

Newsletter

SPECIAL EDITION | ISSUE #58



Our Future Home New Clinic Facility

We're delighted to share this special edition of the Clinic for Special Children's newsletter featuring a transformational project - the Keeping the Promise: Building Hope capital campaign to build a new facility for the Clinic.

For more than 30 years, the Clinic for Special Children has provided services at our current facility in Strasburg, PA. Today, the Clinic treats more than 1,500 active patients and conducts world-class research, while charging minimal fees for these services thanks to the generosity of the community.

However, as each year passes, the operations at our Strasburg location become more challenging. By growing to meet the needs of the community, we've outgrown our space. The Clinic is surrounded by preserved farmland so we cannot expand the current facility. On a normal day, the waiting room is full, exam rooms are at capacity, and the parking lot overflows.

In order to solve this problem and provide ongoing essential medical services to the community, the Clinic purchased a 10-acre property in Lancaster County near Intercourse, PA, to build a new building. Excavation at the site began in November 2022. Building construction started in March and will run through Spring 2024

The new Clinic facility will include more exam rooms, conference rooms for educational events, waiting areas designed for families, and dedicated space for specialists like cardiology, ophthalmology, and audiology doctors.

As of April 10, 2023, over 1,770 supporters have already contributed to this vital project during the initial silent phase of the campaign, allowing us to raise over \$8.9 million to date!

We are deeply grateful to our early supporters, who have allowed us to raise 71% of our total \$12.5 million goal. These funds include donations and pledges of cash, building materials, labor and services. You can learn about the many ways to give to the campaign and the general operations of the Clinic on page 8 of this newsletter.

We're excited to finally share the news of this monumental project with you. Now, we need your help to get us across the finish line and reach our \$12.5 million goal. You can learn more about this important project in the pages of this newsletter. We look forward to keeping you updated on our progress as we move closer to opening the new Clinic - a place of comfort, friendship, and hope for generations to come.

With gratitude,

Laman Bentrager alam D. Hear

Herman Bontrager Chair, Board of Directors

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

SPRING 2023



SPECIAL DATES

Memorial Day - Office Closed Monday, May 29 All Day

Union County Benefit Auction Saturday, June 3 Buffalo Valley Produce Auction | Mifflinburg, PA

Lancaster County Benefit Auction Saturday, June 17 Leola Produce Auction | Leola, PA

Shippensburg Benefit Auction Saturday, June 24 Cumberland Valley Produce Auction | Shippensburg, PA

4th of July - Office Closed Tuesday, July 4 All Day

Ohio Benefit Auction Saturday, July 8 Blooming Grove Auction Inc. | Shiloh, OH

Missouri Benefit Auction Saturday, August 19 Ed Good Family Farm | Memphis, MO

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 | 9:00 AM - 11:00 AM

Finger Lakes Benefit Auction Saturday, October 7

Ontario Produce Auction | Stanley, NY

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

Kevin A. Strauss, MD Medical Director

Updates from Special Children[®]

Staff News Alanna Koehler, PhD



We're delighted to welcome Dr. Alanna Koehler to the Clinic!

Dr. Koehler joined the Clinic in 2022 as our first Assistant Laboratory Director.

In her new role, Dr. Koehler will assist the Laboratory Director, Dr. Erik G. Puffenberger, in managing the biochemical and genetics laboratory at the Clinic. She will work on a blend of hands-on laboratory work, data analysis, and scholarly work.

She spends most of her free time with her rescue dogs and she cares deeply for senior and special needs animals.

Erik G. Puffenberger, PhD



Congratulations to Dr. Erik G. Puffenberger who celebrated his 25th work anniversary at the Clinic in January! Dr. Puffenberger

joined the Clinic in January 1998 and has been instrumental in the Clinic's success over its 34-year history.

We're grateful that Dr. Puffenberger dedicated his career to applying molecular genetics to patient care. His work of building the Clinic laboratory's genetic capabilities has positively impacted so many lives of people facing rare genetic disorders.

Angela M. Sepela, MBA



We're excited to welcome another new team member to the Clinic!

