DDC clinic
Center for Special Needs Children

Spring 2025
Chronicle

Enhancing the quality of life for people with special needs caused by rare genetic disorders.

DDC Clinic: A Turning Point for Baby Sister

This story was provided by Baby Sister's foster mother.

My baby's story is a little different than most. I'm calling her Baby Sister due to the circumstances. That's the name her special cousin gave her. Baby Sister was born May 27, 2022 to a young mom. Although the baby's Apgar scores were normal, she began having issues with feeding and was hospitalized.

She continued having feeding issues, and a G-tube was placed during one of her hospital stays. After some missed appointments, child protective services was called, and Baby Sister was removed from her mom's care and placed with a family member. But due to her continued medical needs, it became too much for the family, and Baby Sister was placed in foster care.

This is where the story begins with our foster family. When she came to us, Baby Sister was seven months old, weighed just 10 lbs, was not using her hands, looked very malnourished, and couldn't roll over. She basically lay on her back when she was awake. Most of that time, she was crying, didn't want to be held, vomited a lot, and stayed constipated.

We began working with doctors at Duke in North Carolina. We were sent for genetic testing at another hospital where Baby Sister was found to have GM3 synthase deficiency. The doctor who tested her called me in July 2023 to inform us of the findings and said we should place her in palliative care because she wouldn't have any quality of life being in foster care.

As a foster mom, I wasn't able to make any decisions for Baby Sister, but I began to research and found DDC Clinic. I went back to our foster care worker and after a lot of conversations, I was granted a pass to take her to the clinic.

We traveled to Ohio where we met Dr. Cruz, Dr. Wang, and nurse Bea Torres-Fults. Our lives were changed forever. They sat down and explained GM3 synthase deficiency to us, and they gave us hope and information so we could plan for a future where we could give Baby Sister a complete life.

Baby Sister has now begun sitting up and eating all her meals by mouth. She pulled out her G-tube, but we haven't had to have it replaced. As of December 2024, she weighed 22 lbs, and she's keeping her weight up.

I'm so grateful for the doctors and nurses at DDC Clinic. They're never too busy for my phone calls and emails. We travel to see them every six months. An appointment that was at first very scary and emotional is now a visit that is exciting as we can share Baby Sister's progress and connect with other parents.

We're so very thankful for DDC Clinic.

About DDC Clinic

DDC Clinic – Center for Special Needs Children is a non-profit primary care and research facility serving patients with complex medical needs. Based in Middlefield, Ohio, and with a satellite location in Titusville, Pennsylvania, our clinic has been recognized internationally for our state-of-the-art genetic research impacting broad-based health concerns such as heart disease, cancer and neurological disorders.

Our mission is to enhance the quality of life for people with special needs caused by rare genetic disorders. Founded in 1998 by five local Amish families committed to helping tomorrow's special children, we now serve over 1,600 patient families in 35 states and several foreign countries.

Our clinic is a unique collaboration of the Amish and non-Amish communities, dedicated doctors and researchers all working together to find answers for parents and treatments for children. The clinic was built on the 'medical home' concept defined by the American Academy of Pediatrics. We provide comprehensive and personalized medical care for special children with over 160 different rare conditions.

Our in-house certified clinical genetics laboratory provides rapid, high quality and affordable testing. We conduct patient centered research – always seeking faster diagnoses, better understanding and improved treatments for our children.

We offer personalized education and support services for patient families. No family is ever turned away based on ability to pay.

DDC Clinic is a gathering place; a place of love, compassion and caring; a place where people take the time to listen and share; a place of faith and hope.

Executive Director's Corner

Celebrations and Blessings

"O give thanks unto the Lord; for he is good: for his mercy endureth forever."

— Psalm 23:5

In 2025, we celebrate two remarkable milestones: the 25th anniversaries of our Annual Benefit Auction and Patchwork Dinner. Begun as a modest fundraiser, Patchwork has blossomed into an extraordinary event where Amish and non-Amish communities gather to celebrate the abundant blessings bestowed upon DDC Clinic's mission of helping people with special needs and rare genetic disorders.

