



Receiving an Ultra Rare Diagnosis Kari Denlinger

The Denlingers had their first child, Kari, thirty-five years ago. When she was a few months old the family questioned her ability to see and noticed seizures. At the time, Kari's clinicians informed them that her situation was grave and that she was severely developmentally disabled. They were provided with an average life expectancy of ten years of age.

Two years after Kari's birth, the family welcomed a son, Ryan, who exhibited similar symptoms to Kari. It became apparent Kari's and Ryan's conditions were genetic in nature. Ryan died when he was six years old.

The Denlinger family visited CSC in 2012. Our researchers and physicians completed genetic testing but no diagnosis was determined at the time. In 2019, Ron, Kari's father, decided to contact CSC to test Kari again as the field of genetics was rapidly changing and gaining knowledge. This time the family met with Dr. Grace Meier, who was a medical resident at Penn Medicine Lancaster General Health who was rotating at CSC at the time. A year and a half later Kari's "needle in the haystack" genetic diagnosis was found.

The first step was running our Plain Insight Panel™ (PIP) test on Kari's and her parents' DNA to see if they matched any of the 1,300 genetic variants on that panel. When no genetic variant of interest was found with the PIP, another panel test was run that looked specifically for known causes of epilepsy. When that test also came up empty, the CSC team conducted whole exome

sequencing to look for variants across 20,000 of Kari's genes.

This time the Denlinger family received the diagnosis they've been on a quest to find for over 30 years - a mitochondrial disorder caused by a mutation in the RARS2 gene. This condition causes intellectual disability, spasticity, and intractable seizures. A stored tissue sample from their son, Ryan, was DNA sequenced and was found to have the same RARS2 genetic variant. Only 44 cases are known worldwide, the genetic mutation was only discovered five years ago, and Kari is the oldest known person with the condition.

"Not only has CSC provided testing and genetic counseling, they also have been such a resource for Kari's needs. Throughout the genetic counseling process, everyone has been so gentle and caring explaining the positive and negative effects of Kari's diagnosis. They walked through the process with us and explained the diagnosis in a way that we were able to clearly understand," explained Ron and Joan, Kari's parents.

The Denlinger family has fostered special needs children for many years. They adopted one of their foster children, a son, Matthew, who is overcoming significant challenges. Thankfully today Kari and Matthew are both doing well. We are continuously inspired by the Denlinger family and appreciate them sharing their story! You can read more of their story at www.joyinaforeignland.com.



SPECIAL DATES

Community Benefit Dinner Wednesday, October 13

Martindale Fellowship Center

4:00 p.m. - 7:30 p.m.

A seafood and ham dinner to benefit the Clinic! Details inside.

Extraordinary Give Friday, November 19

ExtraGive.org

Online Fundraiser - All Day

Support the Clinic during this 24-hour giving day! Details inside.

Thanksgiving | Office Closed November 25 & 26

All day

Christmas Eve | Office Closed Thursday, December 23

Closed from 1 p.m. - 5 p.m.

Christmas Holiday | Office Closed December 24 & 27

All day

New Years Eve | Office Closed Friday, December 31

Closed from 1 p.m. - 5 p.m.

New Years Day | Office Closed Monday, January 3

All day

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

Staff News

Skye Gawn

Development Associate - Operations



We're excited to welcome Skye Gawn to the Clinic! Skye recently joined our team in August.

Skye will work as a Development Associate and will support the Clinic's fundraising efforts, focusing specifically on donor and institutional data management. She will champion all aspects of our donor database, serve as a hub of institutional and donor data, and conduct donor prospect research.

Skye loves all things music and the arts and enjoys living in Lancaster City with her husband and two dogs!

Alexis McVey, RN, CPN

Nurse



We're excited to welcome Alexis McVey, RN, CPN to the Clinic!

Alexis joined our clinical team as a Nurse in August. In her role, she will work with our clinicians to provide exceptional patient care. She will organize and administer immunizations, assist with general patient care, and support specialists who visit the Clinic periodically.

Prior to joining the Clinic, Alexis worked in nursing for adolescent medicine, acute care, primary care, skilled nursing care, and home care. In her free time, she enjoys spending time with her husband and son. She also enjoys reading and restoring old furniture.

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 12 years old or older. Please

contact your doctor with questions regarding the COVID-19 vaccine. If you are interested in being vaccinated, please call the national vaccine hotline at 1-800-232-0233 or visit [Vaccines.gov](https://www.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](https://www.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, we ask that you call us at 717-687-9407 before coming to your appointment. Our clinic staff is now back to 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.

