



Walking a Journey The Hurst Family

When Zach and Rachel Hurst's first child Abigail (Abby) started to miss developmental milestones, they became concerned. "When Abby was several months old, she began to scream during car rides and had a hard time supporting herself in a sitting position," explained Rachel. "We started trying to find an answer and visited many doctors who said she was just delayed, that we should push her with physical therapy, there was nothing to worry about, etc."

For over a year, the Hurst family continued to visit with various practitioners with the hopes of finding an answer. During a hospital visit when Abby was 14 months old, MRI results revealed a concern for pontocerebellar hypoplasia. The family was quickly referred to the Clinic for Special Children - the first time the Hurst family had heard about our clinic in Lancaster County.

During Abby's first visit to the Clinic, our clinical and laboratory teams confirmed that Abby was born with a genetic change in the *TSEN54* gene, which is known to cause pontocerebellar hypoplasia in the Mennonite community. The carrier frequency in the Mennonite community for this specific disorder is 2.3% with an estimated incidence of 1 in 7,600 babies. Children with *TSEN54*-related pontocerebellar hypoplasia usually have a small head size, developmental delay, and involuntary movements. As the disease progresses, children start to have sleep issues, feeding problems, and seizures. Unfortunately, there is no cure - children typically succumb to

the disease by 10 years of age.

At first, Abby primarily came to the Clinic for check-ups. The Hurst family noticed a difference in Abby's care right away. "Before we were referred to the Clinic, we felt like many doctors didn't listen to what we had to say. We didn't feel listened to. The Clinic is completely different. Every person we see when we visit, no matter who we're interacting with, talks to Abby and treats her like a typical kid. Everyone cares about her," shares Zach.

Abby recently started to experience more seizures, and the family is currently working with Dr. Vincent Carson on a medication protocol to control her seizures. "At each visit, Dr. Carson sits down and asks us, the parents, about what's going on and the challenges we're facing. Dr. Carson listens to our goals for Abby and gives us options for her care," says Zach.

Today Abby is three years old and loves her little sister, Joanna. Rachel enjoys taking Abby to play with her cousins, taking her on adventures, and caring for her every day.

"Walking this journey alone would be very lonely. We're blessed to have a great support system of family, friends, and the Clinic," shares the Hurst family. "We feel like we aren't walking this journey alone with the Clinic by our side. We can meet other families from the Clinic who are going through similar challenges as us. Through our faith, we can take each day at a time and are given strength."



SPECIAL DATES

Ohio Benefit Auction Saturday, July 13

Blooming Grove Auction Inc. | Shiloh, OH

Missouri Benefit Auction Saturday, August 17

Ed Good Family Farm | Memphis, MO

Labor Day - Office Closed Monday, September 2

All Day

Blair County Benefit Auction Saturday, September 14

Morrison's Cove Produce | Roaring Spring, PA

Family Fun Day & Open House Saturday, September 21

Clinic for Special Children | Gordonville, PA

Community Benefit Dinner Tuesday, October 1

Martindale Fellowship Center | Ephrata, PA

Finger Lakes Benefit Auction Saturday, October 5

Ontario Produce Auction | Stanley, NY

The Extraordinary Give Friday, November 22

All Day

www.ExtraGive.org

Thanksgiving - Office Closed November 28 & 29

All Day

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



Staff News

Jennifer Giacoio, CMAA & Dawn Sheets, CMAA



Congratulations to Jennifer Giacoio, CMAA, and Dawn Sheets, CMAA for recently obtaining their Certified Medical Administrative Assistant certifications!



Jen and Dawn are the friendly voices you hear when you call into the Clinic and the first smiling faces to greet you through our doors!

We're grateful for Jen and Dawn and the work they do every day for families who visit the Clinic for care.

Helge Hartung, MD



We're delighted to welcome Helge Hartung, MD to the Clinic!

Dr. Hartung will play a vital role as a Physician-Scientist at the Clinic. In this new

role, he will split his time between providing compassionate care to families and serving as a primary investigator for important research projects at the Clinic. He brings over two decades of experience in academic medicine.

