



Pictured: Dr. Vincent Carson and Dr. Laura Poskitt



SPECIAL DATES

Remaining 2020 Benefit Auctions Tentatively Scheduled

View details inside

4th of July Holiday - Office Closed
Friday, July 3

Labor Day - Office Closed
Monday, September 7

CSC Virtual 5k
Saturday, September 19 -
Saturday, September 26

Register today for our 2020 CSC Virtual 5k! Application is enclosed inside.

Community Benefit Dinner
Wednesday, October 14
Martindale Fellowship Center

A seafood and ham style buffet dinner to benefit the Clinic! More details to be released closer to the event date.

2020 Extraordinary Give
Friday, November 20
ExtraGive.org

Online Fundraiser - All Day
Donate to the Clinic during this 24-hour giving day! Share about the Clinic with family and friends and set your own fundraising goal!

As the situation around COVID-19 evolves, the event dates mentioned above could be subject to postponement or cancellation.

For any specific event updates, please call our office at 717-687-9407, check our social media accounts, or visit our website at ClinicforSpecialChildren.org.

Solving the mystery of Aldosterone Deficiency The Beiler Family

Kathy Beiler seemed like a typical newborn baby when she arrived in August 2018, however, the situation quickly changed. When she was two weeks old, her family noticed she was not eating as much and seemed unsatisfied with each feeding. She also began to have trouble sleeping. In the following months, Kathy's family also noticed that she was not gaining weight as quickly as they expected.

During the first 11 months of Kathy's life, the Beilers tried many strategies to help Kathy gain weight, including different formulas and cranial therapies, and reached out to family, friends, and medical doctors. While she grew taller, she still didn't gain weight. It seemed like nothing was working. Eventually they learned of the Clinic for Special Children (CSC) and reached out to try and find answers.

The next week Kathy had a new patient appointment at the Clinic with Dr. Laura Poskitt, a Pediatrician at CSC, and Dr. Matt Demczko, a visiting doctor from Nemours. Kathy's mother, Mary, explains the first visit to the Clinic, "I was very impressed at the thorough examination and was very pleased and relieved that the doctors had a good idea about what they were doing and what could possibly be wrong." At this first visit, Drs. Poskitt and Demczko changed Kathy's formula and did blood work to check for a reason for Kathy's low weight and poor strength.

Later that night the on-call doctor, Dr. Vincent Carson, Pediatric Neurologist at CSC, called the family to report Kathy's blood work results returned showing very low sodium and high potassium

levels. He admitted her to a local hospital to make sure she was safe while changing formulas and stabilizing her electrolyte levels. During Kathy's first day in the hospital, Drs. Poskitt and Carson were concerned that she could have a disorder called Aldosterone Deficiency and drew blood to run a special genetic test at CSC. Aldosterone is critical to keep normal electrolyte levels in the body. Without aldosterone, patients can experience low blood pressure, recurrent dehydration, and failure to thrive (poor growth and development).

Within three days, Kathy's genetic test results came back positive for Aldosterone Deficiency and she was discharged from the hospital that same day. CSC doctors placed Kathy on Florinef (fludricortisone), a synthetic version of aldosterone which her body cannot make, and she began to grow, learn new skills, and her appetite improved. As a result, her weight went from being in the first percentile to a normal weight today.

Kathy is now 22 months old, has normal skills like walking and running, and is improving every day with her medical regimen and the help of a physical therapist. She has three brothers and a sister that dearly love her. The Beiler family looks forward to their visits to CSC and sharing Kathy's improvements with the doctors. The Beilers add, "We as a family are very thankful for the blessings and encouragement we have received from the Clinic, family, and friends. And daily we strive to praise God and continue to look on the sunny side of life."

Thank you to the Beiler family for sharing their inspirational story!

Staff News

Mariah Everett

We're excited to welcome Mariah Everett back to the CSC team! Mariah interned at the Clinic in 2018 and is now returning as a Research Associate. In this role, she will be supporting the Clinic's research efforts and working primarily on the Phenylketonuria



(PKU) program. This program will include both a prospective natural history study of adolescents and adults with the condition as well as an upcoming clinical trial of gene replacement therapy, both sponsored by BioMarin Pharmaceutical, Inc.

She graduated from Swarthmore College in 2018 and spent a year in the Czech Republic teaching English through a Fulbright grant. Welcome back, Mariah!