Save the date! Community Benefit Dinner

**Wednesday, October 13th
4:00 p.m. - 7:30 p.m.**

at the Martindale Fellowship Center

We are looking forward to our 2021 Community Benefit Dinner on Wednesday, October 13th from 4:00 p.m. - 7:30 p.m. at the Martindale Fellowship Center (352 Martindale Road, Ephrata, PA 17522)!

Meals will include a variety of delicious food like oysters, shrimp, ham, cole slaw, green beans, fresh fruit cup, rolls, and a whoopie pie! The cost of the dinner is by donation only. All proceeds will benefit the Clinic for Special Children's mission.

It's Flu Shot Season

Please call the Clinic at 717-687-9407 to schedule your or your child's flu shot. Anyone over six months of age is encouraged to get an annual flu shot. We offer flu shots to our patients and their immediate family members for \$20 per person. The best way to protect yourself and your family is to avoid exposure, practice good handwashing, and receive an annual flu shot.

New HPLC Machine

We recently upgraded our HPLC (high-performance liquid chromatography) machine in our on-site laboratory! The HPLC machine pumps materials at a high pressure and separates out amino acids from blood samples. Similar to how a glucose test is used for the management of diabetes, it allows us to measure amino acid levels in patients with metabolic disorders. Based on their amino acid levels, we can make dietary or clinical care changes to manage their disorder.

Our previous HPLC machine was in operation for over 18 years! Since 2003, the former HPLC machine ran over 25,000 amino acids! We will be keeping our old machine as a backup, but will primarily be using the new machine moving forward. We're looking forward to the new machine improving efficiencies in our on-site laboratory and allow us to provide the best care possible to the families that we serve.

2021 Extraordinary Give

**Friday, November 19th
Midnight - 11:59 p.m.**

ExtraGive.org

We invite you to donate to the Clinic during Lancaster County's largest day of online giving! The ExtraGive benefits more than 500 local non-profit organizations and every dollar donated through ExtraGive.org on Friday, November 19th will be stretched by a pool of \$500,000 from local sponsors. Our goal is to raise \$60,000 in 24 hours for the Clinic's mission!

Donating is simple. On Friday, November 19th visit ExtraGive.org and select 'Clinic for Special Children'. If you would prefer to donate over the phone, please call us on Friday, November 19th between the hours of 9:00 a.m. - 5:00 p.m. and we would be happy to receive your gift over the phone.

Won't have access to internet on the day of the ExtraGive? Call us before or on November 19th, and we'll process your ExtraGive donation for you on the day of ExtraGive.

Visit our info table at New Holland Coffee Co. in downtown Lancaster on Friday, Nov. 19th!

Board of Directors Updates

New Directors and a Fond Farewell

The Clinic for Special Children's Board of Directors has recently welcomed new board members and bid a fond farewell to a long-standing member. Learn more about our new directors and board member emeritus below:

Jan Loeffler Bergen

Jan L. Bergen joined the Clinic's Board of Directors in August 2021. She most recently served as the President and Chief Executive Officer of Penn Medicine Lancaster General Health (LGH). She lives in Lancaster, PA with her husband. She has two daughters and two grandchildren.

Jan joined LGH in January of 2000 as Senior Vice President of Ambulatory Care & Lancaster General Women's & Babies Hospital. In this role, Jan provided administrative leadership and operational oversight for LGH's Ambulatory Services and Women's and Children's Health Services. Then in 2007, Jan served LGH as Executive Vice President for Strategic Implementation & Chief Mission Officer. In October 2010, Jan served for eight months as Chief Executive Officer of LGH while Admiral Thomas E. Beeman was recalled to active duty in the Navy. Following that interim role, in July 2011, Jan served as President, LGH Network & Executive Vice President, Lancaster General Hospital. Jan's responsibilities were expanded in February 2013 to include executive oversight of all operations within LGH, including physician services, hospital operations, ambulatory services, and post acute care. As Chief Operating Officer (COO) of the health system, Ms. Bergen focused on operational performance, growth, and integration of clinical services in support of population health management. In September 2015, Jan was promoted as President & Chief Executive Officer of LGH.



Prior to joining LGH, Jan was Senior Vice President for Bryn Mawr Hospital, a 400 bed acute care facility in Bryn Mawr, PA, which is part of the Jefferson Health System. Jan also served for the Jefferson Health System as President and CEO of Bryn Mawr Rehab, a 200 bed free-standing rehab facility in Paoli, PA. Jan's educational background includes: The George School; Lafayette College, B.A.; University of Pennsylvania and Temple University, Master level course work in business and social work at Temple University, Executive Leadership Programs at Harvard Business School and Wharton at the University of Pennsylvania. Jan received an honorary Doctor of Humane Letters, honoris causa, degree from Lebanon Valley College in May 2018.