Angela M. Sepela, MBA (Angie) joined the Clinic in 2022 as our

new Development Director.

In her role, Angie is responsible for all fundraising and development efforts at the Clinic. Her position includes planning and executing strategies for annual giving, major gifts, foundation grants, corporate giving, event sponsorships, and planned giving initiatives.

In her free time, she likes to read, knit, travel, and spend time with family and friends. Most often you will find Angie with her rescue dog, Keeva, by her side.

Jessica Snyder, PHR, SHRM-CP



We're excited to welcome Jessica Snyder, PHR, SHRM-CP to the Clinic as our Human Resources Generalist!

Jessica joined the

Clinic in January 2023. In her new role, Jessica will coordinate all human resources functions of the Clinic.

She will assist in recruitment, onboarding and training, performance review, implementing and enforcing internal policies, ensuring compliance with PA state and federal labor laws, personnel file management, and benefit management.

In her free time, Jessica likes to spend time with her husband and kids, work outside in her yard, and ride her bike along the Susquehanna River.

2023 CSC Mugs for Sale \$10 each



Our 2023 Clinic for Special Children mug is now available for purchase! Each mug is \$10 and available for purchase on our online web shop (www.Clinic-

forSpecialChildren.org/Store), in person at the Clinic, at our 2023 events, or by giving us a call at 717-687-9407.

This year's 15 oz. charcoal mug features a simple quilt design and the Clinic's logo. The mug has a flared lip, gloss interior, and matte exterior with a light brown bottom accent. Get your new favorite mug today and support the Clinic!

Save the date! 6th Annual Clinic for Special Children 5k Run/Jog/Walk

Saturday, September 16th 9:00 a.m. - 11:00 a.m.

at the Clinic for Special Children

We are excited to announce our 6th annual Clinic for Special Children 5k will be held on Saturday, September 16th at the Clinic! Strollers and wheelchairs are welcome! Registration will open in early summer – applications will be available in our next newsletter, at our 2023 events, and on the Clinic for Special Children website.

We are accepting corporate sponsorships for the event at this time. If you are interested, please contact the Clinic's Development Team at 717-687-9407 or giving@clinicforspecialchildren.org. We hope to see you at our 5k this year!

2023 Central Penn Business Journal Healthcare Heroes Honoree

We are excited to share that the Clinic for Special Children was named the 2023 Healthcare Hero in the 'Special Needs Hero' category by the Central Penn Business Journal! The Clinic was selected based on achievements, community involvement, and inspiring change.

2023 Holiday Schedule Office will be closed for the following holidays:

Good Friday | Friday, April 7 Memorial Day | Monday, May 29 Independence Day | Tuesday, July 4 Labor Day | Monday, September 4

Thanksgiving Day | Thursday, November 23 Day after Thanksgiving | Friday, November 24 Christmas Eve | Friday, December 22 (Closed PM)

Christmas Day | Monday, December 25 Day after Christmas | Tuesday, December 26 New Year's Eve | Friday, December 29 (Closed PM) New Year's Day | Monday, January 1

2

2023 Benefit Auction Season

You're invited to join us!

You're invited to join us at a 2023 benefit auction! Each auction features a day of exciting bidding, delicious food, and great fellowship.

The seven benefit auctions are organized solely by volunteers from the community. Philanthropic sources, like the benefit auctions, fundraisers, individual contributions, and grants make up about 60% of the Clinic's annual operating budget. This vital support allows us to provide timely, accessible, and affordable care to families facing rare genetic disease.

> To learn more about the 2023 auction season, visit our auctions website (*www.ClinicAuctions.org*) to view the most current information.



2023 Auction Calendar

Saturday, June 3 Union County Auction Breakfast at 7 a.m., auction at 8:15 a.m.

June 2 | 4:00 – 8:00 p.m. Tool & Flower Auction + Rib Dinner

Buffalo Valley Produce Auction 22 Violet Road Mifflinburg, PA 17844 **Contact:** Leon Hoover | 570-966-2414

Saturday, June 17 Lancaster County Auction

Breakfast at 6:30 a.m., auction at 8:30 a.m.

