

Heartbreak and Hope – A Mother’s Story

Nine years ago on a beautiful July day, a precious son was born to our family of six. Little did we know what lay ahead, but God’s plans are ever perfect. Five minutes after he was born at Middlefield Care Center, we had a lot of concerned doctors and nurses around our little angel. His oxygen was in the mid 80s and he was very blue.

They called Dr. Tumbush to come take a look at our son. (Thank you, Dr. Tumbush!) He said our baby had a murmur, and he needed medical help, and soon. He was taken by Life Flight ground to University Hospitals Rainbow Babies and Children’s. I got to hold him for just 15 minutes before they put him into an incubator with wires, tubes, etc.

What a shock. Everything was normal one minute, and the next we didn’t know what was going to happen. My husband went with our precious son, and I had to stay behind. He called me 45 minutes later to say that we almost lost him twice on the way to the hospital.

The doctors gave us very little hope that our baby would be okay, but they wanted to keep trying. At two days old, he had surgery. As parents, it was hard for us to grasp. Babies are so fragile — how could they do surgery on a two day old? But our surgeon was very caring and understanding, which made it easier. Everything was in God’s hands. We had to try and leave it there. It was God’s will, not ours.

We were told our son had PAIVS (pulmonary atresia with intact ventricular septum). His whole right side had a lot of abnormal valves. Only God knew what the outcome would be. We had many unsure days in CTICU. One day, my sister was holding our precious son. I had just stepped out of the room when I saw my aunt come running out the door to say that my son had stopped breathing. Oh the sinking feeling. That was only one of many episodes he had. We had to take CPR classes before we were allowed to bring our son home.

We spent two weeks in ICU and more in the step-down unit. Then came the homecoming, the excitement, and the unsure feelings. But God was with us. We monitored our son hourly, measured his blood oxygen levels, and did daily weight checks.

We had many ups and downs. There were medical appointments weekly, and sometimes twice weekly. Our son kept getting worse. At nine months old, he had open heart surgery. “Cast your fears on Jesus, He will help you through,” we thought. He spent many days in the hospital in his first two years, but then an amazing thing happened.

We had been taking our son to DDC Clinic for his blood work. Could we do GAP testing to see if there was something genetic? A few days later, we had an appointment. Would they find something? Our hearts were heavy, but we needed to trust. Six weeks later, we learned DDC Clinic found nothing to cause all this. Thankfully, they were not giving up.

They suggested a bigger test — the last thing we could do. My husband, son and I got tested. After six weeks, DDC Clinic called. “We found something. Can you come in?” I’ll never forget that day, and I am sure there are many mothers who know what I mean. I wanted to know, yet I didn’t. It didn’t make sense, but after seeing my son go through surgery over and over, it was so very hard. Our son had three major cath lab visits, 10 regular cath lab visits, and one open heart surgery.

That day at DDC Clinic we got the shocking news. My husband and son have a very rare genetic defect that the clinic had never seen. We didn’t know what was going to happen. I was numb. But after hours of research, they had information for us, and we finally had answers.

The mountain looked so steep, but DDC Clinic went above and beyond. They set us up with heart doctors who specialize in genetics. They were amazing and did everything to help us in any way possible. It was suggested that we test our other

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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 2,500 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 270 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.

Each of You is a Blessing

"Thanks be unto God for his unspeakable gift."

— 2 Corinthians 9:15



As we draw closer to another Thanksgiving holiday, I'm again reminded of the blessings the Lord has so generously provided. We are grateful for each of you!

Our Founders

Thank you for your vision to improve care for families affected by genetic conditions in a setting that is sensitive and accepting of our Amish culture. Through your painful trials and personal circumstances, you sought to help future generations, knowing that others would benefit more than yourselves from these efforts.

Our Board

Thank you for your various contributions to our mission. You attend many meetings, events, etc., while sacrificing time away from family. You contribute financially to our fundraisers and help with odd jobs and maintenance on our building and grounds. Most people never realize how much you give so willingly.