Our first benefit auction, held in November 2001 at the Middlefield Auction Pavilion, raised almost $30,000. After outgrowing that space, we moved to the Buster Miller auction barn in 2015. Today, this event has flourished beyond our wildest dreams, generating over $400,000 last year. The auction now draws families from neighboring states and features breakfast, lunch, and dinner. Also included is a huge raffle that draws support from across the country.

Every day at DDC Clinic, we witness miracles through collaboration between our clinical staff, researchers, families, and supporters. When communities come together with purpose and compassion, extraordinary things happen. Children receive diagnoses that would otherwise remain mysteries. Families find support and understanding. Researchers make breakthroughs that change lives. These daily miracles remind us that when we join hands in service, we become instruments of hope and healing.

Our support extends far beyond our immediate community. Joining forces with neighboring communities, our friends in Spartansburg, Pennsylvania and Shiloh, Ohio, generously share proceeds from their annual benefit auctions to support DDC Clinic.

We are deeply grateful for God's blessings to DDC Clinic through the extraordinary generosity of our communities, volunteers, donors, board, and staff. You are all invaluable to DDC Clinic and the special children, families, and individuals we serve here, and all over the world. Thank you!

May you all be blessed as abundantly as you have blessed us,

Eli Miller

Eli Miller
Executive Director

Our 25th Patchwork Benefit
A Record-Breaking Success

Our Patchwork Benefit held in April achieved unprecedented success, raising more than $165,000—a 50% increase from last year's $110,000. This remarkable accomplishment brought together 250 members from both Amish and non-Amish communities in support of our clinic's life-changing work.

Event Highlights

Our inaugural Fund-A-Need surpassed expectations, raising $50,600 and exceeding our $50,000 goal. Additional donations continued arriving even during checkout, exemplifying Executive Director Eli Miller's observation that "every great endeavor requires many hands."

This year's event featured a moving video testimonial from a patient, Molly, and her mother from Australia, who have developed a close relationship with DDC Clinic. Their story powerfully demonstrated our global impact and inspired generous giving from attendees.

Our Future Plans

Please save the date for next year's event: **April 11, 2026,**

at the EOUV Club in Novelty, Ohio. We're committed to making it even more impressive than this year's success.

With your continued support, we'll persist in our mission to stitch together a brighter future through research breakthroughs and compassionate patient care.

UPMC Specialists Visit DDC Clinic's Titusville Office

Amish children and teenagers affected by a rare genetic liver disorder received comprehensive care close to home when two UPMC liver specialists visited DDC Clinic in Titusville, Pennsylvania on January 31.

One of the doctors was Dr. Kyle Soltys, a pediatric liver transplant surgeon at UPMC Children's Hospital of Pittsburgh and Associate Professor of Surgery at the University of Pittsburgh School of Medicine. He was joined by pediatric hepatologist Dr. James Squires, Associate Professor of Pediatrics, Associate Director of Hepatology, and Director of the Pediatric Transplant Hepatology Fellowship Program at the University of Pittsburgh School of Medicine.

The two specialists came to see patients with Byler's Disease, also known as Progressive Familial Intrahepatic Cholestasis. Byler's Disease is a rare genetic disorder affecting the liver's ability to release bile, which can lead to progressive liver disease and possible liver failure.

Byler's Disease occurs in about 1 in 50,000 to 100,000 births in the general population, although the occurrence is higher among the Amish. Symptoms include yellowing of the skin and eyes, itchy skin, fatigue, enlarged liver and spleen, pale stools, dark urine, and abdominal pain.

Photo by Rebecca Hazen, Titusville News-Journal

The UPMC doctors examined and evaluated the young patients, providing the specialized liver care needed by those affected with Byler's Disease to help manage symptoms and improve quality of life.

"We're committed to delivering the best possible patient care close to home," said Dr. Heng Wang, Medical Director at DDC Clinic in Middlefield, Ohio. "By bringing in specialists like Dr. Soltys and Dr. Squires, we can provide our patients with the same comprehensive care they would get at a large metropolitan medical center."

