

Newsletter

ISSUE #55 SPRING 2022



Caring for a neighbor facing rare genetic disease The Esh Family

Jake and Mary Jane Esh, along with their four children, have lived as neighbors to the Clinic for Special Children in Strasburg for a number of years. They heard about the Clinic's work in the community and even participated in our annual 5k race, but never thought that they'd need the Clinic's services for their own family. When they welcomed their daughter, Caroline, in the Spring of 2021, they were grateful to live so close to the care that they would need for months to come.

When Caroline was born, Mary Jane noticed her daughter's small head and knew her newborn had Amish Lethal Microcephaly (ALM). ALM is a rare genetic disorder in which an infant is born with a very small head and underdeveloped brain. The disorder is almost always terminal by one to two years of life.

"The midwife called the Clinic shortly after Caroline's birth and Keturah came over that same afternoon. She brought over a basket of comfort items that included a fan, weighted blanket, soothing toys, and formula. It was such a comfort to have the Clinic there for us," Mary Jane explains. This visit by Keturah Beiler, Nurse & Cherished Lives Program Manager at the Clinic, was the first of many home visits to occur over the next several months. With Caroline's terminal diagnosis, the family enrolled in Cherished Lives, the Clinic's home-based palliative care program (learn more about this program on pages 4 and 5 of this newsletter).

As a part of Cherished Lives, Keturah and Clinic physicians would continue to meet with the family to discuss their goals of care for Caroline and learn how to best support the family during this time. "It's hard to put into words what the Clinic's support meant to us. It was a relief to be so close to the support that was so well provided to us," explains Jake and Mary Jane.

The Esh family expressed how grateful they were for the Cherished Lives program through the Clinic, "the palliative care at the Clinic is a big improvement from even just five to 10 years ago. The care and support you are providing families along this journey is indispensable. Keturah's visits to our home were bright spots for us, as well as our children. Cherished Lives was a very uplifting, encouraging, and supportive program for us. We are thankful that it was available to us and to other families."

Sadly, Caroline died in August 2021 at five months of age. The family continues to keep Caroline's memory alive by sharing about their times with her as a family, plaques and memory tables with mementos from Caroline's life, and connecting with other families facing ALM. "We had a lot of support from our community during and after our time with Caroline. Although we have deeply grieved our loss, Caroline brought our family so much joy and we feel having one of God's special little ones with us was a rich experience – one we would not wish to trade. We have reason to thank God with all our hearts. His mercies are new every morning," says Jake and Mary Jane.

At the Clinic, we feel grateful to have known Caroline and to have her cherished life bring us closer to our neighbors.



Good Friday - Office Closed Friday, April 15 All Day

Memorial Day - Office Closed Monday, May 30 All Day

Union County Benefit Auction Saturday, June 4

Buffalo Valley Produce Auction | Mifflinburg, PA

Lancaster County Benefit Auction Saturday, June 18

Leola Produce Auction | Lancaster, PA

Shippensburg Benefit Auction Saturday, June 25

Cumberland Valley Produce Auction | Shippensburg, PA

Ohio Benefit Auction Saturday, July 9

Blooming Grove Auction Inc. | Shiloh, OH

Missouri Benefit Auction Saturday, August 20

Ed Good Family Farm | Memphis, MO

Blair County Benefit Auction Saturday, September 10

Morrison's Cove Produce | Roaring Spring, PA

Clinic for Special Children 5k Saturday, September 17

At the Clinic

Mark your calendars and save the date for our 5th annual 5k run/jog/walk!

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

Updates from 🔰



Staff News

Keturah Beiler, BSN, RN & Ashlin Rodrigues



We are celebrating a set of work anniversaries this Spring! Keturah Beiler, BSN, RN, Nurse and Cherished Lives Program Manager, and Ashlin



Rodrigues, Laboratory Scientist, are both celebrating their 5 year anniversaries of working at the Clinic!

Keturah joined the Clinic on February 1,

2017 and Ashlin joined the staff on April 17, 2017. We are grateful to both Keturah and Ashlin for their work in supporting Clinic families everyday.

Congratulations, Keturah and Ashlin!

Candace Kendig, RMA



Candace recently earned her Bachelor's Degree in Healthcare Management from Central Penn College! She joined the Clinic as a Medical Reception-

ist in 2017 and was promoted to Office Manager in 2020. "It's rewarding to work at the Clinic knowing that every day we positively impact children and families living with rare genetic disorders. I enjoy supporting the patient families that visit the Clinic and providing a welcoming environment for them," says Candace.

