



We've Moved! to Gordonville, PA

Home, sweet home! On Monday, April 1, 2024, we officially moved into our new, expanded facility in Gordonville, PA. After many years of planning for this next phase, we're excited to welcome families to our new facility. We're grateful to the many donors, businesses, families, and community members who have provided essential support to make this project a reality. While we've been working on our new facility, our everyday work of caring for patients has continued with no delays or interruptions. This wouldn't have been possible without a community of supporters.

Our new facility allows us to keep improving and expanding what we offer to the families we serve. The much-needed additional space and upgrades enable us to work more efficiently and collaboratively. For example, we can now host more clinics with over 18 visiting specialists, which reduces critical barriers to care and will provide new services on-site. Multiple discussion rooms and meeting spaces will give families comfortable spaces to relax when they're here for all-day visits and provide private spaces for in-depth conversations with physicians.

Thoughtfully designed exam rooms provide adequate space for accompanying family members and accessibility devices and will feature more comfortable exam tables. We also have several

rooms designed specifically for adults who visit us for their complex care. With a large assembly room, we can again host educational family days at the Clinic instead of renting space.

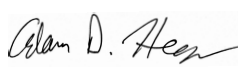
Our new integrated laboratory provides a more efficient workspace for scientists and researchers, allowing them to increase testing capacity and find answers more quickly. And, to the joy of many children, we now have a fully accessible playground. The entire building has been designed with input from staff, board members, families, and collaborators to make it more comfortable, accessible, and efficient for everyone who visits the Clinic.

We are sincerely grateful to over 2,600 supporters of our capital campaign so far. If you haven't supported the campaign yet, there's still time! We are still actively raising funds to finish the campaign, and you can learn more about how to give on page 4. With your support, vulnerable families will have a place to turn to when they need specialized care for generations to come.

With gratitude,



Herman Bontrager
Chair, Board of Directors



Adam D. Heaps, MS, MBA
Executive Director



SPECIAL DATES

Memorial Day - Office Closed Monday, May 27

All Day

Union County Benefit Auction Saturday, June 1

Buffalo Valley Produce Auction | Mifflinburg, PA

Lancaster County Benefit Auction Saturday, June 15

Leola Produce Auction | Leola, PA

Shippensburg Benefit Auction Saturday, June 22

Cumberland Valley Produce Auction | Shippensburg, PA

4th of July - Office Closed Thursday, July 4

All Day

Ohio Benefit Auction Saturday, July 13

Blooming Grove Auction Inc. | Shiloh, OH

Missouri Benefit Auction Saturday, August 17

Ed Good Family Farm | Memphis, MO

Blair County Benefit Auction Saturday, September 14

Morrison's Cove Produce | Roaring Spring, PA

Community Benefit Dinner Tuesday, October 1

Martindale Fellowship Center | Ephrata, PA

Finger Lakes Benefit Auction Saturday, October 5

Ontario Produce Auction | Stanley, NY

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



New Addresses & Move Details

We're excited to share that the Clinic for Special Children has officially moved to our new, expanded facility in Gordonville, PA effective April 1, 2024. All of our services, including office visits for patients and laboratory testing, are now provided at our new location (20 Community Lane, Gordonville, PA 17529). Our relocation is permanent and our former Strasburg location is closed and no longer offers patient care or laboratory testing.

Please ensure that you use our updated contact information below for mailing, shipping, and navigation for our new facility.

CHANGED

Street Address

20 Community Lane, Gordonville, PA 17529

Mailing Address

P.O. Box 500, Intercourse, PA 17534

NO CHANGES

Phone | 717-687-9407

Fax | 717-687-9237

Email | queries@ClinicforSpecialChildren.org

Website | www.ClinicforSpecialChildren.org

Office Hours | Monday - Friday, 9 a.m. - 5 p.m.

Staff News

Anne Thomas, LPN



We're delighted to welcome Anne Thomas, LPN to the Clinic! Anne joined our team in January as a Licensed Practical Nurse.

In her new role, she will help with daily clinical and administrative needs like rooming patients, phlebotomy, scheduling appointments, and more!

Anne enjoys spending time with her family, hiking, visiting the beach, and cooking new recipes (she's a self-proclaimed foodie!).