Although this was their first visit to Titusville, the UPMC doctors have worked with Dr. Wang and DDC Clinic for more than 10 years providing specialized care and surgery, and facilitating patient access to clinical trials. As part of their ongoing partnership, DDC Clinic recently took part in UPMC's Byler Disease Day in Pittsburgh on May 7.

CLOSING THE GAP

Improving Accessibility and Affordability

Living with a rare genetic disease is challenging, particularly for families in the Plain community. In the tight-knit, rural communities where most Old Order Amish and Mennonite families live, the barriers to care are real—whether it's distance, limited resources, or cultural beliefs that make seeking help feel like an uphill battle.

For these families, getting the right care at the right time is crucial to prevent disease progression, reduce unnecessary disability, and ensure the best possible long-term outcome. But for many, access to specialized care often feels out of reach, especially when dealing with complex, rare conditions that require expert diagnosis and treatment.

The Challenge of Access

When it comes to managing complex genetic diseases, timing is everything. For Amish families, getting to the right specialist can mean long, exhausting trips—often hours away, requiring time off from work, school, or farm duties.

These journeys are not just physically demanding, but they also place a heavy financial strain on the family. It's heartbreaking when a family is faced with a diagnosis they don't fully understand, only to also worry about how they will afford life-saving treatment.

The Importance of Trust in Care

When a child is diagnosed with a rare genetic disease, it's essential that families have someone they trust to help them navigate the maze of treatment options. This relationship doesn't just lead to better care—it provides the emotional support families need when everything feels overwhelming. That's why it's so important for us to come together and close the gap in healthcare accessibility and affordability.

DDC Clinic – Bridging the Gap

DDC Clinic represents a unique collaboration between Amish and non-Amish communities, dedicated physicians, and researchers all working together to find answers for families. This grassroots initiative, built by and for the community, has made a world of difference.

Our clinic provides highly specialized, much-needed medical services while respecting the cultural values of the Amish community. Our goal is to offer peace of mind to families, knowing that the help they need is always within reach.

For over two decades, we've worked hard to understand the unique needs of the Amish community. The trust we've built ensures families can receive the best possible care when they need it most.

We also partner with major medical centers for care coordination, advocate for necessary treatments, and help families navigate the complexities of the healthcare system. By bringing specialists into these communities, we reduce the need for long-distance travel and ensure continuous, personalized care close to home.

Expanding Access: New Locations, New Opportunities

In an effort to further improve access to our specialized services, we opened a DDC Clinic branch in Pennsylvania last year, with additional outreach clinics serving Central Ohio and Southwestern Pennsylvania to come this year. We're particularly grateful for our new Family Heart Center, where the community can access state-of-the-art diagnostic procedures like echocardiograms and e-Patches, as well as personalized treatments, all within their local community.

Keeping Healthcare Affordable

Over the years, we've come to understand that affordability is one of the key factors in improving healthcare access for families who don't use health insurance. That's why we've made it a priority to keep our service fees at a level that's accessible to these families.

Since opening our doors in 2002, we've kept our service fee schedule nearly identical to what it was 24 years ago. In fact, many of the state-of-the-art services our patients receive at DDC Clinic are only a fraction of the cost at larger medical centers:

- Two-hour highly specialized office visits (a rare offering at other places)
- Diagnostic lab tests
- Genetic Awareness Panel (GAP)
- EKGs and echocardiograms
- Extended EKG monitoring

A Path Forward: Together, We Can Make a Difference

Improving healthcare for the families dealing with rare genetic diseases requires a collective effort. Let's work together to close the healthcare gap. Let's ensure every family has access to the care and support they need. Every child deserves a chance at a better outcome—and together, we can help make that happen.

Understanding Genetics

What is GM3 synthase deficiency?

For a parent, some of the most concerning things to notice in their new baby are signs of seizures, feeding problems, slowing growth and severe irritability. For many parents of babies with GM3 synthase deficiency, these are often the first signs of the condition.