Her past and present civic activities include; Junior League of Lancaster, The Heart Association (Heart Ball Chair), American Cancer Society Board of Directors, United Way Board of Directors, Lancaster County Business Group on Health Board of Directors, Lancaster County Community Foundation Board of Directors, North Museum Board of Directors, Lancaster Country Day School Board of Trustees, James Street Improvement District Board of Directors, Ecore International Board of Directors, Milton Hershey School/Hershey Trust Company Board of Directors, Smart Health Innovation Lab Board of Managers.

Elam Esh

Elam Esh joined the Clinic's Board of Directors at the end of 2020. Elam served for several years on the Clinic's Development Committee before joining the board, where he advised on fundraising strategies and best practices. He is the founder and owner of Country Value Woodworks LLC. Started in 1990, they are manufacturers of household furniture and supply furniture stores throughout the US. They specialize in helping furniture stores make a profit by providing them with furniture their customers want. Elam's brother Jonas joined him in ownership in 2001.

In addition to the Clinic, Elam has served the non-profit community through many different positions including 25+ year volunteer fire fighter, Anabaptist Financial Advisory Group Member, Old Colony Mennonite Support Board member, PA Furniture Builders Group advisory member, former Cross Keys Business Group chairman, and former CEO of Plant Saver and Advanced Post Solutions. He lives in Lancaster County with his wife Emma. They have six children - four girls and two boys. Their oldest daughter is married and has three children. Elam and his family are members of the Old Order Amish church in New Providence district.

When asked about why the Clinic's mission resonates with him, Elam explains, "I have always been a big fan of the Clinic's work. I've watched it progress over the years. I've seen the impact it has on special children. It is amazing work! In my eyes, the Clinic doctors and staff have been unsung heroes. I feel blessed to be in a position, and be able to, serve the Clinic and our community in this capacity."

Jake Zook

Jake Zook has retired from the Clinic's Board of Directors effective August 2021. Jake joined the Clinic's Board of Directors in 2003 and has been instrumental in the Clinic's success over its 32-year history. He served on the Lancaster County auction committee from 1990 (the very first auction!) until 2019. Many of those years he was in charge of the food stands. He and his wife run Sadie's Salads. Upon his retirement from the board, Jake was elected as a board member emeritus. We are so grateful to Jake for his many years of service and dedication to the Clinic's mission.

Genetic Testing at the Clinic

Learn about our genetic testing pipeline

The journey to achieve a genetic diagnosis can be challenging for many families. At the Clinic for Special Children (CSC), we have a series of steps called our genetic testing pipeline, that we consistently use in order to efficiently arrive at a genetic diagnosis. Currently, about 74% of CSC patients receive a specific, genetic diagnosis. Our pipeline steps are outlined below:

Initial Visit

The first step is to see one of our doctors. First visits are scheduled for two hours and cost \$100, a price that has not increased in more than 10 years. During this visit, our doctors, nurses, and genetic counselors will collect a family history and do a comprehensive examination. For some patients, their symptoms may not be consistent with a genetic disorder and a full genetic workup is not needed. If the doctor suspects a genetic disorder, then the patient moves to the next step in the pipeline.

Targeted Mutation Tests/Panels

For the second step in our pipeline, a doctor may order a targeted mutation test from a “catalog” of over 310 genetic variants (changes in the DNA) known to cause medical issues in Amish and Mennonite individuals. For this test, blood is collected from the patient and our laboratory team will extract, isolate, and purify DNA from the blood. Testing for the first variant costs \$50, and additional variants cost \$35, a price that also has not changed in more than 10 years. Given our vast clinical experience, we are sometimes able to identify a genetic variant of concern during the first visit.

In other cases, the patient’s symptoms may not match a known variant or there may be too many possible variants to test individually, so the doctor may instead want to run a genetic panel. Panel tests typically look for all variants in a subset of genes known to cause a specific medical condition, like epilepsy or hearing loss. These are typically mailed to outside testing labs. The CSC does offer the Plain Insight Panel™ (PIP), a test developed and run by our laboratory. The PIP currently includes about 1,300 variants that are known or suspected to cause disease, and are more common in the Plain communities of North America. Thanks to generous donors and foundations, PIP tests are offered for \$99 although each test costs CSC about \$500 to run. The PIP checks for variants that are commonly managed at CSC as well as some that are very rare.