Leola Produce Auction 135 Brethren Church Road Leola, PA 17540 **Contact:** Mark Martin | 717-733-3070

Saturday, June 24 Shippensburg Auction

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

Cumberland Valley Produce Auction 101 Springfield Road Shippensburg, PA 17257 Contact: Elvin Oberholtzer | 717-532-9088

Saturday, July 8 Ohio Auction

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

Blooming Grove Auction Inc. 1091 Free Road Shiloh, OH 44878 **Contact:** Michael Newswanger | 419-896-2184

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

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.

ClinicforSpecialChildren.org



A New Building Campaign for the





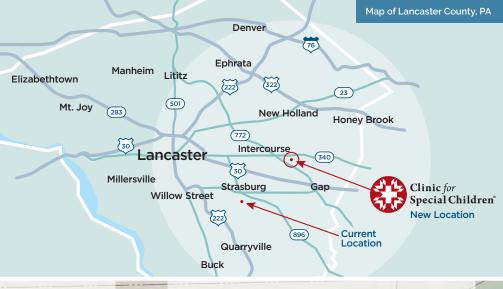
In order to keep our promise of caring for the most vulnerable, we're excited to share that the Clinic is building a new facility near Intercourse in Lancaster County, PA. Read on to learn about the thoughtful design of the new Clinic and how the building will allow us to better care for children and adults that seek our care.

Please help us spread the word about our project and if you can, we're deeply appreciative of any size gift to support the project. You can learn about ways to give on page 8 of this newsletter. For more information, visit the project's webpage at www.ClinicforSpecialChildren.org/campaign.

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.

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.

Old Philadelphia Pike



For the Community

The Clinic will sit behind our neighbor, the Community Care Center (CCC), who is building their own new facility. The CCC is a care facility for Plain adults with special needs.

A Familiar Experience

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 walking path, and a garden area.



Clinic for Special Children[®]

A New, Thoughtfully Designed Clinic



Patient-centered Design

The new three-floor Clinic 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. 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.

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.





Larger Lab for 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 while conducting advanced genetic research.

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





Alayna Wenger's Story

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 for their family,

Lucinda and Lydell like the idea of the new facility off Old Philadelphia Pike. "It's well thought-out," notes Lydell.

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."



GIFTS IN KIND

Our goal is to create a new building with the support of many local businesses and suppliers – creating a new Clinic for the community, by the community.

In-kind gifts of materials or services to the *Keeping the Promise*: *Building Hope* capital campaign are essential to meeting our \$12.5 million goal. In-kind gifts will be counted as donations to the campaign and can be eligible for tax-deductions.

We are currently looking for the following in-kind materials or services listed below for the site work and construction phases of the project.

Products Needed

- Trucking/hauling
- Aggregate stone
- Commercial drywall
- Framing lumber
- Cabinetry & countertops
- Paint
- Carpet & tile
- Furniture
- Trash removal
- Signage
- Window shades & blinds

Services/Labor Needed

- Stone veneer installers
- Concrete flatwork services
- Certified electrician contractors
- Framing & finish carpenters
- Siding installers
- Painting & interior detailing
- Cabinet installers
- Commercial flooring installers
- Interior cleaning
- Site work cleanup
- Landscaping/lawn care services

If you are interested in learning more about donating a gift-in-kind product or service, please contact:

Phone | Elam Stoltzfus, Owner's Representative, (717) 629-3159
Email | BuildingHope@ClinicforSpecialChildren.org
Mail | Clinic for Special Children, PO Box 128, Strasburg, PA 17579



2023 FAMILY DAYS

Each year we host a variety of family days focused on providing educational opportunities and fellowship for families affected by specific genetic disorders. If you receive an invite for one of our family days this year, we hope you can join us!