Dr. Hartung, his wife, and two teenage children enjoy traveling and outdoor activities such as hiking, camping, and canyoning. He shares his home with two boisterous hound dogs and is an avid gardener and beekeeper!

Christine Hendrickson, RN, BSN, PED-BC



Congratulations to Christine Hendrickson, RN, BSN, PED-BC! She recently graduated with her Bachelor of Science in Nursing from Cham-

berlain University! Christine has been at the Clinic as a Nurse since 2002 and is known by many of the families who visit us.

We're very grateful for the compassionate care that Christine provides every day.

Stephen D. Ratcliffe, MD



Congratulations to Stephen D. Ratcliffe, MD, who recently retired from the Clinic!

Dr. Ratcliffe originally joined our board of directors nearly 10

years ago. In 2019, Dr. Ratcliffe transitioned from the board to a part-time staff member, our Senior Consulting Physician.

Over the years, Dr. Ratcliffe has helped the Clinic connect with local physicians and primary care practices, create educational opportunities for Family Medicine Residents, and more!

We wish Dr. Ratcliffe the best of luck as he begins his well-earned retirement.

BaconFest

Sponsored by Stoltzfus Meats

We're excited to be a part of the first BaconFest to be held on Saturday, August 10th from 10 AM - 6 PM at the Intercourse Community Park (3730 Old Philadelphia Pike, Gordonville, PA 17529)! The park is just minutes down the street from our new location in Gordonville.

The event will feature local food trucks, live music and entertainment, bacon-based competitions, demonstrations, bacon samples, and much more!

A portion of the proceeds from sales at Scott's Artisan Wood-Fired Pizza & Sourdough Bread will be donated to the Clinic!

Stop by to enjoy a good (and yummy!) time and support the Clinic. Thank you to Stoltzfus Meats for organizing this community event!

Clinic for Special Children 5k Reminder for 2024

It's been 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 Kelly Woodson, Event Manager, at 717-687-9407 or kwoodson@clinicforspecialchildren.org if interested.

Matching Gift Opportunity!

We are excited to share that the Clinic currently has a 1-for-1 giving match up to \$20,000. The match is available thanks to a local family foundation and is for the Clinic to use wherever the funds are needed the most.

To help us fulfill the matching funds, please give via the giving envelope included in this newsletter. The first \$20,000 in funds received will be matched dollar for dollar.

Thank you to the foundation for supporting this exciting giving opportunity!

Remaining 2024 Family Days

We're looking forward to hosting the remaining family educational days for 2024!

Please see below for event information. If you receive an invite for a family day, we hope you can join us!

All of our family days this year will be held at our new Clinic for Special Children facility (20 Community Lane, Gordonville, PA 17529).

If you have any questions about our family days, please contact Kelly Woodson, Event Manager, at 717-687-9407.

Phenylketonuria (PKU) Family Day

Friday,
August 9th

Family Fun Day & Open House

Saturday,
September 21st

Adult Patient Family Day

Wednesday,
October 23rd

Family Fun Day & Open House



Saturday, September 21st

Time TBD

Clinic for Special Children
Gordonville, PA

Patients and their families are invited to join the Clinic's staff and board of directors for a free day of fun & fellowship!

Get to know the Clinic's staff and board, our new facility, and other families. Enjoy activities, delicious food, and games at the Clinic.

This special event is for families to have an opportunity, outside of a clinical setting, to enjoy our new building and spend time at the Clinic.

We will be mailing invitations with further details closer to the event. Stay tuned!