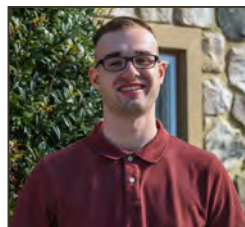
Ashlin Rodrigues, MS



Congratulations to Ashlin Rodrigues, MS, for starting a new role at the Clinic! She joined our team in 2017 as a Laboratory Scientist, and is now moving into a newly created role on our research team as a Clinical Research Analyst!

Last year Ashlin graduated with her Master of Science degree in Bioinformatics from the University of Delaware. We're excited to have Ashlin continue her career at the Clinic in her new research-focused role!

Sean Schreckengast



We're excited to welcome Sean Schreckengast to the Clinic! Sean joined our team in February as a Laboratory Scientist. As a Laboratory Scientist, Sean will work behind the scenes in our laboratory running a variety of tests that detect and manage rare genetic disorders.

In his free time, Sean enjoys playing his guitar, playing video games, and spending time with friends and family. He enjoys rooting for Philadelphia sports teams, especially the Phillies!

Leadership Team Updates

We're excited to share about new appointments to the Clinic's Leadership Team! Visit page 7 to read more about these changes to our medical, nursing, and research teams!

2024 CSC Mugs for Sale \$10 each



Our 2024 Clinic for Special Children mug is now available for purchase! Each mug is \$10 and available for purchase on our online webshop (www.ClinicforSpecialChildren.org/Store), in person at the

Clinic, at our 2024 events, or by giving us a call at 717-687-9407.

This year's 14 oz. mug features a black satin exterior contrasted by a red reactive glaze interior. To commemorate this special year of the move to our new facility, the front of the mug features an outline drawing of our new building! All proceeds from the mug sales benefit the Clinic.

2024 Holiday Schedule

Our office will be closed for the following holidays:

Good Friday | Friday, March 29

Memorial Day | Monday, May 27

Independence Day | Thursday, July 4

Labor Day | Monday, September 2

Thanksgiving Day | Thursday, November 28
Day after Thanksgiving | Friday, November 29

Christmas Eve | Tuesday, December 24 (Closed PM)

Christmas Day | Wednesday, December 25

Day after Christmas | Thursday, December 26

New Year's Eve | Tuesday, December 31 (Closed PM)

Clinic for Special Children 5k Update for 2024

It's going to be a big year with our move to our new neighborhood in Gordonville, PA! To give us time to settle and plan for a race in a new area, we will not host our 5k in 2024. While we will miss seeing everyone this year, we're looking for volunteers to help us plan for our 2025 race! Contact Angie Sepela, Development Director, at 717-687-9407 or asepela@clinicforspecialchildren.org if interested.

Perinatal Bereavement Rituals and Practices Among U.S. Cultural Groups Book

Keturah Beiler, BSN, RN, CHPPN, recently co-authored a chapter in the newly released textbook *Perinatal Bereavement Rituals and Practices Among U.S. Cultural Groups*. In chapter three, Keturah shares how families in the Amish and Mennonite communities approach bereavement rituals and how she coordinates our Cherished Lives Program to support families along their bereavement journey.

ClinicforSpecialChildren.org

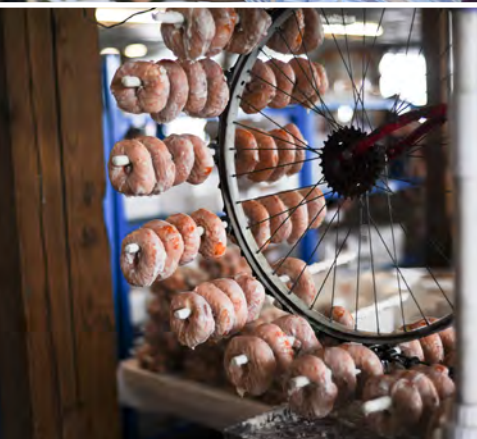
2024 Benefit Auction Season

Please join us!

You and your family are invited to join us at a 2024 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 benefit auctions, fundraisers, individual contributions, and grants, make up 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 2024 auction season,
visit our auctions website (www.ClinicAuctions.org) to view the most current information.