Congratulations, Candace!

Important COVID-19 Updates

Vaccine

We have reviewed the available data from studies on the authorized COVID-19 vaccines, which show the vaccines are both effective and safe

The COVID-19 vaccine is now available for individuals who are 5 years old or older. Please contact your doctor with questions regarding the COVID-19 vaccine. If you are interested in receiving the COVID-19 vaccine, please call the national vaccine hotline at 1-800-232-0233 or visit Vaccines.gov for more information.

For individuals near Lancaster County, you can contact the WellSpan Health COVID-19 hotline at 855-851-3641. For information on Lancaster County's available vaccine locations, visit VaccinateLancaster.org.

Office Operations

We continue to require mask wearing for all visitors to our clinic facility. If you have a scheduled appointment and are feeling unwell, please give us a call to let us know before your appointment at 717-687-9407. Our clinic staff is operating at full capacity, as our full-time staff are fully vaccinated for COVID-19. If you have any questions before your visit, please contact us at 717-687-9407.

Low Protein Cookbook Calling all low protein cooks!

The Center for Special Children in Wisconsin is putting together a family-style low protein cookbook for the Plain community! Many families prepare low protein foods for loved ones with phenylketonuria (PKU), maple syrup urine disease (MSUD), propionic acidemia (PA), and glutaric acidemia type 1 (GA1). Their goal is to compile low protein recipes for the tasty dishes from your kitchens to share with other families from the Plain community. This will be a valuable resource for all families who do low protein cooking - whether you have been cooking low protein foods for years or just getting started.

They are looking for all types of recipes (snacks and appetizers, soups, main dishes, breakfast items, pantry items, breads, noodles, desserts, kid-friendly foods and anything else you want to share). No recipe is too simple or too complex! Recipes can include specialty low protein ingredients (like premade mixes or low protein pantry items) as well as recipes that use standard ingredients. They will analyze the recipes for leucine, phenylalanine, and protein and that nutritional information will be included with each recipe.

Please contact the Center for Special Children at 608-625-4039 for recipe submission forms. Please complete all sections on the form to make sure they have all the needed information. Only submit recipes on the forms; please do not submit recipes without the form as they might be missing important details. There is no limit to the number of recipes you can submit.

If you would like to share submit quotes, tips, or other words of encouragement to be included in the book, please request Tip Forms from the Center for Special Children at 608-625-4039. Recipe Submission and Tip Forms will not be mailed back, so please do not send anything that needs to be returned. Please submit completed Recipe and Tip Forms within 4 weeks of this announcement.

This project is funded by a grant from the Midwest Genetics Network, a program dedicated to improving access to genetics services. They will be working with the dietitians and nutrition assistants from the UW Waisman Center to compile and analyze recipes. Once completed and printed, the low protein cookbooks will be available at no cost to Plain families who prepare low protein foods. Questions? Please contact the Center for Special Children at 608-625-4039.

SMART Thank You

We would like to thank the patients, families, neighbors, scholars, and teachers who made 2021 a HUGE success for gathering SMART control data. SMART is a series of tests designed to evaluate patients with muscle disease. With your help, we have gathered much needed skill tests on almost 400 people in one year, and we enjoyed every minute of our time together.

We visited six schools, numerous immunization appointments, one youth event, many patient siblings, and multiple members of the CSC staff and their families. This data will help us to track the progress of our patients with muscle disease. And this project has shown us again how lucky we are to have such an amazing community dedicated to making a difference.

Thank you from the CSC Research Team!

2022 Benefit Auction Season

You're invited to join us!

Do you enjoy bidding on unique items? Or eating fresh baked goods and food? How about watching a community come together in support of an important mission? Join us at one of our 2022 auctions!

The six benefit auctions are organized solely by volunteers from the community. Philanthropic sources, like the benefit auctions, fundraisers, 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 vulnerable families facing rare genetic disease.

To learn more about the 2022 auction season, visit our auctions website (www.ClinicAuctions.org) to view the most current auction information.



2022 Auction Calendar

7:00 a.m. | Breakfast 8:30 a.m. | Auctions Begin CSC Remarks and Quilts to Follow

Saturday, June 4th **Union County Auction**

Tool & Flower Auction & Rib Dinner | June 3 | 4-8 p.m.