Getting a diagnosis after these symptoms appear can be challenging for some families, especially if they have no experience with the condition and no family history. It can be difficult to know where to turn for help. Long hospital stays and many sleepless nights can leave parents wondering if they will ever find answers.

At DDC Clinic, we provide care to many families and patients who have been affected by GM3 synthase deficiency. Our goal is not just to care for these patients and their families, but also to increase awareness and understanding of this condition.

What Causes GM3 synthase deficiency?

GM3 synthase deficiency is caused by a problem with a **gene called *ST3GAL5***. You can think of genes like instruction manuals or cookbooks for your body: they provide your body with instructions for how all the different body parts are supposed to work.

The *ST3GAL5* gene is important because it provides the body with instructions for making a healthy nervous system. The brain and other parts of the nervous system rely on the instructions from this gene to make an **enzyme** called GM3 synthase. When the *ST3GAL5* gene isn't working, there is little or no GM3 synthase produced. When your body doesn't produce enough of something we use the term **deficiency**. This is where GM3 synthase deficiency gets its name.

Usually, people are born with two copies of the *ST3GAL5* gene: they inherit one copy from their mother and one from their father. Most of the time both copies work well and help the body produce the GM3 synthase it needs.

If someone has a copy of the *ST3GAL5* gene that isn't working correctly, they don't show any signs or symptoms of GM3 synthase deficiency. They still have a second working copy that their body can use as a back-up. However, these people are considered **carriers** for the condition.

If two people who are carriers have children together, there's a chance they'll both pass on their copy of *ST3GAL5* that's not working. When this happens, the baby will be born with GM3 synthase deficiency.

How the Amish Community is Impacted

GM3 synthase deficiency is generally thought of as a rare condition. In fact, there are only several hundred reported cases across the world. However, for individuals of Amish ancestry, the condition is much more common. This is because a specific genetic change in the *ST3GAL5* gene is somewhat common in the Amish community.

In fact, around 1 out of every 60 people in the Amish community are carriers for this condition. For people from the Geauga settlement, around 1 in 10 are carriers. Genetic testing and counseling can help couples know if they're carriers who might have children affected by this condition.

If both parents are carriers, there's a 1 in 4 or 25% chance that each baby will have GM3 synthase deficiency. This type of inheritance pattern is known as **recessive inheritance**. Someone is more likely to be a carrier if they have family members who are affected. However, it's important to remember that we cannot control which genes we inherit or which ones we pass on.

Care and Support

In the long term, babies born with GM3 synthase deficiency will have significant special needs and do not walk or talk. They might require a special feeding tube to get their nutrition and may need to take medication to help prevent or reduce the number of seizures they experience. Growth will often slow down after birth. They may have involuntary movements, and they frequently have vision and hearing problems.

When faced with such a serious condition, parents and families may wonder if there is any hope for children affected by this disease. Currently, there is no cure for GM3 synthase deficiency, and care is mostly focused on support.

Scientists and doctors in various parts of the world are working to better understand the condition and come up with potential treatments that could improve the quality of life for children with GM3 synthase deficiency. DDC Clinic continues working with other scientists and doctors as part of this effort.

In the meantime, we continue to provide compassionate care for patients and families affected by this condition and support them along their journey.

DONOR SPOTLIGHT

Our Personal Journey with DDC Clinic

Being asked to write this personal note for DDC Clinic brought a time of remembering how those beginning steps led to what has become an internationally recognized medical clinic.

We remember the humble but thoughtful drive of a few remarkable people to acquaint a broader community with a need that few had recognized; the dream of what could be accomplished; and the commitment to create what eventually became a source of hope for Geauga County Amish and others throughout the world with rare genetic conditions.

We remember visits with community leaders, UH Geauga Medical Center administrators, Metzenbaum personnel, and established hospital research experts. In those meetings, the enthusiasm and hopeful dreams of a few dedicated leaders brought a spark of interest from the community.

Enough interest that those leaders became energized to begin a concerted effort to develop a plan, build a relationship with Pennsylvania Amish community leader Dr. Holmes Morton, and put together a team to bring to fruition the idea of how this clinic could become a reality for families looking for answers. Answers to the challenges their children faced, born with unknown conditions which led to physical impairment and, for many, lifelong challenges or premature death.