2024 Auction Calendar

Most auctions will feature
CSC remarks and quilts midday.

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

Saturday, June 1 Union County Auction

Breakfast at 7 a.m., auction at 8:15 a.m.

May 31 | 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 15 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 22 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 13 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

Saturday, August 17 Missouri Auction

Airplane Candy Drop at 9:30 a.m.

Auction at 10:15 a.m.

Aug. 16 | 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 14 Blair County Auction

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

Sept. 13 | 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 5 Finger Lakes Auction

Auction at 8:00 a.m.

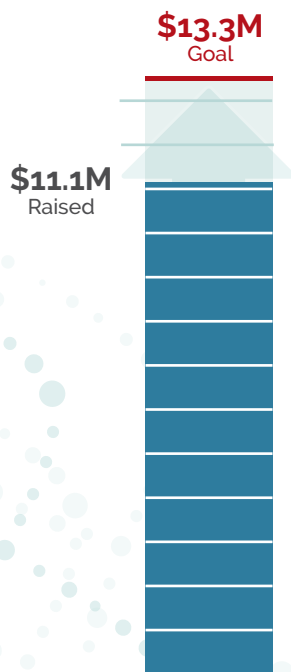
Oct. 4 | Starts at 4:30 p.m.
Tool & Craft Auction and Rib Dinner

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

Carrier Testing at the Auctions!

The Plain Insight Panel™ (PIP) will be available from
10 a.m. - 2 p.m. at the auctions, except for Ohio.
Cost is \$99 per person for the PIP.

ON OUR WAY TO REACHING OUR GOAL



We need your help to cross the finish line!

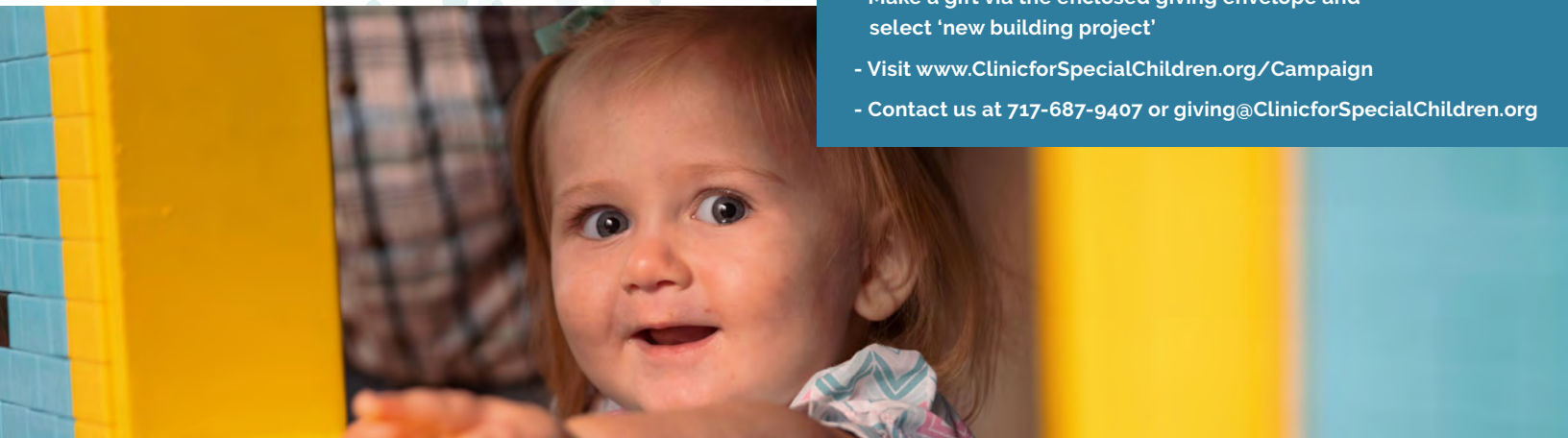
Even though we have recently moved into our new building, **we are still actively raising funds to finish our new building capital campaign.** As of March 8, 2024, we still need to raise \$2.2 million to reach our goal.