Our Staff

Thank you for your compassion and dedication to our patient families. Working with people from different cultures can be challenging, but you do it extremely well. Your commitment to improving better understanding and treatment of these devastating disorders is a blessing to our communities and ultimately the rest of the world. The work you do each day is having a global impact, as our humble clinic makes new discoveries and builds new pathways to future treatments for genetic disorders.

Our Supporters

Thank you for your belief in our mission and for trusting us to do our work. Without your support, our work comes to a standstill. You're truly vital to DDC Clinic, and you will surely be rewarded for your generosity!

May each of you be blessed as you have blessed us.

Eli Miller
Executive Director

DDC CLINIC DISCOVERY DAY:

A Celebration of Community and Innovation

There's no better feeling than opening our doors to share what we do with Northeast Ohio and around the world. We extend a heartfelt thank you to the nearly 50 people who joined us for our Discovery Day Open House on September 25th — neighbors, new patients, physicians from University Hospitals and Akron Children's Hospital, and so many dedicated medical professionals and community leaders.

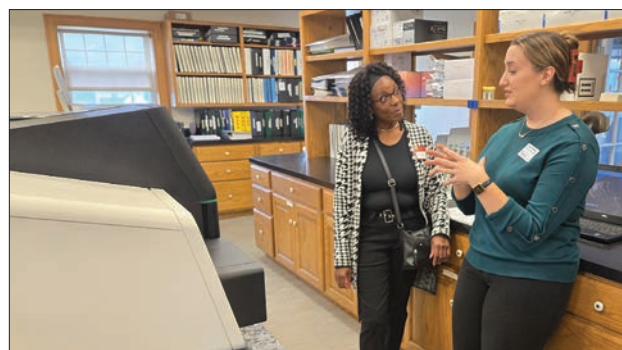
Our guests toured our state-of-the-art facilities during the self-guided station experience, engaging with our incredible staff and medical research team in our research laboratory, Family Heart Center, and clinical areas. Attendees discovered what makes DDC Clinic truly special through featured presentations by Dr. Heng Wang, Medical Director/CEO, and Eli Miller, Executive Director, who shared our clinic's history, growth, and vision.

As a clinic conducting world-class research into rare genetic conditions, we're proud to produce answers for thousands of families locally, nationally, and globally. Our advanced diagnostic equipment showcase demonstrated how cutting-edge discoveries, precise diagnoses, and innovative treatments become reality every day.

People from around the world are taking notice of our groundbreaking work in rare genetic conditions, drawn to witness this remarkable gem nestled in our community. For more information, follow us on LinkedIn and Facebook or visit ddclclinic.org.



Dr. Heng Wang, Medical Director, speaks about our clinic's work.



Senior Lab Technologist Julia Szekely talks with a guest.

Titusville Clinic Celebrates One-Year Milestone



Dr. Nicole Stevens

Our Titusville clinic recently marked an important anniversary — its first year of providing comprehensive, specialized care close to home for families in western Pennsylvania.

Established in 2024, our Titusville location is the realization of DDC Clinic's vision to expand services to communities outside of our own. For families in nearby Spartansburg and other Plain communities, that means no longer having to travel nearly two hours to our Middlefield, Ohio campus to access expert medical care for their special needs children.

According to Dr. Nicole Stevens, chief healthcare provider at our Titusville office, the new clinic has a powerful story to tell about its first year of operation.

Since opening its doors, DDC Clinic's first satellite office has made a real impact in the community:

- More than 200 patients served across the region
- More than 140 families welcomed to the clinic
- More than \$500,000 saved in expenses for patient families
- More than 100 new diagnoses made, providing families with long-awaited answers

"Our first year in Titusville has demonstrated the tremendous need in this community for a clinic such as ours," says Dr. Stevens. "Every diagnosis we make, every treatment plan we implement, represents hope restored and futures brightened."