Remaining 2024 Benefit Auctions



**Most auctions will feature
CSC remarks and quilts midday.**

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

Saturday, 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

Country Breakfast at 6:30 a.m., 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

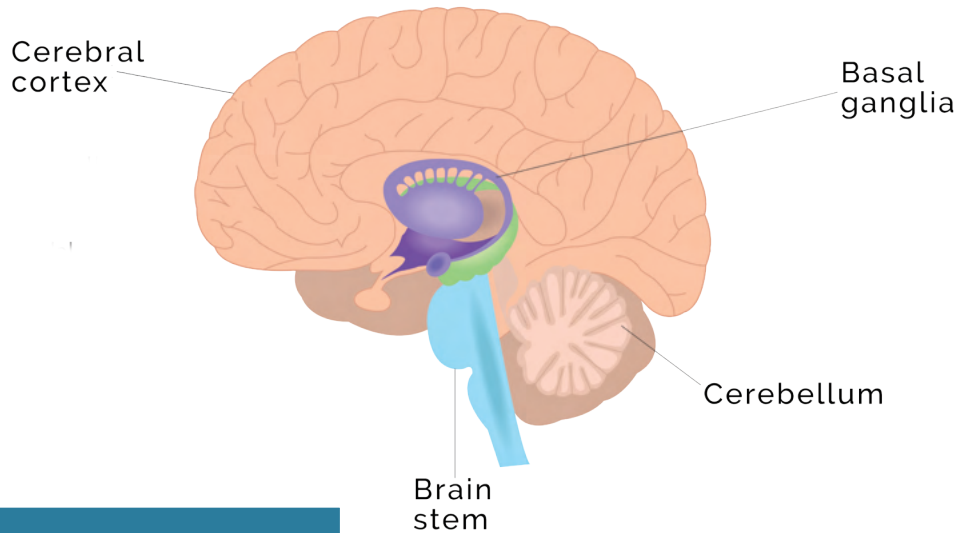
Carrier Testing at the Auctions!

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.

The Brain

“The least movement is of importance to all nature. The entire ocean is affected by a pebble.”

– Blaise Pascal



What are 'movement disorders'?

By Vincent J. Carson, MD

Movement is a crucial part of our everyday lives. We rely on movement for almost everything that we do. For this reason, a medical problem that interferes with our ability to move normally can make it incredibly hard to do everyday tasks that we typically take for granted. How does the brain control body muscles to create coordinated and purposeful movement?

The brain has billions of brain cells called neurons. Each neuron has an axon, which is a long cable. When activated, the neuron sends an electrical signal down its axon and releases chemicals known as neurotransmitters. Now, say you want to lift a cup of coffee with your hand. First, a neuron (upper motor neuron) located on the brain's surface (cerebral cortex) sends a signal down its axon, traveling from the brain to the spinal cord. There, the axon releases neurotransmitters, activating a second neuron (lower motor neuron). This neuron sends a signal down its axon, which leaves the spinal cord and forms part of the nerve in the arm, ultimately ending at the specific muscle that you want to move. The axon then releases neurotransmitters onto the muscle, resulting in muscle contraction, which lifts the coffee mug so that you can sip the coffee.

If the signal from the brain is interrupted at any point along its path to the muscle, the muscle will not receive the signal to contract resulting in **weakness**. The pattern of weakness (locations of affected muscles) provides clues to where the signal was interrupted. Loss of upper motor neurons and their axons results in weakness and spasticity. **Spasticity** features include stiffness and overly active deep tendon reflexes commonly seen in cerebral palsy or after a stroke. On the other hand, loss of lower motor neurons and their axons causes **flaccid paralysis**, lack of deep tendon reflexes, and loss of muscle mass (muscle atrophy). Flaccid paralysis occurs in spinal muscular atrophy, neuropathy, and muscle diseases.

The brain has additional processes for ensuring coordinated movement. The basal ganglia are deep brain structures that are composed of neurons. When you decide to lift the cup of coffee with your hand, the

basal ganglia neurons ensure that this is the only movement you are trying to do with your hand at that moment. You can't simultaneously write a letter and lift a cup of coffee with the same hand. The basal ganglia neurons prevent competing movement plans, which ensures that the lifting of the cup of coffee is a smooth process (no spilling of the coffee). If there is a loss of neurons in the basal ganglia, then competing unwanted involuntary movements may occur, such as dystonia or chorea.