Completing the campaign will allow us to fully fund the construction of the new building so we do not need to take on any debt to pay the remaining building costs.

It will also allow us to establish two critical funds: the sustainability and innovation funds. **We are looking for gifts of all sizes to help us finish the campaign.**

TO DONATE

- Make a gift via the enclosed giving envelope and select 'new building project'
- Visit www.ClinicforSpecialChildren.org/Campaign
- Contact us at 717-687-9407 or giving@ClinicforSpecialChildren.org



SUSTAINABILITY FUND

While designed to be highly efficient, the new Clinic facility is much larger and 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 very rapidly and we strive to keep pace in order to provide state-of-the-art services and programs.

We asked families:

What are you looking forward to the most about the Clinic's new facility?

The Rodriguez Family

“The new facility is the natural manifestation of decades of patient work, love, and science applied with compassion toward children and families in need of specialized care. It’s the next step toward growing that care and making certain that every child can go just as far as their heart desires.... to reach for any and all the stars without regard to their circumstances.”



The Hoover Family

“The Clinic has been amazing at caring for our son and we are so thankful for the team there. We are excited to see the new building and all the space and resources that it will be able to provide to the staff and the patients as they continue to grow.”

Shane Musser

“I will appreciate the new facilities, especially the bigger waiting room, but I hope not to visit it often!”



Conor Martin

“I’m excited that there will be bigger offices so it doesn’t feel so full, and OF COURSE the new playground!”



From Infant to Young Adult

Crystal Martin's Story

Crystal Martin has been coming to the Clinic since she was two days old. That was 26 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. "The doctors 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 Laboratory 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 at the Clinic's new facility will be a great benefit," she says. "The new location is 15 minutes closer for me, too."



LEADERSHIP TEAM

We're excited to introduce our 2024 leadership team! For 35 years, the Clinic has evolved to meet the changing needs of the communities we serve. In our daily work, we continue to adapt to an ever-increasing demand for our clinical, laboratory, and research services. In recognition of these changing needs and opportunities, we refined certain roles at the Clinic and also created some new ones.

As part of this transition, Dr. Kevin Strauss took on a new role at the Clinic as our *Head of Therapeutic Development*. He will lead collaborative research work to develop life-changing therapies for disorders that commonly afflict people of Plain ancestry.

In recognition of our demand for clinical and research services, several staff members received appointments to the Clinic's leadership team, including Dr. Laura Poskitt as *Medical Director* and Alexis McVey, BSN, RN, CPN as *Nursing Director*. Karlla W. Brigatti, MS, CGC, has expanded her responsibilities for leading our research efforts with her appointment as the Clinic's *Research Director*.

You can view all members of our leadership team listed below. Congratulations to Alexis, Karlla, Dr. Poskitt, and Dr. Strauss on their new roles at the Clinic!

Clinic's Leadership Team



Karlla W. Brigatti
MS, CGC
Research Director



Adam D. Heaps
MS, MBA
Executive Director



Alexis McVey
BSN, RN, CPN
Nursing Director



Laura Poskitt
DO
Medical Director



Erik G. Puffenberger
PhD
Laboratory Director



Angela M. Sepela
MBA
Development Director

2024 FAMILY DAYS & EVENTS

Each year, we host a variety of family days focused on several specific genetic disorders. Our family days include educational sessions, fellowship, and collaboration. If you receive an invite for one of our family days or events this year, we hope you can join us!

Congenital adrenal hyperplasia (CAH)

Friday, June 7th

Bereavement Dinner

Wednesday, July 17th

Phenylketonuria (PKU) Family Day

Friday, August 9th

Patient Family Open House Saturday, September 21st

Adult Patient Family Day

Wednesday, October 23rd

*Family days will be held
at our new location unless
otherwise noted:*

Clinic for Special Children

20 Community Lane
Gordonville, PA 17529

*To learn more about our 2024
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