To date, the Titusville clinic has diagnosed and treated patients with several rare genetic disorders, including cardiogenetic, thrombophilia, and mitochondrial diseases, providing a path

forward where there was once uncertainty.

Now in its second year, the clinic plans to expand patient capacity to serve additional families and introduce new treatments that have shown promise in our research collaborations. Looking ahead, the clinic plans to add pediatric and adult cardiac services, providing patients with access to echocardiograms and visits with cardiologists at the Titusville location.

"When I see a child who was once limited by their condition now thriving because of proper treatment, or when I can finally give parents the answers they've been seeking for years, I'm reminded why we do this work," says Dr. Stevens.

"DDC Clinic represents more than medical care. We represent hope, community, and the belief that every person — regardless of how rare their condition — deserves specialized, compassionate care close to home."



CLOSING THE GAP

DDC Clinic Expands GAP Testing Capabilities

One of the important ways we're closing the gap between the Plain Community and the healthcare system is through our firm commitment to provide affordable and accessible genetic testing to our patient families.

This past June, we proudly introduced a significantly enhanced version of our innovative Genetic Awareness Panel (GAP). Completed months ahead of schedule, GAP Version 4 is a major advancement in our genetic testing capabilities. With the addition of 40 disease-causing mutations, our molecular diagnostic laboratory can now test for 270 genetic conditions found in Amish communities.

"This is another critical step forward in the growth of DDC Clinic and in our capacity to deliver highly personalized patient care to the Plain Community," said Dr. Heng Wang, Medical Director. "With GAP, we can offer affordable, accurate genetic testing that can change the course of a patient's health journey."

Developed in 2018 by our clinic's molecular diagnostics laboratory, GAP is a powerful, state-of-the-art diagnostic tool that uses a patient's blood sample to simultaneously test for hundreds of rare genetic conditions. Since its launch, GAP has dramatically improved early diagnosis, helping to prevent the progression of devastating genetic disorders and life-threatening health complications.

In children and adults, GAP can identify predisposition to genetic disorders, diagnose suspected genetic disorders, and check for carrier status for genetic disorders which could get passed on to future generations. When used as a supplement to state newborn screenings, GAP can detect conditions not tested for in standard screenings.

Before GAP, Amish families often had to cope with a long, drawn out diagnostic process. Delays in diagnosis and treatment were often detrimental to children, and frequent hospitalizations

were stressful, creating financial and emotional hardship for families.

"The enormous benefits of GAP testing for our patients and their families cannot be overstated," said Dr. Wang. "Proven to be life-changing, even life saving, GAP has provided long-awaited answers to families who have been impacted for generations by undiagnosed conditions."

Committed to keeping the cost of genetic testing reasonable, we have not increased pricing for our enhanced GAP testing for new patients. In addition, patients who previously had GAP testing at our clinic can get testing with the new version for only 50% of the full cost.

GAP is truly personalized medicine in action. Through GAP, we're building bridges between the Plain Community and the healthcare system, and transforming how genetic conditions are identified, diagnosed, and managed across all life stages.

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children, and I thought, NO! But we did additional testing, and our youngest daughter tested positive. I felt so overwhelmed. It was hard to accept that this was the road we would be traveling on.

Our daughter has a lot of issues due to her genetic condition, but there is a reason for everything. As a mother, every day with my angels is a blessing from God. My biggest question is, if we would've known nine years ago, what could we have done differently? But then, I thank God we have DDC Clinic and a caring staff to help us no matter what comes our way.

Rainbow Babies and Children's Hospital told us that most babies pass away before doctors realize they have PAIVS. They said thank God we had Dr. Tumbush.

Dr. Tumbush, you will always have a special place in our hearts. We miss you, but we're very thankful that you are now at DDC Clinic. It makes it even more special to us.

DDC Clinic, keep doing what you are doing. The community needs you! I'm sure it's not always easy but if we stand together, all things are possible.