Candace Kendig

Join us in congratulating Candace Kendig who recently started in a new position at CSC as the Clinical and Research Administrator. Candace joined CSC in 2017 as a Medical Receptionist.



She is currently pursuing a Bachelor's Degree in Healthcare Management at Central

Penn College with an anticipated graduation in the Spring of 2021. When asked why she's passionate about the CSC, she says "I am passionate about working for CSC because it is very rewarding knowing that every day our work positively impacts children and families." Congratulations, Candace!

Dawn Wade

We're excited to announce that Dawn Wade has joined CSC as a Medical Receptionist. Dawn received her Medical Office Specialist diploma from the Consolidated School of Business. Prior to joining CSC, she had 10 years of experience working as a Medical Re-

ceptionist and Transcriptionist for local medical practices and 10 years working as an Administrative Assistant at a local construction company.

Dawn was born and raised in Lancaster County. She's a mother and grandmother who enjoys spending time with family and friends. Welcome, Dawn!

2020 Event Changes

After careful consideration and due to COVID-19 public health safety guidelines, the following Clinic for Special Children events have been changed for this year:

Cancelled this year

2020 Union County Benefit Auction

Originally scheduled for

Saturday, June 6 at Buffalo Valley Produce Auction

2020 Lancaster County Benefit Auction

Originally scheduled for

Saturday, June 20 at Leola Produce Auction

Translational Medicine in Plain Populations Conference

Originally scheduled for

Thursday, July 30 - Friday, July 31 at

Franklin & Marshall College

Fall Family Fun Day

Originally scheduled for

Saturday, October 10 at Strasburg Rail Road

Postponed this year

2020 Shippensburg Benefit Auction

Originally scheduled for

Saturday, June 27 at

Cumberland Valley Produce Auction

NEW DATE

Saturday, August 22 at

Cumberland Valley Produce Auction

The decision to change these events was not made lightly, as benefit auctions and donations make up about 40% of the Clinic's annual operating budget. Visit page 4 of this newsletter to learn more about how you can help children and adults with rare genetic disorders during this time.

We continue to monitor the COVID-19 situation, and any changes to Clinic events scheduled

for the remainder of this year will be communicated as they are decided.

While we are saddened to alter these events, the health of our patients, supporters, and community is our top priority.

We greatly appreciate your support during this time!

Register today!

2020 Clinic for Special Children Virtual 5k Run/Jog/Walk

Saturday, September 19 - Saturday September 26

Runners, joggers, and walkers are invited to participate in the **2020 Clinic for Special Children Virtual 5k!** After careful consideration and due to COVID-19 public health safety guidelines, this year's race has been moved to a virtual format. Between Saturday, September 19th and Saturday, September 26th, runners, joggers, and walkers can complete a 5k route of their choice in support of the Clinic for Special Children. Your participation in our virtual 5k race this year will help us bring in vital fundraising for our mission during this unprecedented time.

Registration is open for the virtual 5k - an application is included inside this newsletter and online registration is also available on the Clinic's website (www.ClinicforSpecialChildren.org). More event details are also included on the application and website.

If you are interested in becoming a sponsor of this year's virtual race, please contact Emily Seitz, Development Director, at 717-687-9407 or by emailing eseitz@clinicforspecialchildren.org.

Save the Date!

Community Benefit Dinner Martindale Fellowship Center

Wednesday, October 14 at the Martindale Fellowship Center

We are looking forward to our 2020 Community Benefit Dinner at the Martindale Fellowship Center (352 Martindale Rd., Ephrata, PA 17522)! We will release further details for this event closer to the event date, as we will be monitoring the situation around COVID-19. Stay tuned!



COVID-19 Updates at the Clinic

By Dr. Kevin A. Strauss, Medical Director

To meet the challenge of the COVID-19 pandemic, we are continuously striving to provide accessible and high-quality medical care while also ensuring that the Clinic for Special Children (CSC) is a safe place for our patients and their families. Beginning June 8, 2020, we plan to increase the CSC's capacity for on-site visits, home visits for the Cherished Lives program, research studies, and immunization clinics.

This decision was made out of our patients' growing need for on-site services during this unprecedented time. We want to be clear that COVID-19 is still a very real and critical health risk, and will likely remain so for many months to come. Our medical team strongly urges that you continue to follow all precautionary guidelines emanating from the U.S. Center for Disease Control (CDC), state governor's office, and your local health department. *Failing to do so puts lives at risk.*

Our team has been working diligently to establish a set of safety guidelines to protect our patients, their families, and our staff as we increase these services in the face of an ongoing COVID-19 risk. Examples of these precautions include:

- We will screen each person who enters the building for fever and signs of illness.
- Each family will receive a call before their appointment for the purpose of screening and guidance.
- We will ask each person who enters CSC to wear a mask and practice social distancing. Members of the CSC clinical team will wear personal protective equipment (PPE) during all visits.

