergy & Immunology at the University of South Florida (USF)*

During her time at Harvard University Medical School, Dr. Jolan Walter worked with Dr. Kevin Strauss, Medical Director at the Clinic for Special Children, and Dr. Nicholas Rider at the Milton S. Hershey Medical Center to study children from Old Order Mennonite families with a rare genetic disorder called cartilage-hair hypoplasia. Since 2007, Dr. Walter has been focused on studying patients with different forms of severe combined immunodeficiency (SCID) in the Old Order Mennonite community. Several of these patients have a form of partial recombination-activating gene (RAG) deficiency resulting in atypical SCID, which is less severe than typical SCID. To learn more about SCID, please read the Hoover family's story on the front page of this newsletter.

Dr. Walter has been working with Dr. Strauss on identifying genetic variants of typical and atypical SCID, observing how the disease progresses with age, and determining how infectious agents such as exposure to a common virus called cytomegalovirus (CMV), the gut microbiome, and diet affect physical symptoms of the disease. She and Dr. Strauss are also attempting to improve targeted therapies for SCID which do not require a matched tissue donor. The latter involves genome editing of the *RAG1* SCID gene in collaboration with researchers in Israel. She has assembled a highly skilled team of clinical study coordinators, MD/PhD students, basic scientists and clinicians to accomplish these goals.

Currently, Dr. Jolan E. Walter is Chief of Pediatric Allergy and Immunology at the University of South Florida (USF) and at Johns Hopkins All Children's Hospital (JHACH) in St. Petersburg, FL as well as Robert A. Good Endowed Chair of Pediatrics. In addition, she is the Director of the Jeffrey Modell Diagnostic & Research Center for inborn errors of immunity at JHACH.

Working with Dr. Walter, the Clinic for Special Children has obtained blood and stool samples from children and adults of Mennonite families who have genetic variants of partial *RAG1* or *RAG2* deficiency. Interestingly, the severity of disease experienced due to the *RAG1* variant ranges

widely from early death due to repeated infections to relatively healthy with mild or no symptoms. The teams of Drs. Walter and Strauss are investigating whether the severity and symptoms experienced are influenced by the types of bacteria residing in the intestines and by previous infections throughout life or even at birth. Dr. Walter is leading national and international efforts on similar research questions in a larger cohort of patients with partial *RAG* deficiency.

Some of Dr. Walter's team's findings on partial *RAG* deficiency include patients from Mennonite communities and were published in a high-ranking peer-reviewed journal, *Nature Immunology*.

In a separate project, Drs. Walter and Strauss are collaborating with genome editing experts in Israel along with immunologists in Dr. Walter's laboratory in Florida to potentially develop a cure for *RAG1* SCID. Their Israeli collaborators are using genome editing to replace the entire *RAG1* gene. Their team will isolate stem cells from blood and bone marrow samples from affected individuals of the Mennonite and Amish communities. Then they will edit the gene and develop the stem cells into immune cells in the laboratory.

Dr. Walter is a physician-scientist with a passion for caring for and educating patients with variants of SCID and other genetic disorders of immune deficiency and dysregulation. She participated in the SCID Family Day hosted by the Clinic for Special Children in July 2022 to inform the Mennonite and Amish communities about SCID and its atypical variants. Topics included inheritance of the disease, immune defects, autoimmune complications, stem cell transplantation and gene therapy.

She and her team are very grateful to Dr. Kevin Strauss, Dr. Laura Poskitt, Karla Brigatti, MS, CGC, and Millie Young, BSN, RNC at the Clinic for Special Children who continue to support her efforts to improve early diagnosis, prevention and new treatments for the Old Order Mennonite and Amish communities with inborn errors of immunity, especially SCID due to *RAG* deficiency.