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

Saturday, June 18th Lancaster County Auction

Leola Produce Auction 135 Brethren Church Road Leola, PA 17540

Contact: Mark Martin | 717-733-3070 *Breakfast starts at 6:30 a.m.

Saturday, June 25th **Shippensburg Auction**

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

Saturday, July 9th **Ohio Auction**

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

Saturday, August 20th Missouri Auction

Food & Fellowship | Aug. 19 | 5-8 p.m.

Ed Good Family Farm 10507 County Road 813 Memphis, MO 63555 Contact: Harlan Burkholder | 660-341-4113

Saturday, September 10th Blair County Auction

Rib Dinner & Auction Preview | Sept. 9 | 4:30 p.m.

Morrison's Cove Produce 4826 Woodbury Pike Roaring Spring, PA 16673 **Contact:** Mervin Martin | 814-793-3529

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



Palliative care is a field of medicine focused on providing relief from distressing symptoms in patients with serious life-threatening illnesses. The goal of palliative care is to provide comfort and improve quality of life for patients and their families. Although palliative care is traditionally thought of as end-of-life care (hospice), it can begin at any stage of

Palliative care approach

illness.

The palliative care approach is a specialized and personalized form of medicine for each patient and their needs. When establishing palliative care, providers commonly meet with the patient and their family to discuss and understand their goals of care. Goals of care conversations enable parents to tell the medical team about their values, what matters most to them, and what their hopes and fears are for their child. A personalized care plan is then created based on the goals of care established in the initial meeting.

Palliative care is a comprehensive approach that encompasses the physical, psychological, social, and spiritual aspects of improving a patient's quality of life. According to the World Health Organization (WHO), an estimated 40 million people are in need of palliative care and only about 14% of those people currently receive it.

Worldwide, palliative care is also required for wide variety of diseases. The most common diseases cared for through palliative care are chronic, including cardiovascular diseases, cancer, respiratory diseases, AIDS, and diabetes. "Pain and difficulty breathing are two of the most frequent and serious symptoms experienced by patients in need of palliative care," according to the WHO.

Why is palliative care beneficial?

In addition to improving the quality of life for patients and their

families, early delivery of palliative care reduces unnecessary hospital admissions and the use of health services, according to the WHO. A benefit of palliative care is that it can be used in addition to life-prolonging or curative treatments. This means that patients don't need to chose between accessing these treatments and utilizing palliative care services.

"Palliative care not only improves the quality of life of patients and their families, reducing mental and physical distress and discomfort, but also can help patients live longer," according to Harvard Medical School Health Publishing. "The prolonged survival is thought to be due to improved quality of life, appropriate administration of disease-directed treatments, and early referral to hospice for intensive symptom management and stabilization."

What types of palliative care services are provided at the Clinic?

At the Clinic, our palliative care program is called Cherished Lives and is provided at no cost thanks to generous donations. Patients are enrolled into Cherished Lives by our clinical team based on diagnosis and prognosis. A wide variety of services can be provided under palliative care. Several of the services provided through our Cherished Lives program include access to comfort medications and treatments, clinical provider home visits, access to medical equipment at home, emotional support resources, and access to grief and/or counseling services.

What diagnoses are commonly enrolled in palliative care?

At the Clinic, we care for patients with multiple different rare genetic disorders that ultimately are life-limiting. The most common disorders enrolled in our Cherished Lives program are Amish Lethal Microcephaly, and TNNT1 Myopathy (commonly called 'chicken/pigeon breast disease').

Cherished Lives at the Clinic

Interview with Keturah Beiler, BSN, RN, Nurse and Cherished Lives Program Manager

Learn more about Cherished Lives in an interview with Nurse and Cherished Lives Program Manager, Keturah Beiler, BSN, RN.

How would you describe Cherished Lives?

Cherished Lives is the Clinic's palliative care program. It is a free-of-charge, home-based program that reflects our view that every life, even a short one, should be cherished. We provide culturally-sensitive palliative care for patients and their loved ones.

We coordinate care for patients in their own homes and connect them with medical equipment, local hospice services, and counseling services when necessary.

We understand that infant and child death affect the entire family (parents, siblings, aunts, uncles, grandparents, and more) and we help provide physical, emotional, and spiritual care to the family. We present resources to the family if they are interested, like bereavement. We follow the child and family from diagnosis, to end of life and bereavement.