Something I would do differently is to not wait to get genetic testing! The

sooner the better. If you have questions or concerns, DDC Clinic is just a phone call away, and they are all very caring and supportive. Thank you all!

Our son loves DDC Clinic. He doesn't talk much, but he has a smile to share with everyone he meets, and he doesn't give up. Our daughter is more shy in crowds, but they are both a ray of sunshine. I tell myself I need them and their smiles, and that's why God put them in my hands. So let's all keep on keeping on. God will always be with us.

– A grateful mother and her seven blessings

Understanding Genetics

What Exactly Are Chromosomes?

At DDC Clinic, we often use illustrations to help families understand genetics. The illustration we use most often is to compare genes to a recipe. Just like a recipe provides instructions on how to make a particular type of food, different genes provide instructions about how different parts of the body are supposed to function.

If a recipe has a misspelling, the dish may not turn out very well. For example, a cup of sugar is replaced with a cup of salt. When genes have a misspelling, they no longer work correctly and can cause genetic conditions.

Each person has around 20,000 genes providing all kinds of instructions for the body. Most of the genetic conditions that we know of today are caused by problems (or misspellings) with individual genes.

Many of the genetic conditions that we see on a daily basis, such as Cohen syndrome, hypertrophic cardiomyopathy, and GM3 synthase deficiency, are caused by misspellings in an individual gene. **However, sometimes people have genetic changes that affect many genes, and this is where chromosomes come in.**

Where Do Chromosomes Come From?

If we think of genes like different recipes, chromosomes can be thought of as entire cookbooks. Each chromosome contains hundreds of genes in a specific order just as a cookbook might have many recipes. Individual genes are too small to see, but chromosomes can be seen when scientists and doctors look at them under a microscope.

Usually, people have 23 pairs of chromosomes. This means there are 46 chromosomes in total: two chromosomes per pair.

When a baby is conceived, he or she usually receives one copy of each chromosome from their mother and one copy from their father. This is why chromosomes come in pairs. The chromosome pairs are given numbers from 1 to 22. Someone will normally have two copies of chromosome #1, two copies of chromosome #2, two copies of chromosome #3, and so on.

The twenty-third pair of chromosomes is not given a number. Instead, these chromosomes are called X and Y. Females usually have two X chromosomes. Males usually have one X and one Y chromosome.

Extra or Missing Chromosomes

Sometimes people can have differences in the number of chromosomes which can cause many different genetic conditions. People can have extra chromosomes (47 or 48 in total) or missing chromosomes (44 or 45).

One of the most well-known genetic conditions is Down syndrome. This condition is caused when a baby has three copies of chromosome #21, rather than two. Because of this extra chromosome, babies born with Down syndrome have 47 total chromosomes instead of 46. These children can have many different medical problems, such as heart defects, low muscle tone, or hearing problems.

Other genetic conditions are caused when someone is missing a part of a chromosome. These people still have 46 chromosomes in total, but one of the chromosomes is missing a piece and is smaller than it should be. If we

think of chromosomes like a book, this is like missing some of the pages, or even several chapters.

Similar conditions can also be caused when someone has an extra part of a chromosome. This can be thought of as printing the same chapter multiple times. There are many conditions caused by having extra or missing pieces of chromosomes, and the exact symptoms depend on which chromosome is involved.

Most conditions caused by chromosome differences are not inherited. In some cases, people may be born with two of their chromosomes that are stuck together. These people are normally healthy — there are no extra or missing pages. However, they may experience multiple pregnancy losses, or they may have children who are born with extra or missing chromosomes.

Detecting Chromosome Differences

Genetic testing can diagnose conditions caused by chromosome differences and ensure patients receive proper treatment and care for their condition. Testing can also help parents to understand if these conditions might occur again in any future children. These tests generally involve examining someone's blood to count how many chromosomes they have, and if there are any extra or missing pieces.