- The use of waiting rooms will be restricted with limited access.
- We will follow strict disinfecting procedures and, for an extra level of protection, plan to install antimicrobial air purifiers throughout the building.
- For the safety of our patients and staff, we will limit the number of people in the building, and will therefore ask that only the patient and one (1) parent/caregiver attend routine office visits.

We will continue to offer telehealth services, where appropriate, to patients who do not need to come into the office for a visit. The Clinic continues to offer normal operating hours, Monday – Friday from 9:00 a.m. until 5:00 p.m.

We plan to continually update our policies and procedures to reflect current health and safety recommendations and will communicate any important changes as they occur. We appreciate your patience and support as we continue to face this challenge together, with the strength that comes from common purpose and mutual trust.

Yours Sincerely,

Kevin A. Strauss, M.D.
Medical Director

How You Can Help the Clinic

A letter from the Union & Lancaster auctions

Dear Friends,

These are challenging times for us all. We've had to adjust to a new way of living in only a few short weeks, and the things that traditionally bring us comfort and meaning – gathering with family and friends, work, being of service to our communities – look very different now.

This year the Clinic for Special Children (CSC) faces an unprecedented situation: COVID-19 threatens to cancel or significantly alter the six auctions upon which the Clinic depends for a large portion of its revenue. **As of this letter writing, the Union County Benefit Auction, scheduled for June 5th and 6th, and the Lancaster County Benefit Auction, scheduled for June 20th, are cancelled for this year. Auction proceeds and philanthropic support make up approximately 40% of the Clinic's annual budget, or \$1.5 million.**

You have generously supported the Clinic for Special Children's mission of caring for children and adults with rare genetic conditions and complex medical needs in the past by participating in one or more of our auctions or making a gift directly to the Clinic. Our doors remain open amidst this public health emergency so CSC clinicians can continue providing vital care to patients and their families who rely on our services. **We're committed to meeting their needs, and we cannot do this work without your support.**

If you are able to make a gift in these trying times, please consider donating to the Clinic for Special Children so that we can continue serving our patients. We invite your help to replace the funds that will not come in due to cancellation of 2020 auctions. Simply use the enclosed envelope, or visit www.ClinicforSpecialChildren.org/give to make a gift online. With your help, we can weather this storm together.

We wish you and your family health, safety, and peace during this difficult time.

Thank you for caring,

Union Auction Committee: Jerry Hoover, Leon Hoover, Mervin Horning, Floyd Martin, Glen Martin, Jason Martin, Daniel Lapp, Elton Nolt, Roy Stoltzfus, David Weaver, & Aaron Zimmerman

Lancaster Auction Committee: David Esh, Elmer L. Esh, Enos S. Glick, Enos Hoover, Harvey Hoover, Jason Horning, Leonard Hurst, Stevie Huyard, Amos H. King, Daniel B. Lapp, David Lamar Martin, Harold Martin, Mark N. Martin, Michael Martin, Roy Martin, Jacob Petersheim, Benueel Riehl, Mahlon Shirk, Isaac Stoltzfus, Melvin Stoltzfus, Menno Stoltzfus, Melvin Ray Zimmerman, & Jacob E. Zook

CSC Leadership: Herman Bontrager, Board Chair, Adam Heaps, MS, MBA, Executive Director, & Kevin Strauss, M.D., Medical Director

Please note: If you support the Union or Lancaster auctions, please designate on the enclosed giving envelope which auction you regularly attend.

Mark your Calendars for the remaining 2020 Benefit Auctions

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

The remaining benefit auctions for 2020 are tentatively scheduled by their auction committees for the dates below. As the situation around COVID-19 evolves, the auctions are subject to postponement or cancellation. Should an auction be postponed or cancelled, information will be communicated via our main website (www.ClinicforSpecialChildren.org), our auctions website (www.ClinicAuctions.org), social channels, and/or from the auction committees.

The annual CSC benefit auctions and charitable donations make up approximately 40% of the Clinic's annual revenue! This support makes it possible for the Clinic to continue to provide affordable, specialized care to children and adults living with rare genetic disorders.