How did you become started with Cherished Lives?

Before coming to the Clinic, I went into nursing school because of meaningful personal experiences with hospice nurses. When I realized that there was a need here at CSC for more support for families facing terminal illness, I was compelled to walk beside them.

When I started working full-time at the Clinic in 2018, it seemed there was a need for a more formalized program. It was a moment when my passion for palliative care and the needs of the Clinic aligned. Soon after starting at the Clinic, I got involved with doing several home visits for Clinic patients. At the time, I didn't realize how many terminal rare genetic diagnoses were made at the Clinic. I worked with Dr. Vincent Carson and Dr. Kevin Strauss, Clinical Operations Director and Medical Director at the Clinic, to start a more formalized program, focused on providing comprehensive care to children with life-threatening genetic disorders at the Clinic. In 2019, we had an influx of babies born that qualified for palliative care services. In 2020 and 2021, the program really took off and I kept doing more home visits as the program grew in scope and size.

Dr. Vincent Carson and Dr. Kevin Strauss were very instrumental in vision casting and providing training opportunities for me to become more specialized in palliative care. I've done training in palliative care through Harvard Medical School and I'm a member of a number of palliative care professional organizations.

How do families join the program?

Cherished Lives is focused on specific life-limiting or terminal diagnoses that we see here at the Clinic. It's not unusual for us to get a call from a midwife that tells us a family is expecting a baby with one of these disorders. If the terminal diagnosis is not obvious before birth, new families will come to us on their own or after someone recommends them to come see us. Once the family visits and the patient is enrolled in the Cherished Lives program, we will then develop a home visit schedule that feels right for them and they will reach out to us if they have any urgent issues.

What does Cherished Lives mean to you?

I think it's so inspiring to be in the homes of these families. Caring for children through the Cherished Lives program gives my life and work meaning. Several words come to mind - inspiring, purposeful, and meaningful.

I am compelled to be with these families in their time of need as it resembles a calling for me. I want to be there. I want to walk alongside them. I realize how difficult that journey can be and I want to partner with them. When I am in their homes, there are times that it feels like 'holy ground'. To be invited into their stories and to bear witness of their suffering is not something I take lightly.

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

What are some stand out memories throughout your time with Cherished Lives?

One of the things that is inspiring from being around the families is seeing how resilient they are. Having close encounters with families and children going through the dying process has taught me better how to live. I have seen parents care for their children in the present – not worrying about the future. They take a moment at a time and enjoy taking care of their child for as long as they are here. When parents share with me those last few minutes of their child's life here on earth I feel such a weight to be gifted with their stories of heartbreak. So many families reference the hope they have of being united with little one again someday, their faith brings much strength and purpose.

Another thing that I'm learning is how important it is to stop and pay attention to what's happening on the inside of me as a healthcare provider. That's something that we're trying to be more intentional about at the Clinic. We reflect and honor the lives of those that have passed and take care of our own grief as healthcare providers.

What's something that you'd say to families that have been in Cherished Lives or will be in the future some day?

One of the things that I think is the very purpose of Cherished Lives is that these families don't have to walk alone. It's our desire to support these families so that they are not alone. We can walk alongside them during a super difficult time, as a healthcare provider and a friend.

Some families will have multiple children born with the same terminal diagnosis and they are very passionate about caring well for these children for as long as they have them. It's an inner courage that is profound to witness. It's amazing to see how the larger Plain community serves as a continual source of strength for the families as they go through this difficult time.

These families are amazing. I learn so much from them being in their home and how they care for the baby now, but knowing they will not have them for much longer. They choose to walk in joy as long as they have their baby to hold.

Why the name Cherished Lives?

One thing that we are committed to at the Clinic is cherishing and honoring lives, no matter how short. The 'Cherished Lives' name fit right in with the mission, values, and vision for the program. We want to provide the best care possible for these children, for as long as they are with us.

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Collaborator Spotlight

Erin A. Teeple, MD, Division of General Surgery, Department of Surgery, Nemours Children's Hospital, Delaware

Dr. Erin Teeple has helped provide compassionate care to many Clinic for Special Children families over recent years. As a Pediatric General Surgeon at Nemours Children's Health System in Wilmington, Delaware, Dr. Teeple often addresses issues of feeding tubes, hernias, and any bowel problems requiring surgery that arise in patients. She commonly works with families that come to the Clinic for general care, as well as families enrolled in Cherished Lives. It's common for babies and children in palliative care to experience feeding difficulties and feeding tubes can help them get the proper nutrition that they need as well as medicines that may be needed for comfort. Dr. Teeple works very closely with the doctors and nurses at the Clinic to help reduce the burden on families and facilitate the surgical care that they need.