This type of genetic testing is available at DDC Clinic to our patients as well as to outside doctors or medical providers who suspect that their patients may have a chromosomal condition. For more information, call 440-632-1668 or email lab@ddcclinic.org.

DONOR SPOTLIGHT

Why DDC Clinic Matters To Us



In this article, longtime donors Bob and Linda Toth reflect on their early memories of DDC Clinic.

“Nothing is ever too much to do for a child” guides the mission of the National Christ Child Society established 138 years ago. Founder Mary Virginia Merrick, paralyzed

from age 17, knew God wanted her to see the Christ Child in every child. The organization’s motto isn’t complicated — it tells you when there’s a child in need, you get moving.

Just like DDC Clinic. Years ago before there was a clinic, we attended the first Amish Wedding Dinners and heard about a vision to bring much needed medical care to children affected by genetic conditions. Stories were told, ideas were explained, and hats were passed. Everyone shared these stories with others and invited them to come and find out about this wonderful new clinic that needed to be built.

We’ve met some wonderful people since those first dinners — planning the first auctions, coming up with the Patchwork name, getting more people involved, and making new friends along the way. Volunteers made things happen. We involved our children because they needed to learn how they could make a difference.

So many people saw the need for this clinic — doctors, hospital staff and administrators, Metzenbaun Center personnel, and others who heard the story. So, the “big ask” began. We saw businesses, churches and organizations like the Christ Child Society contribute time, talent and treasure to make DDC Clinic happen.

Twenty-five years later, we still see that same commitment. The Patchwork and Amish auctions still give people in the community a way, no matter how small, to support the dream that started years ago. Volunteers set up, take down, sew, cook, build, transport and give from their hearts in many ways.

Anyone who has had any part in DDC Clinic becoming what it is today must feel a certain pride and joy when they pass by the building on Madison Road.

We thank all of you who heard the story and knew what you needed to do. Mary Virginia Merrick had it right. “Nothing is ever too much to do for a child.”

– Bob and Linda Toth

MEET OUR NEW PHYSICIAN ASSISTANT

This past summer, we welcomed Kyle Whittemore to our DDC Clinic family. As our physician assistant, Kyle provides day-to-day patient care and assists with research projects.



Kyle Whittemore

Kyle’s medical experience began in the U.S. Army Reserves. Trained as a combat medic, he was sent to Honduras where he instructed their local military on how to medically provide for their citizens.

Kyle subsequently enlisted as a full-time soldier, obtaining advanced training in anesthesia, battlefield surgery, microbiology, and critical care in field conditions, hospitals and clinical settings. Kyle says the experience taught him that limited resources and accessibility should never exempt someone from quality care.

After retiring from the military, Kyle decided to continue his career path in the world of healthcare. He wanted to work with families, providing quality care to every patient he was blessed to serve. Today, Kyle is living his dream at DDC Clinic.

“I’m thoroughly impressed with DDC Clinic’s mission, and I’m honored and privileged to be part of their team,” says Kyle.

Kyle is a graduate of Baldwin Wallace University, where he earned his Master of Medical Science Physician Assistant Program degree. He and his wife have three children.

Compassionate Care. Global Impact.

A Conversation with DDC Clinic

Thursday, November 13 | 5:30 – 8:00 p.m.

LOCKKEEPERS RESTAURANT
8001 ROCKSIDE RD, INDEPENDENCE, OH

Do you know someone who would like to learn more about DDC Clinic and support our groundbreaking work in rare genetic diseases? We welcome guests who are new to DDC Clinic to attend an informational event with a special presentation by Medical Director, Dr. Heng Wang.

Space is limited. RSVP by October 31st at 440-632-1668.

GROWTH AND INNOVATION: Q&A with Our Leadership

DDC Clinic's mission is to provide specialized care for rare genetic disorders, bringing hope and healing to families who need it most. Our commitment extends beyond medical treatment to building lasting relationships within the communities we serve.

We sat down with Executive Director Eli Miller and Medical Director Dr. Heng Wang to discuss our continued growth, innovative approaches, and the future of specialized genetic care.