Dystonia is a movement disorder characterized by involuntary muscle contraction resulting in twisting postures, which interfere with the person's intended movement. **Chorea** is a movement disorder that features dance-like, random, involuntary movements. In addition, the basal ganglia neurons have an important role in the initiation and speed of movements. There are neurons in the brainstem that project to the basal ganglia, releasing the neurotransmitter dopamine. Degeneration of these neurons leads to dopamine deficiency in the basal ganglia. This causes **Parkinson's disease**, which features tremors, slow movements, and rigidity.

In addition, the cerebellum plays an important role in coordinating movement. The cerebellum is behind the brainstem (back of the head). The cerebellum receives a copy of the intended movement plan from the upper motor neurons. It also receives sensory information from the spinal cord regarding where your joints and muscles are in space. The cerebellum adjusts the movement plan based on the sensory input, fine-tuning the movements so that they are on target. Thus, the loss of neurons in the cerebellum results in ataxia. **Ataxia** is a movement disorder characterized by clumsy, uncoordinated movement and problems with balance.

The control of movement by the brain is complicated, involving the cerebral cortex, basal ganglia, brainstem, cerebellum, spinal cord, nerves, and muscles. The constellation of symptoms can help us determine the structures involved and the underlying diagnosis. This can inform us of the best way to manage the symptoms.



Collaborator Spotlight

The Seating & Mobility Clinic at Nemours Children's Health System

Many of the children seen at the Clinic for Special Children who experience movement disorders will commonly use mobility devices and aids. Types of mobility devices include wheelchairs, walkers, power scooters, and more. At the Clinic, we offer specialty services in mobility thanks to The Seating and Mobility Clinic at Nemours Children's Health!

The Seating and Mobility Clinic at Nemours offers a team-based approach to the evaluation and recommendation of wheelchair seating and other specialty equipment for children from birth to 18 years of age. The seating clinic was established over 35 years ago at Nemours to meet the seating and mobility needs of children served by the health system.

The services provided by The Seating and Mobility Clinic include equipment evaluations for toileting/bathing equipment, safety beds, special needs car seats and activity chairs, as well as manual and power wheelchairs, power scooters, and special needs strollers. Evaluations are commonly performed at the main Nemours hospital in Wilmington, Delaware, where the team has an array of 'demo' equipment. This allows them to provide a thorough, hands-on approach to assessing a child's needs while being able to show the family/caregiver(s) actual equipment.

Denise Peischl, BSBME, a member of the seating clinic team, remarks on how The Seating and Mobility Clinic at Nemours first started working with the Clinic for Special Children. "I have been involved with the Clinic for Special Children for the past ten years, attending with another Nemours visiting specialist, Freeman Miller, MD. Dr. Miller specializes as a Pediatric Orthopedic Surgeon. Nemours has a long-standing relationship with the Clinic for Special Children and provides support through several specialty programs. I am a resource to the physicians and staff at the Clinic for Special Children. I work closely with Dr. Freeman Miller; we see patients every other month at the Clinic for Special Children in Gordonville."

Children and families are referred to The Seating and Mobility Clinic by internal Nemours physicians as well as outside physicians (like the

Clinic for Special Children). The seating clinic team works closely with many colleagues at Nemours, including orthopedic surgeons, pediatricians, developmental medicine, neurology, rehabilitation medicine, and other specialty care teams. The Seating and Mobility Clinic team includes a rehabilitation engineer, a physical therapist, an occupational therapist, a rehab technician, and the wheelchair vendor along with the family/caregiver(s) and the patient.

"Our goal is to promote independence and improved functioning and access in home, school, and community environments," explains Denise. "We are proud when we can supply supportive equipment that helps the patient and family in their everyday life. We strive to support the active participation of patients with their families and in their respective communities. Our passion is to provide compassionate, patient-centered care to all families, which aligns nicely with the mission of the Clinic for Special Children."

"The Seating and Mobility Clinic at Nemours provides families with high-quality, well-fitting wheelchairs," explains Dr. Laura Poskitt, Medical Director at the Clinic for Special Children. "Many children with mobility difficulty develop pressure sores and pain from ill-fitting seating, wheelchairs, and strollers. The Nemours team helps to optimize each seating solution with custom padding and support for that child's unique needs. As children grow, the Nemours team can follow along and tailor changes to suit that child. Many self-pay families appreciate that, with the Nemours team's help, they can retrofit a used chair or stroller to save money."