Dr. Teeple was born and raised in a western suburb of Philadelphia in Delaware County, Pennsylvania. She completed her undergraduate studies at Lafayette College in Easton, PA and her postgraduate studies Thomas Jefferson Medical College in Philadelphia, PA. She did her General Surgery residency at Christiana Care in DE, her adult Colorectal Surgery Fellowship at Brigham and Women's Hospital in Boston, Massachusetts, and her Pediatric Surgery Fellowship at Nemours Children's Hospital in Wilmington, DE.

Dr. Teeple was first introduced to the Clinic by her colleague Dr. Jennifer Hagerty, Director of Robotic Surgery and Pediatric Urologist from Nemours Children's Health, who visits the Clinic periodically to care for patients (read more about Dr. Jennifer Hagerty in the Summer 2020 edition of the Clinic newsletter). When Dr. Teeple first started visiting the Clinic she realized, "I was able to be helpful as a Pediatric General Surgeon and I continue to try to be as helpful as I

can be."

When asked about why she chose to focus her career on pediatric surgery, Dr. Teeple explains, "My passion to serve children and their families struck before my cerebral interest in colorectal surgery. Children are our most precious resource and deserve all resources to let their light shine. I have learned the anatomy and physiology of the preterm neonate to the adult in order to serve children and their families to the best of my ability. The anatomy and physiology of the gastrointestinal system is a subspecialty interest of mine because pooping is actually a really complex and important process!"

As an accomplished professional, it's not the writing articles and book chapters, professional ranks, or granted funding that Dr. Teeple finds most rewarding in her career. "What remains most worthwhile on a daily basis is the ability to guide and comfort families and offer skilled help when needed. Therefore, my relationships with my patients and their families are my proudest accomplishments," Dr. Teeple explains.

"I am deeply grateful to be connected to the Clinic for Special Children," Dr. Teeple remarks. "It serves constantly as a return to purpose for me as a physician. As healthcare becomes more and more complicated, my ability to serve at the Clinic grounds me in what is truly important: skilled and collaborative care for our children to optimize outcomes. Thank you for this extraordinary privilege."

In turn, we are deeply grateful to the service that Dr. Teeple continues to provide families that entrust the Clinic with their care. Her expertise and service, along with many of our other trusted collaborators, allows us to provide compassionate, cutting-edge, and affordable care for families facing rare genetic disease.

2022 AMBASSADORS

Meet the 2022 Clinic for Special Children ambassador families! Throughout the year, they will be sharing their stories to help raise awareness of the Clinic. Thank you to the families for their continued support of the Clinic for Special Children's mission!



Jevon & Josiah King 2 years old & 1 year old

CODAS Syndrome

Jevon and Josiah King are adorable and cheerful brothers that have a special bond as they both were diagnosed with CODAS Syndrome. The King family visits the Clinic for monthly check-ins and CSC serves as their primary care physician by providing and coordinating compassionate care. Jevon loves books and music and communicates by signing. Last year he "sang" a song at his church's Christmas service. Josiah loves to play peek-a-boo and is almost ready to crawl!



Rose Snyder | 5 years old

Down Syndrome

Rose is a joyful little girl whose special qualities endear her to all that come to know her. Shortly after birth, Rose was diagnosed with Down Syndrome. From her first visits as a newborn to undergoing cardiac, hearing, and eye examinations with visiting specialists, Rose has been comprehensively cared for by the Clinic. She is an enthusiastic lover of music, and especially enjoys playing her little guitar or her sister's violin. She greets everyone that she sees in church or school with equal joy, which reminds us all to do the same.



Estelle Weaver | 2 years old

Phenylketonuria (PKU)

Estelle is a cheerful and happy-go-lucky toddler who loves playing in the snow! Shortly after her birth, Estelle was diagnosed with the rare metabolic disorder Phenylketonuria (PKU) via the state newborn "heel stick" test. Estelle visits the Clinic regularly for check-in appointments and ongoing management of her PKU levels. Some of Estelle's favorite things are when her brothers read stories to her and sitting beside her big sister when she plays the piano!