Ohio Auction | 7.11.20

Blooming Grove Produce Auction Inc.
1091 Free Road, Shiloh, OH 44878

Contact: Michael Newswanger | 419-896-2184

Shippensburg Auction | 8.22.20

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

Missouri Auction | 8.22.20

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

Blair County Auction | 9.12.20

Morrison's Cove Produce
4826 Woodbury Pike, Roaring Spring, PA 16673
Contact: Mervin Z. Martin | 814-793-3530



ClinicforSpecialChildren.org



Collaborator Spotlight: Dr. Jennifer A. Hagerty, Urology, Nemours Children's Health System

Since she was a child, Dr. Jennifer Hagerty always wanted to help others and felt that becoming a doctor would be a natural extension to her caring nature. She knew early on in her education that she wanted to be a surgeon. As soon as she did a rotation in urology, a field of medicine that focuses on diseases of the urinary tract system and male reproductive system, she knew she found her calling.

Dr. Hagerty says, "As soon as I did my urology rotation, I had that gut feeling we all have when we find what we want to do for our careers. I love being in the operating room and being able to fix a problem, but I also enjoy the complexity that is seen in the office. The diversity of issues that we care for as urologists is extensive and I find that to be intellectually stimulating. I knew that taking care of children and being a urologist was what I was meant to do."

Dr. Hagerty joined Nemours/A.I. duPont Hospital for Children in Wilmington, DE in 2010 and is currently the Director of Robotic Surgery and a Pediatric Urologist. She also serves as an Assistant Professor of Urology and Pediatrics at the Sidney Kimmel Medical College of Thomas Jefferson University in Philadelphia, PA. She grew up in the Philadelphia region and completed her undergraduate studies at Ursinus College. For medical school, she attended the Philadelphia College of Osteopathic Medicine, completed her residency at the Philadelphia College of Osteopathic Medicine, and had a fellowship in Pediatric Urology at Northwestern University in Chicago, IL.

Dr. Hagerty's clinical interests include robotic assisted, minimally invasive pediatric surgery, InterStim neuro-modulation in children, endourology, complex urinary tract reconstruction including urethral stricture repairs, and extension of applications of Epic electronic medical records to pediatric urology.

She first learned about the Clinic for Special Children (CSC) about eight years ago after caring for one of the Clinic's patients at the Nemours/A.I. duPont Hospital for Children in Wilmington, DE. Dr. Kevin A. Strauss, Medical Director at CSC, invited Dr. Hagerty for a tour of the clinic shortly thereafter. Dr. Hagerty explains how she felt after her tour of CSC, "I was immediately very excited to be a little part of this tremendous team."

Dr. Hagerty visits CSC once every other month to see patients. She typically sees about half a dozen patients and their families when she is at CSC. She sees a variety of patients including those with urinary incontinence to others with complex genital anomalies who many need surgical repair. She also sees patients with more common medical needs like hernias, undescended testicles, day and night incontinence, hypospadias, kidney stones, neurogenic bladder, and hydronephrosis. Although some of these conditions require medical treatments, many necessitate surgeries. Dr. Hagerty explains, "I do a lot of minor surgeries but also large reconstructions including robotic surgery."

When asked why she's passionate about CSC, Dr. Hagerty says, "The Clinic provides an immense resource for the children in the community. This is not only through direct medical care for the individual patients but also by the research into answers regarding rare genetic conditions that affect others. I am in awe at all the Clinic does and am privileged to be a small part of the Clinic's mission."

In her free time, Dr. Hagerty enjoys baking! She has been perfecting her french macarons and is a self-proclaimed amateur chocolatier. She also enjoys spending time with her family, including her husband and her two teenage boys.

We are so grateful to Dr. Hagerty for providing essential services to our patients and their families!