Chromosomal Microarray

If targeted tests and/or panels are uninformative, the third step is a test called a chromosomal microarray. The specific microarray technology used in our laboratory is called a CytoScan. The microarray examines more than 2.6 million specific points in the patient’s DNA, screening for places where there is too little (known as a deletion) or too much (known as a duplication) DNA. For example, Down syndrome is caused by three copies of chromosome 21 (rather than the normal two copies, one from each parent), and would be identified by a microarray. For CSC patients, a CytoScan is typically run at no cost.



Exome Sequencing

If the chromosomal microarray does not identify any abnormalities, as in Kari Denlinger’s story on page 1, we proceed to the fourth step in our pipeline, which is known as exome sequencing. This is an extensive test that examines large areas of DNA in great detail, focusing on the approximately 20,000 genes known to be the blueprints for creating proteins used by the body. It is currently the most comprehensive genetic test used in routine clinical practice. Patient DNA is typically sent to a research collaborator (such as the Regeneron Genetics Center) or another outside lab for this special test, which is expensive and time-consuming. Thanks to research agreements and financial assistance programs, this test typically has no cost to families. Exome sequencing yields an enormous amount of data which must be carefully sifted through to identify the specific variant(s) causing the patient’s symptoms. This process can take a lot of time because so many genetic variants are identified (about 50,000 per individual!) and yet the vast majority are not harmful.

What happens next? Why is this important?

If all these steps are completed and an answer is still not identified, it does not mean the journey is over. New knowledge about DNA variants is being generated constantly by researchers worldwide, so exome sequencing data can be re-evaluated at a later date to identify a genetic cause of disease that was overlooked during the initial analysis. At CSC we are constantly searching for new technology that can be used to find answers to challenging cases.

Why invest the time and resources in this process? First, a genetic diagnosis can change therapy. For example, if a specific genetic cause of epilepsy can be determined, it may guide what medication is used to control seizures. Even if it does not change therapy, a genetic diagnosis can provide peace of mind to families. In addition, knowing the genetic cause can help determine the risk of disease for additional children from the same couple or close family members. New DNA variants found to cause disease can be added to the PIP, increasing its ability to diagnose future patients. Lastly, a specific genetic diagnosis allows CSC to collect information about patients who we know have the same disorder in order to understand the disorder better. Ultimately, we try to use this information to identify new, innovative therapies and strategies to improve the quality of life for all patients.



Collaborator Spotlight

Erin Crowgey, PhD, Research Scientist at Nemours Children's Health

Early in 2019, the Clinic for Special Children (CSC) launched a new on-site genetic testing service called the Plain Insight Panel™. This test, using next generation sequencing technology, was made possible through a collaboration with Nemours Children's Hospital, Delaware and ArcherDX (Boulder, CO). Dr. Erin Crowgey, a Research Scientist at Nemours Children's Health, was instrumental in bringing the PIP test to CSC.

Dr. Crowgey first learned about CSC from Dr. Edward "Andy" Anders Kolb, Director of Blood & Bone Marrow Transplantation at Nemours Children's Health. Drs. Crowgey and Kolb attended one of CSC's Immunology Family Days together. Dr. Crowgey explains her first impression of CSC, "I was amazed with the extensive genomics work being conducted and the involvement of the community. It was a fun event and I really enjoyed Dr. Kevin A. Strauss's approach to translating science to community members."

For years CSC along with members of the Plain Community Health Consortium (PCHC) created an extensive list of rare genetic variants found in the North American Amish and Mennonite communities. Nemours Children's Health funded the development of a test that looked for all of these genetic variants at once - the Plain Insight Panel (PIP). The PIP is a targeted, next generation sequencing (NGS) panel test specific to the genetic regions of interest - those that cause rare genetic disorders in the Plain community. "Specifically, I helped in selecting the correct technology to use for creating the PIP. I worked on analyzing the performance of the PIP and established data analysis procedures that would work for CSC and Nemours," explains Dr. Crowgey.

The PIP testing has been instrumental to managing the health of Plain patients all over North America. In addition, Dr. Crowgey explains, "We have successfully implemented the PIP for the Dover, DE Amish community through a clinical translational research study (principal investigator Dr. Matthew M. Demczko with funding provided by the Delaware Clinical and Translational Research ACCEL Program). Additionally we have performed a comprehensive comparison between the PIP and whole exome sequencing tests that look at all protein-coding regions of genes for approximately 300 patients."

Dr. Crowgey had a long-standing interest in genomics and bioinformatics.