The quiet enthusiasm caught on, and soon a small house – the clinic's first location – became a place of hope for many. Then along came Dr. Heng Wang who spent hours upon hours visiting families and bringing a light into their homes – the light of hope. We watched him grow this medical miracle, built on authenticated research, to a respected level of recognition among the medical world.

With awe and respect we watched the clinic's team of researchers and doctors build a reputation that required growth in physical space and staffing. We watched as the stream of families grew and their children experienced improved health and abilities. *And that included one of our own grandchildren whose life has been remarkably turned around because of Dr. Wang.*

We share our story because we believe this is an incredible story of faith, resilience and having the right persons in the right place at the right time. Only in Geauga County!

– Jim and Nancy Patterson

DDC Clinic's Medical Team Contributes to Scientific Journal

Through sharing the knowledge we gain from our research, diagnoses, and treatments, we not only help physicians and families around the world, we also grow and strengthen our clinic's reputation as a leader in treating rare genetic disorders.

Dr. Wang, Dr. Xin, Dr. Cruz and nurse Valerie Sency contributed to these prestigious scientific journals and online resources in 2024.

Ophthalmic Genetics
"Ectopia lentis associated with a 20-base deletion in the *ADAMTSL4* gene in the Old Order Amish population" (2024)

Physiological Reports
"Characterization of a novel variant in KCNJ16, encoding Kir5.1 channel" (2024)

Brain
"Gain-of-function and loss-of-function variants in GRIA3 lead to distinct neurodevelopmental phenotypes" (2024)

Frontiers in Immunology
"Genetic variations in NLRP3 and NLRP12 genes in adult-onset patients with autoinflammatory diseases: a comparative study" (2024)

View more at ddcclinic.org/selected-publications/

CLEVELAND *foundation*

Cleveland Foundation Invests $100,000 in DDC Clinic

The Cleveland Foundation continues its commitment to our mission with a $100,000 grant to our Family Heart Center. Though just one year old, the center builds on a foundation of support that began two years ago when our valued partner helped launch this initiative with their initial funding.

Report to the Community

A Year of Growth and Compassionate Care

As we look back on 2024, our hearts are filled with gratitude for the remarkable journey we've shared with our patients, families, and communities. This past year marked significant milestones that expanded our reach while staying true to our mission of providing specialized care to those who need it most.

We proudly opened our Titusville, Pennsylvania office, bringing specialized medical care closer to families in western Pennsylvania and New York. The impact was immediate with nearly a hundred new patients and established patients enjoying more convenient care and access to crucial genetic testing. Behind each number is a family spared a long journey for the care they deserve.

Spring of last year brought the launch of our Family Heart Center, offering comprehensive cardiogenetic services to both children and adults. Through thoughtful collaborations with Cleveland Clinic and University Hospitals, we've conducted 142 patient visits and 161 echocardiograms—saving our community approximately $400,000 while providing care close to home.

Our growth required expanding our DDC Clinic team. Nine dedicated professionals joined our family of caregivers, each bringing unique skills but sharing our common mission. From physicians to genetic counselors, from lab technicians to administrative staff, these individuals strengthen our ability to serve with excellence and compassion.

Our financial foundation is rock-solid. Cash reserves consistently exceed ten months of operational budget year-round—far surpassing the industry standard of 3-6 months for nonprofits. This demonstrates our disciplined management and secures our mission's future.

None of this would be possible without our extraordinary donors, whose generosity fuels every aspect of our mission. Their unwavering commitment has transformed countless lives this year, funding critical services for families who might otherwise go without specialized care. These compassionate partners don't just provide financial support—they offer hope, believing in our vision of accessible care for all regardless of geography or circumstance.

Our patient community now spans 38 states and 7 countries, with new patients this year coming from as far as Texas, Tennessee, and New Jersey. Our genetic lab continues to advance accessibility, reducing testing costs while expanding coverage to over 220 rare diseases. We performed over 1,200 genetic tests, with samples from 15 states, saving our community more than $1.2 million.