Our Staff

Keturah Beiler, RN
Nurse

Lauren Bowser
Research Fellow

Karlla Brigatti, MS, LCGC
Research Operations Director

Vincent Carson, MD
Pediatric Neurologist

Kelly Cullen
Communications Manager

Mariah Everett
Research Associate

Adam D. Heaps, MS, MBA
Executive Director

Christine Hendrickson, RNC
Nurse

Candace Kendig
Clinical and Research Administrator

Lavina King
Community Liaison

Yalonda L. Kosek
Office Coordinator

KaLynn Loeven
Laboratory Scientist

Julia Martin
Development Assistant

Laura Poskitt, DO
Pediatrician

Erik G. Puffenberger, PhD
Laboratory Director

Stephen D. Ratcliffe, MD, MSPH
Senior Consulting Physician

Donna L. Robinson, CRNP
Nurse Practitioner

Ashlin Rodrigues
Laboratory Scientist

Caitlin Russell, MS, MPH, LCGC
Genetic Counselor

Emily Seitz
Development Director

Kevin A. Strauss, MD
Medical Director

William Van Ess, MS, CFE
Accountant

Dawn Wade
Medical Receptionist

Millie Young, RNC
Research Nurse

Board of Directors

Cindy Bo, MBA
Chair-Charity Committee and Secretary

Herman Bontrager
Chairman

Peter Crino, MD, PhD

Leon Hoover

Leonard Hurst

Mark Martin
Treasurer

Jacob Petersheim

Stephen Tift, MD

Glen Zimmerman
Chair-Development Committee

Jacob Zook
Vice Chairman



Donor Spotlight

Plain Community Makes COVID-19 Masks

In late March, Jonas and Elam Esh's business, Country Value Woodworks (CVW), was closed due to Pennsylvania's COVID-19 stay-at-home order. Shortly thereafter, Jonas received a call from Sylvan Stoltzfus of Bird-in-Hand Fabrics regarding a desperate need for masks for healthcare workers due to the pandemic. Within a week, Jonas and Elam pivoted their furniture business into a sewing shop with an average of 45-50 people working each day to sew masks. "We felt a purpose to fill this dire need in our community," explains Jonas. Elam and Jonas expressed their gratitude for how members of the Plain community stepped in quickly to help with their large effort.

Hinkletown Sewing Machine Shop lent 10 machines and provided all the necessary materials and support to ensure the Eshs' mask operation had the tools they needed. Elam's daughter, Esther, jumped at the opportunity to train 15-20 new people each morning on how to sew the masks - a daunting feat that she handled with grace. Jeff, a maintenance technician at CVW kept all the machines running every day, and while he didn't know about sewing machines initially, he became an expert in no time. Ultimately, hundreds of volunteers worked together to make this project a reality. "A true community effort," Elam explains.

To help bolster the operation, Mennonite Disaster Services stepped in to source materials and provide logistical support to distribute the masks. In just four weeks, Jonas and Elam's operation was able to produce over 33,100 masks for healthcare workers. Their workers and volunteers sewed for 6,050 hours or 756 eight-hour days, used 38,600 feet or 7.3 miles of elastic, and used 24,828 square feet or 2,758 square yards/0.57 acres of fabric. Their efforts will leave a lasting impact on our community.

One local healthcare organization that received handmade masks from the Plain community is Nemours/A.I. duPont Hospital for Children in Wilmington, DE. Cindy Bo, Operational Vice-President and Chief Strategy & Business Officer at Nemours and CSC board member, was tasked in early March to source masks for every Nemours associate. In addition to setting up their own in-house sewing shop, Cindy created a social media post to broadcast Nemours' need for masks. Her call was answered by CSC staff members Keturah Beiler and Julia Martin, and from there relayed to the Anabaptist COVID-19 Response Team. The Response Team was able to secure about 5,000 homemade masks for Nemours associates and coordinate their delivery to the Nemours/A.I. duPont Hospital for Children in Wilmington, Delaware.

"We have been truly humbled by the outpouring of support from the Plain community," said Cindy. As a way to thank the community, several Nemours associates made gifts to CSC.

If you are interested in sewing masks, Nemours will continue accepting donations and distributing them. Please contact Kelly Cullen at 717-687-9407 or kcullen@clinicforspecialchildren.org for more information.

In these challenging times, this story is a helpful reminder that the kindness of strangers can truly make an enormous impact.

CLINIC HAPPENINGS



CSC staff members attended the Lancaster County Community Foundation's annual 'Grants and Opportunities' meeting in March.



Dr. Katie Zurbach, a 3rd year resident at Nemours/A.I. duPont Hospital for Children visited us for several weeks.



Molly, a Human Genetics and Genetic Counseling graduate student from Thomas Jefferson University, visited the Clinic for several weeks on a rotation.



In February, the Crain Family Foundation and the Newkirk family hosted their annual 'Swing Fore the Kids' TopGolf fundraising event in support of the Clinic!



CSC team members helped spread the word about rare diseases on 2020 Rare Disease Day! This annual day raises awareness for people living with rare diseases across the world.