Karla W. Brigatti, MS, CGC
Research Director

Vincent Carson, MD
Pediatric Neurologist

Joelle Williamson Clark, MPH
Clinical Research Manager

Kelly Cullen
Marketing & Communications Manager

Skye Gawn
Gift Processing & Data Entry Coordinator

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 II

Julia Martin
Development Associate

Alexis McVey, BSN, RN, CPN
Nursing Director

Grace L. Meier, MD
Family Medicine Physician

Laura Poskitt, DO
Medical Director

Erik G. Puffenberger, PhD
Laboratory Director

Stephen D. Ratcliffe, MD, MSPH
Senior Consulting Physician

Donna L. Robinson, MSN, CRNP
Nurse Practitioner

Ashlin Rodrigues, MS
Clinical Research Analyst

Sean Schreckengast
Laboratory Scientist I

Angela M. Sepela, MBA
Development Director

Dawn Sheets
Medical Receptionist

Jessica Snyder, PHR, SHRM-CP
Human Resources Generalist

Kevin A. Strauss, MD
Head of Therapeutic Development

Erin Sweigert
Research Associate

Anne Thomas, LPN
Licensed Practical Nurse

Sarah Thomas, RMA
Medical Assistant

William Van Ess, MS, CFE
Accounting Manager

Susan Walther, MS, CGC
Genetic Counselor

Kelly Woodson
Event Manager

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

Jonathan H. Salvin, MD

Stephen Tiftt, MD

Glen Zimmerman | *Chair-Development Committee*



Pictured L to R: Brent Mullet, Andrea Esh, Sherry Miller, and Craig Mullet

In-Kind Donor Spotlight ProVia

At the forefront of ProVia are the company's values: integrity, generosity, and compassion. Founded in 1977 by two brothers in Sugarcreek, OH, ProVia manufactures windows, doors, vinyl siding, and roofing. Today, the company employs over 2,000 employees, has six manufacturing plants, and sells its products across the United States. While ProVia's growth over 45 years has been exponential, it's something else that founder Bill Mullet is most proud of. "We've stayed true to our purpose. Every person and company should know their purpose. It surprises people that our products aren't mentioned in our purpose statement. The most important part of our work is: To let our light shine before others so that they may see our good works and give glory to our Father who is in heaven (adapted from Matthew 5:16)."

Bill first heard about the Clinic for Special Children from the Clinic's board chair, Herman Bontrager. "When Bill and I got to know each other almost 60 years ago doing alternative service in El Salvador, neither of us imagined that our paths would cross at the Clinic for Special Children in this way," shares Herman.

"Herman called me and explained the important work the Clinic does to improve the health of children. He shared about the Clinic's new building project and inquired about windows for the new building," explains Bill. In a sequence of events, Bill shared the word about the Clinic's need with his son Craig, Vice President of Corporate Care at ProVia, and his son-in-law Gene Esh at Premiere Distribution, and the three men worked together to support the Clinic's project with a gift of all new windows for the entire building.

"It was easy for us to identify with the Clinic's need and good cause. It's our goal to contribute where funds or projects are used to serve humanity and the well-being of others who need assistance. It's my obligation as a believer to continue contributing to society with a service or a product, even though I retired from ProVia about ten years ago," explains Bill. "ProVia is now run by my four children, and I'm so happy that they've continued to prioritize our purpose and fully understand the importance of giving to others." Bill's children, the current shareholders and owners of ProVia, are pictured above.

"I am deeply grateful and humbled by the amazing generosity of Bill and his children in providing top-quality ProVia windows for the new Clinic. What a blessing to reconnect with Bill and learn the wonderful story of ProVia's success and commitment to serve the community and to join efforts to strengthen the work of the Clinic," says Herman.

Building Our New Home

January 2023 - December 2023

What a difference a year makes!
Enjoy this gallery of photos showing
the phases of construction on our new
facility throughout 2023!



January 2023



April 2023



May 2023



June 2023



July 2023



August 2023



September 2023



November 2023



December 2023



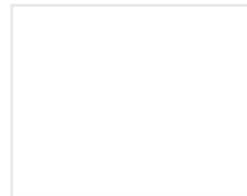
**Clinic for
Special Children®**

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ClinicforSpecialChildren.org



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A New Building Campaign for the



**Clinic for
Special Children®**



**HOME
SWEET
HOME**

A special edition of the Clinic's newsletter commemorating our move to our new, expanded facility in Gordonville, PA.



**Clinic for
Special Children®**