Bereavement Dinner Thursday, April 20th

Midwife Conference Wednesday, May 31st

STRADA Deficiency (Pretzel syndrome) Tuesday, June 20th

Ellis-van Creveld (EVC) Thursday, July 13th

Spinal Muscular Atrophy

Friday, August 25th

TNNT1 Myopathy (Chicken breast disease) Tuesday, September 26th

GA-1 (Glutaric acidemia type 1) **Tuesday, October 31**st

All family days will be held at: **Strasburg Mennonite Church** 1514 Village Road, Strasburg, PA 17579

To learn more about our 2023 Clinic for Special Children fundraising events, please view the included calendar insert in this newsletter.

Our Staff

Amy Albright, MS, CGC Genetic Counselor

Keturah Beiler, BSN, RN, CHPPN Nurse & Cherished Lives Program Manager Ashton Bollinger <u>Research A</u>ssociate

Karlla W. Brigatti, MS, CGC <u>Research Operations Director</u>

Vincent Carson, MD Managing Physician

Kelly Cullen Communications Manager

Skye Gawn Development Associate - Operations

Jennifer Giacoio 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 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

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

Jan L. Bergen 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 Stephen Tifft, MD Glen Zimmerman | Chair-Development Committee

WAYS TO SUPPORT THE GENERAL OPERATING OF THE CLINIC

While this special edition newsletter focuses on the new building campaign, there are a variety of ways to support the Clinic's ongoing operational needs as well! There is an opportunity to provide monetary support towards the operating of the Clinic or the new building campaign via the enclosed giving envelope. We are grateful for the many ways in which people support our mission!



Attend a Clinic auction or special event



Make a monetary gift via the enclosed giving envelope

(select 'General operating fund')



Participate in our planned giving program



Share about the Clinic's work with friends and family



Follow the Clinic's social media channels



Sign up to receive Clinic emails

HOW TO SUPPORT THE BUILDING CAMPAIGN



Make a monetary gift via the enclosed giving envelope (select 'New building project')



Gifts of in-kind labor, materials, etc.



Multi-year pledges



Volunteering

B

Planned giving

To support the Clinic's general operating *and/or* the new building campaign, you can give through the enclosed giving envelope or contact us at:

Clinic for Special Children, PO Box 128, Strasburg, PA 17579 Development Team 717-687-9407 **or** giving@ClinicforSpecialChildren.org

To make an anonymous gift to the Clinic's general operating *and/or* to the new building campaign through the Anabaptist Foundation:

Anabaptist Foundation Charitable Gift Fund 55 Whisper Creek Drive, Lewisburg, PA 17837 1-800-653-9817 (ask for information on the Charitable Gift Fund Program) **or** giftfund@afweb.org

Groundbreaking & Tree Planting Ceremony

April 4, 2023

On Tuesday, April 4, 2023, the Clinic's 34th anniversary, we commemorated the start of construction on the Clinic's future home with a groundbreaking and tree planting ceremony. A maple tree was planted in honor and memory of all of the special families the Clinic has served over three decades. Please enjoy this selection of photos from the special day.

63

WAY TO S

OUR GOAL









Promise

Promise

Promise

63

 \odot Promise

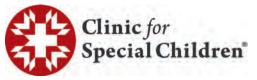
()



4. Climic for hildre







535 Bunker Hill Road PO Box 128 Strasburg, PA 17579

tel (717) 687-9407 fax (717) 687-9237

ClinicforSpecialChildren.org

You can unsubscribe from our newsletter mailing list by calling us at 717–687–9407, emailing queries@clinicforspecialchildren.org, or mailing us (Clinic for Special Children, Attn: Kelly Cullen, PO Box 128, Strasburg, PA 17579).



The Clinic for Special Children is a Pennsylvania non-profit corporation and a 501(c)3 public charity for US federal and state tax purposes (Tax ID # 23-2555373). The official registration and financial information of The Clinic for Special Children, Inc. may be obtained from the Pennsylvania Department of State by calling toll free, within Pennsylvania, 1 (800) 732-0999. Registration does not imply endorsement.



A New Building Campaign for the





ANNOUNCING OUR NEW BUILDING CAMPAIGN

A special edition of the Clinic's newsletter about building and raising funds for our new home

Clinic for Special Children[®]