RECENTLY PUBLISHED PAPERS

Cole J. Ferguson, Olivia Urso, Tatyana Bodrug, Brandon M. Gassaway, Edmond R. Watson, Jesuraj R. Prabu, Pablo Lara-Gonzalez, Raquel C. Martinez-Chacin, Dennis Y. Wu, Karlla W. Brigatti, Erik G. Puffenberger, Cora M. Taylor, Barbara Haas-Givler, Robert N. Jinks, Kevin A. Strauss, Arshad Desai, Harrison W. Gabel, Steven P. Gygi, Brenda A. Schulman, Nicholas G. Brown, Azad Bonni. APC7 mediates ubiquitin signaling in constitutive heterochromatin in the developing mammalian brain. Molecular Cell. 2021 Dec 22; Vol. 82, Issue 1, P90-105.E13. doi: 10.1016/j. molcel.2021.11.031.

Sarah A F Henkel, Claudia M Salgado, Miguel Reyes-Mugica, Kyle A Soltys, Kevin Strauss, George V Mazariegos, Robert H Squires, Patrick J McKiernan, Xingyu Zhang, James E Squires. Long-term liver transplant outcomes for progressive familial intrahepatic cholestasis type 1: The Pittsburgh experience. Pediatric Transplantation. 2021 Dec;25(8):e14108. doi: 10.1111/ petr.14108. Epub 2021 Aug 2.

Erik G. Puffenberger. Mendelian disease research in the Plain populations of Lancaster County, Pennsylvania. American Journal of Medical Genetics Part A. 2021 Nov 10. doi: 10.1002/ajmg.a.62489.

*bolded names indicate current CSC staff authors

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Our Staff

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

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Karlla W. Brigatti, MS, CGC Research Operations Director

Vincent Carson, MD
Clinical Operations Director

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

Lavina King Community Liaison

KaLynn Loeven Laboratory Scientist

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New Additions to Development Committee Written by Emily Seitz, PhD, Development Director

It takes an enormous amount of effort to raise the \$2,600,000 in donations the Clinic for Special Children relies on each year to serve patients living with rare genetic diseases, and the Clinic's Development Committee is integral to this work. The Development Committee meets six times a year to provide vision and strategy, and this small and mighty group has been quite successful. Over the past two years they have helped the Clinic grow its philanthropic budget by \$1,000,000.

Each member of this group brings diverse life experiences and skill sets to the mission of raising funds for the Clinic, and this diversity of opinion and experience is at the core of the team's success. The Clinic engages a broad group of donors so that we can do the work of caring for people living with genetic illnesses and conducting cutting-edge, patient-centered research. We rely on support from the Plain communities we serve and the broader Lancaster and Central Pennsylvania community, as well as corporate, academic, and industry partners. We couldn't do our work without the contributions from each piece of this funding puzzle.

We're excited to have two new members join us in this work as we look to the group's future of supporting the Clinic's continued growth. Ashley Bowen, PhD, will join the group in June and brings a breadth of communications experience from her work at the Science History Institute, the National Institute of Health's National Library of Medicine, and the American Historical Association. Currently the Creative Execution Manager at Heritage Werks, Dr. Bowen is a skilled science communicator and looks forward to leveraging her experience in service of the Clinic's mission. Isaac Nolt is the owner of Fieldline Equipment, LLC, a farm equipment manufacturing company located in Leola, Pennsylvania. Alongside his six sons, Isaac manufactures forage carts and blowers sold throughout the United States. Isaac comes to the committee with a wealth of business experience and community connections. We welcome both to the Clinic and look forward to partnering with them in this work.

CHERISHED MOMENTS

A gallery featuring moments from Cherished Lives, shared with permission from families











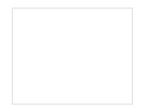




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ClinicforSpecialChildren.org















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 # 23-255373). 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.

2022 Benefit Auctions

for the Clinic for Special Children

See inside for more details!

June

- 4 Union County, PA
- 18 Lancaster County, PA
- 25 Shippensburg, PA

July

- 9 Shiloh, OH
- **August**
- **20** Memphis, MO

September

10 Blair County, PA

The Clinic's Mission

"To serve children and adults who suffer from genetic and other complex medical disorders by providing comprehensive medical, laboratory, and consultative services, and by increasing and disseminating knowledge of science and medicine."