She's originally from a small farming town in Ohio and earned her bachelor's degree at Valparaiso University in Indiana. She was a NCAA Division I athlete in soccer and was fortunate enough to have a full tuition scholarship. She completed her master's degree at Miami University in Ohio with a focus on Immunology. Then, she attended the University of Delaware for her PhD, concentrating on bioinformatics and genomics. Bioinformatics is a study that combines research in biology, medicine, and information technology for collecting and analyzing data.

"I love genomics and conducting complex analysis. My team and I have worked extensively on understanding the genomic landscape of pediatric cancers. Similar to the PIP, we developed a custom NGS panel test to identifying complex genomic changes associated with pediatric cancers. Recently, I have implemented a pediatric genomics laboratory (PGL) at Nemours Children's Hospital, Delaware. This team of molecular biologists and bioinformaticians are developing cutting-edge genomic tests, including the PIP, and offering them as both research and diagnostic tools to clinicians. Their primary focus is pediatric cancers and rare diseases. My team and I have developed innovative techniques and data analytic procedures for uncovering these rare and complex genomic changes," explains Dr. Crowgey.

She is proud of her work with clinicians to create better genomic diagnostic tools which can be used in real-time at the patient's bedside. Dr. Crowgey exclaims, "It has been exciting to be at Nemours Children's Hospital, Delaware and develop a genomics laboratory specific to children. I am very fortunate to have amazing mentors here, including Drs. Kolb and Mary M. Lee." Her team's mission is to improve outcomes for patients by providing high-quality genomics information to the clinical care teams. "It makes me extremely happy and proud knowing we are helping at least one child and their care team," she says.

Dr. Crowgey and the Nemours team's collaboration with CSC has helped provide high-quality and responsive care to patients with rare genetic disorders. We are excited to see the future of Dr. Crowgey's endeavors and are grateful to her for her dedication to CSC's mission. Thank you, Dr. Crowgey, and the Nemours Children's Hospital, Delaware!

Our Staff

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L to R: Heather Wilson, MSW,CFRE, CAE (PAMED), Adam Heaps, MS, MBA (CSC), Karlla Brigatti, MS, CGC (CSC), Vincent Carson, MD (CSC) & Martin Raniowski, MA, FCPP, CAE (PAMED)

Pennsylvania Medical Society Community Care Grant

The Clinic for Special Children (CSC) recently received a \$60,000 Community Care Grant from the Pennsylvania Medical Society (PAMED) to support the Plain Insight Panel™ program, an expanded carrier screening test and counseling service developed by researchers and collaborators at CSC that is able to determine a person's carrier status for a wide variety of genetic conditions commonly found in the Plain communities of North America. Funds

“The Plain Insight Panel (PIP) is a crucial tool to help medical providers identify couples whose future children would benefit from rapid genetic testing shortly after birth.”

of the actual cost for each panel, so philanthropic support from organizations like PAMED is essential to our ability to keep the test affordable and accessible for our patients. We are grateful for PAMED's investment in the mission of this project.”

“I am so thrilled that the PAMED Community Care Grant is going to such a worthwhile cause. The CSC staff are truly experts in genetic research and comprehensive care for the Plain community, and the work being done by CSC through the PIP program is making a positive lifelong impact of hundreds of families and thousands of children. It shows what can happen when a small group of passionate people come together to make a difference,” says Martin Raniowski, MA, FCPP, CAE, Executive Vice President of PAMED.

PAMED partnered with Highmark, Inc. to distribute nearly \$4 million in grant monies to independent physicians and practices working to improve health care and make it more accessible to people across Pennsylvania. PAMED is a physician-led, member-driven organization that represents all physicians and medical students throughout the state. You can learn more about their work at www.pamedsoc.org.

from the Community Care Grant ensure CSC can continue offering the test at affordable rates for patients and their families.

“The Plain Insight Panel (PIP) is a crucial tool to help medical providers identify couples whose future children would benefit from rapid genetic testing shortly after birth,” says Adam Heaps, MS, MBA, Executive Director of CSC. “Patient fees offset about 20%



Martin and Heather from the Pennsylvania Medical Society tour the Clinic.

AROUND THE CLINIC

Thank you to everyone that joined us for our 2021 Clinic for Special Children events!
A selection of photos from our 2021 benefit auction season and our
4th annual Clinic for Special Children 5k are shared below!





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2021 Extraordinary Give

Lancaster County's Largest Day of Online Giving!

Save the date for the 2021 ExtraGive on Friday, November 19th!
Last year over \$55,000 was raised in 24 hours to support the Clinic's mission.
Will you help us reach our goal of \$60,000 this year?

Ultra Rare Disorders at the Clinic

Read about Kari Denlinger's odyssey of finding a genetic diagnosis and how the Clinic was able to help along her journey.

Our 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."