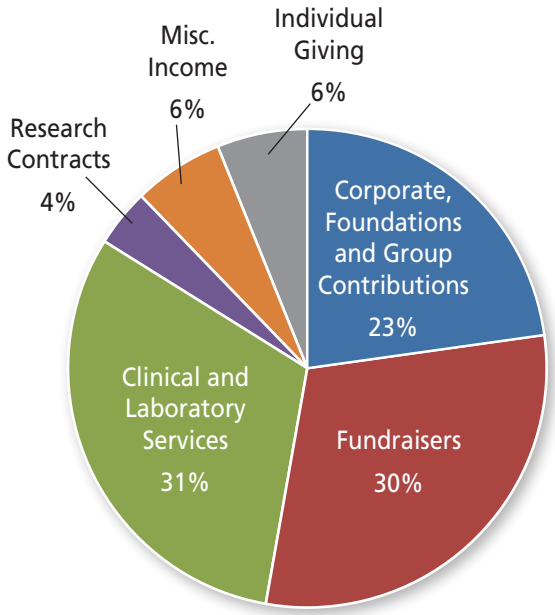
Research remains central to our mission, with multiple collaborations yielding impressive results. Our Genetic Diversity study enrolled more than 200 individuals, twice the expected number. We've published in prestigious journals like *Brain* and *Frontiers in Immunology*, with more publications in review or preparation.

Educational outreach flourished through hosting international delegations including a group from Japan, co-hosting the National Cohen Syndrome Gathering, and organizing the successful three-day Cardiogenetics and Family Health Summit. These events brought together world-renowned specialists, fostering dialogue and advancement in specialized care.

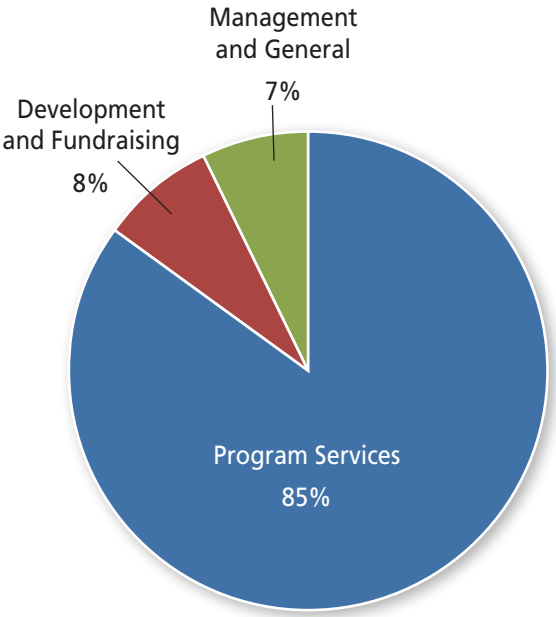
As we reflect on 2024, we see not just statistics but stories—of families finding answers, of communities accessing care, of hope rekindled. Each achievement represents our collective commitment to serving with expertise and heart. With profound gratitude to all who've been part of this journey, we look forward to continuing this mission of compassionate, specialized care in the years ahead.

2024 Financial Report

Revenue



Expenses



DDC clinic
Center for Special Needs Children

14567 Madison Road
Middlefield, Ohio 44062

440-632-1668
ddcclinic.org

Stay connected with us!

Enhancing the quality of life for people with special needs caused by rare genetic disorders.

Support Our Benefit Auctions

Mark your calendars! Bring your family and friends, and enjoy a day of food, fellowship and fun. Bid on a wide array of items, ranging from ordinary to unique.

Proceeds support our mission and help to provide life-changing care to special needs children.

Shiloh Community Auction
July 12
Shiloh, OH

Spartansburg Community Auction
August 1
Spartansburg, PA

Geauga Benefit Auction
August 22
Middlefield, OH

For more information, visit ddcclinic.org/events.
To donate auction items, call Eli Miller at 440-632-1668.