## Our Staff

Amy Albright, MS, CGC  
Genetic Counselor

Keturah Beiler, BSN, RN, CHPPN  
Nurse & Cherished Lives Program Manager

Karlla W. Brigatti, MS, CGC  
Research Operations Director

Vincent Carson, MD  
Pediatric Neurologist

Joelle Williamson Clark, MPH  
Clinical Research Manager

Kelly Cullen  
Communications Manager

Skye Gawn  
Development Associate - Operations

Jennifer Giaccio  
Medical Receptionist

Adam D. Heaps, MS, MBA  
Executive Director

Christine Hendrickson, RNC  
Nurse

Candace Kendig, RMA  
Office Manager

Alanna Koehler, PhD  
Assistant Laboratory Director

Lavina King  
Community Liaison

KaLynn Loeven  
Laboratory Scientist

Julia Martin  
Development Associate

Alexis McVey, BSN, RN, CPN  
Nurse Manager

Grace Meier, MD  
Family Medicine Physician

Laura Poskitt, DO  
Pediatrician

Erik G. Puffenberger, PhD  
Laboratory Director

Stephen D. Ratcliffe, MD, MSPH  
Senior Consulting Physician

Donna L. Robinson, MSN, CRNP  
Nurse Practitioner

Ashlin Rodrigues, MS  
Laboratory Scientist

Angela M. Sepela, MBA  
Development Director

Dawn Sheets  
Medical Receptionist

Jessica Snyder, PHR, SHRM-CP  
Human Resources Generalist

Kevin A. Strauss, MD  
Medical Director

Erin Sweigert  
Research Associate

Sarah Thomas, RMA  
Medical Assistant

William Van Ess, MS, CFE  
Accounting Manager

Susan Walther, MS, CGC  
Genetic Counselor

Kelly Woodson  
Event and Volunteer Manager

Millie Young, BSN, RNC  
Research Nurse

## Board of Directors

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Cindy Bo, MBA | Secretary

Herman Bontrager | Chair of the Board

Elam Esh

Leon Hoover | Vice Chair

Leonard Hurst

Mark Martin | Treasurer and Chair-Finance Committee

Jacob Petersheim

Jonathan H. Salvin, MD

Stephen Tift, MD

Glen Zimmerman | Chair-Development Committee



## By the community, for the community *Gifts-in-kind committee*

Every month a group of local business owners, contractors, and trade representatives gather in the early morning hours for an important meeting. The scene is quite unique; competitors sit side-by-side and work together to achieve the same goal. Everyone in attendance has the Clinic for Special Children on their minds and hearts. The objective of the meeting? To source donations of materials and labor from the local community to help build the new Clinic for Special Children facility near Intercourse, PA.

This group – the gifts-in-kind committee – is comprised of dedicated and passionate volunteers. Over the past year their work has resulted in an impressive response from the community. As of July 10, 2023, over \$1.6 million of materials and labor has been donated to help build the new Clinic. The committee's work is a manifestation of 'by the community, for the community.'

Word of the committee's work has reached far beyond the local Lancaster community. Generous companies located in West Virginia, Maryland, and North Carolina have also joined in the effort to provide in-kind gifts to the new Clinic.

Glen Zimmerman, member of the Clinic's board of directors and chair of the gifts-in-kind committee remarks, "It is truly inspiring to see so many people graciously giving their time and talents to make this project a reality. The power of the committee working together

has been awe-inspiring. Through the work of the committee, vendors that have heard about the project from "a friend of a friend" have stepped up and contributed. When people understand the mission of the Clinic, they are all in and want to help. We're grateful to the many hands that have made light work."

Gifts of in-kind labor and materials are essential to the success of the Clinic's new building project. We wouldn't be able to complete this transformational project without the help of the community. With the support of many, including the gifts-in-kind committee, we'll ensure the Clinic keeps its long-standing promise to care for children as they age, seek the promise of life-saving therapies, and be here for individuals and families whenever they need care.

If you're interested in learning more about the project and our current gifts-in-kind needs, call our project informational hotline at 717-207-8607. We look forward to opening the new Clinic next year – a place built by the community, for the community.



### THANK YOU to the Gifts-in-Kind Committee!

Glen Zimmerman | Chair  
Jacob Petersheim | Co-Chair  
Elam Stoltzfus | Owner's Representative  
Delmas Fox  
Delmar High  
John Kauffman  
John Kauffman  
Christ King  
Crit Lapp  
Leroy Martin  
Nelson Martin  
Dale Nolt  
John Smucker  
Elmer Stoltzfus  
John Stoltzfus, Jr.  
Levi Stoltzfus  
Nathan Zimmerman



# Keeping the Promise: Building Hope

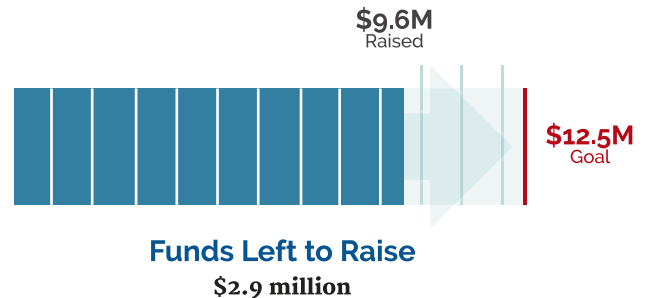
## Project Updates

**The new Clinic facility is taking shape!** Since the last Clinic for Special Children newsletter in April, the new facility is now clearly defined with a foundation, steel frame, and set concrete floors. Framing recently started and will continue through the end of July. Our goal is to have the exterior construction complete by early Fall. Enjoy several recent construction photos showing the building progress!

On the fundraising side, we're excited to share that we're at 77% of our \$12.5 million goal as of July 10, 2023. We are deeply grateful for the many supporters who have helped us get this far in the campaign. While we still have \$2.9 million left to raise, we are hopeful that we can finish the campaign strong.

## ON OUR WAY TO REACHING OUR GOAL

**As of July 10, 2023**  
Over 2,000 supporters and  
\$9.6 million raised (77% of \$12.5 million goal)



## STAY UP-TO-DATE ON OUR PROJECT!



**Call our project hotline**  
(717) 207-8607

We've set up a hotline to share regular project updates! Call in to learn about our current project needs, construction progress, and more.



**Visit our website**  
[www.ClinicforSpecialChildren.org](http://www.ClinicforSpecialChildren.org)

You can view construction and fundraising updates on our website! Visit our 'New Building' page for all of the latest details.



**Watch our videos**  
YouTube (@ClinicSpecialChild)

In addition to posting drone and time-lapse videos on our website, we also have a dedicated YouTube playlist where we share all project videos.



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Charles Wankrop	20
To 50 lb. Rn Hair 300	90