Discussing Our Path Forward

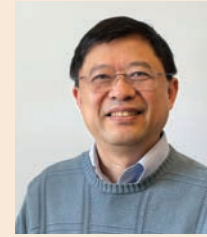
1. As we celebrate one year of the Titusville location, what has surprised you most about the community's response to DDC Clinic's expansion into Pennsylvania, and how has this influenced your vision for future growth?

Eli Miller: The city of Titusville's warm welcome has been a delightful surprise. This enthusiastic response reflects the deep appreciation people have for organizations like DDC Clinic whose mission is to serve unique populations, creating ripple effects that benefit the entire world. The community's embrace has strengthened our commitment to this region. We recently purchased the DDC Clinic office building and property in Titusville, establishing a permanent, long-term presence.

Dr. Heng Wang: I've been pleasantly surprised by how seamlessly our Titusville location launched and continues to operate. This success stems from the incredible support we've received from countless community members, for which we're deeply grateful. Their partnership has shown us the power of collaborative healthcare delivery.

2. Looking ahead to the next five years, what new services or specialized programs do you envision DDC Clinic developing to better serve families dealing with rare genetic disorders?

Eli Miller: DDC Clinic's strength lies in being a truly patient-centered organization—we let the people we serve guide our growth and



Dr. Heng Wang
M.D., Ph.D.



Eli Miller

development. Expanded services for genetic heart conditions are already on our strategic roadmap. We're also developing essential programs like genetic testing initiatives for newborns and young adults, addressing critical gaps in early detection and intervention.

Dr. Heng Wang: Our future services will focus on closing the gap through improving accessibility and affordability. We're committed to breaking down barriers that prevent families from accessing specialized care by bringing specialists directly into communities and maintaining accessible fee schedules for families who don't use health insurance.

Dr. Wang Takes Center Stage at International Medical Conference

We're thrilled to announce that our own Dr. Heng Wang was an invited speaker at the prestigious *12th International Conference on Neuroacanthocytosis, Cohen Syndrome, and VPS13-related Disorders* held in Switzerland this past September. This special invitation reflects global recognition of Dr. Wang's exceptional expertise in rare disease management.

Dr. Wang presented on two pivotal topics: "Building Bridges to the Future: Insights from Two Decades of Comprehensive Medical Care for Over 100 Cohen Syndrome Patients" and "Disease Management — Clinical Perspective." His presentations showcased the depth of experience and patient-centered approach that define our clinic's commitment to rare disease care.

The conference brought together an international community of clinicians, researchers, patients, families, and advocacy groups. This collaborative platform focused on advancing understanding of VPS13-associated diseases, including Neuroacanthocytosis syndromes, Cohen syndrome, VPS13C-related Parkinsonism, and VPS13D-related ataxia.

The event's objectives aligned perfectly with DDC Clinic's mission: enhancing collaboration between scientists and clinicians, involving patients and families in research priorities, and exploring novel treatment approaches. Dr. Wang's speaking engagement represented more than individual recognition — it highlighted our clinic's two decades of providing comprehensive care to more than 100 Cohen syndrome patients.

International recognition such as this reinforces DDC Clinic's reputation as a center of excellence in rare disease care. Dr. Wang's participation ensures that our patients benefit from the latest advancements in understanding and managing complex conditions.

Congratulations to Dr. Wang on this well-deserved recognition of his expertise and dedication to improving lives through exceptional medical care.



Dr. Wang and colleagues at the conference.



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THREE AUCTIONS, *Incredible Results*

This summer featured three important fundraisers — the Shiloh Community Auction, the Spartansburg, Pennsylvania Community Auction, and the Geauga Community Benefit Auction.

Together, these auctions successfully raised a substantial portion of the critical operating funds we need.

Thank you to our good friends in these communities who participated, donated and supported these events. Your incredible generosity helps us continue to provide life-changing care to children with special needs.