Thank you to Nemours Children's Health and The Seating and Mobility Clinic team for partnering with us and providing this critical service to families. For more information or assistance, families can contact their Clinic for Special Children provider or Nemours Children's Health.

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 J. 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, CMAA
Medical Receptionist

Helge Hartung, MD
Physician-Scientist

Adam D. Heaps, MS, MBA
Executive Director

Christine Hendrickson, RN, BSN, PED-BC
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

Donna L. Robinson, MSN, CRNP
Nurse Practitioner

Ashlin Rodrigues, MS
Clinical Research Analyst

Sean Schreckengast
Laboratory Scientist I

Dawn Sheets, CMAA
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

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Donor Spotlight

Bank of Bird-in-Hand

In December 2013, Bank of Bird-in-Hand opened its doors in the heart of Lancaster County's Plain Community in the quaint village of Bird-in-Hand.

The Bank was established out of the realization that there was a need in Lancaster County for a different banking experience – one focused on relationships rather than transactions, one that was willing to go off the beaten path to meet its customer's needs. Since 2013, the Bank has continued to grow, opening branches and GELT Bus stops across Lancaster, Chester, Berks, and Lebanon Counties and in the Lykens Valley, Dauphin County.

Members of the Plain Community have been strong advocates and customers of the Bank since its very beginnings. As a community bank, they are responsive to the needs of their customers and realized that they had many mutual customer relationships with the Clinic and would be a natural banking partner. Over time, the Bank has become involved in the Clinic's annual Lancaster County Benefit Auction in Leola with their mobile branch (GELT Bus fleet) onsite for the event.

"Because we recognize and value the work that the Clinic for Special Children is doing, we have continued to strengthen our relationship over the years, especially regarding potential lending needs for the Clinic. When the Clinic formed its fundraising committee for the *Keeping the Promise: Building Hope* capital campaign in support of the new building project, we were honored to have Lori Maley, CPA, Bank of Bird-in-Hand's President and CEO, serve as a representative and assist with fundraising efforts," explains Amanda Hall, Director of Marketing at Bank of Bird-in-Hand.

"Serving on the *Keeping the Promise: Building Hope* capital campaign committee has been an eye-opening experience for me," shares Maley. "I've learned about the transformative impact early intervention can have on a patient's quality of life and the costs associated with that care. If not for the Clinic for Special Children, many patients would experience debilitating, life-long complications. Supporting the Clinic's new building project is saving lives, plain and simple."

Bank of Bird-in-Hand feels a great responsibility to support people in the community for whom traditional banking services are inconvenient or inaccessible, similar to the Clinic's mission focused on healthcare access. "We are deeply grateful for Bank of Bird-in-Hand's continued support – from their mobile banking bus at our auction to providing a letter of credit for our new building project and serving on our capital campaign committee. We're thankful that they're our new neighbors and we look forward to working with them for many years," shares Adam Heaps, MS, MBA, Executive Director at the Clinic.

Cutting the Ribbon at Our New Home

June 20, 2024

It's official!

On June 20, 2024, we celebrated the opening of the new Clinic for Special Children in Gordonville with a ceremonial ribbon cutting. Enjoy photos from the event below!





**Clinic for
Special Children®**

PO Box 500
Intercourse, PA 17534

tel (717) 687-9407

fax (717) 687-9237

ClinicforSpecialChildren.org



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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.

Remaining 2024 Benefit Auctions

You're Invited!

We're just halfway through the 2024 benefit auction season! Join us for fun days filled with energetic bidding, delicious food, and more.

Flip to page 3 to view the schedule of remaining auctions.

Matching Gift Opportunity

Thanks to a local family foundation, we currently have a \$20,000 dollar-for-dollar match! All proceeds will be used where most needed at the Clinic for Special Children.

View more details on page 2.

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."