

DDC Clinic Opens Pennsylvania Office

After significant planning, hard work, and generous support from our friends, we're pleased to announce the opening of DDC Clinic's new satellite location in western Pennsylvania.

Our new Titusville office, which opened on February 15th, brings highly specialized healthcare close to Spartansburg and other Plain communities. For years, Amish families from Pennsylvania have made the two-hour trip to our clinic in Middlefield to get testing and medical care for their special needs children. Since many of the genetic disorders diagnosed in Amish families in Pennsylvania and Ohio are the same, DDC Clinic's doctors understand how to treat these disorders.

"Pennsylvania families came all the way to our clinic because there were no physicians near them who could diagnose and treat these rare genetic diseases," said Dr. Heng Wang, DDC Clinic Medical Director. "There was a very real need for us to bring our services to their area. With our new clinic in Titusville, families now have affordable, expert medical care close to home, and many more families will be able to access the special care their children need."

Offering primary and urgent care to both Amish and non-Amish children and adults with genetic disorders, the Titusville clinic is staffed by an experienced family nurse practitioner and certified medical assistant who handle most patient needs. Our Middlefield physicians, Dr. Wang and Dr. Cruz, provide additional care, visiting our Titusville clinic about once a month to see patients. When genetic laboratory testing is needed, patients' blood samples are sent to DDC Clinic's lab in Middlefield.

Nicole Stevens, family nurse practitioner and head of our Titusville office, was already familiar with DDC Clinic before she joined our team. She previously owned and operated a private practice which provided affordable healthcare to uninsured families. During that time, she worked closely with Amish families, and began her relationship with DDC Clinic working to diagnose and coordinate treatment for local families with genetic disorders.

"I'm honored to be a part of DDC Clinic's Titusville office and serve as the local provider of specialized care to those who are affected by genetic disease," said Nicole.

Housed in a former urgent care center, Titusville's DDC Clinic location is equipped with three exam rooms, and has been freshly updated with new flooring, lighting, paint and a wider door to accommodate wheelchairs. The cheery, comfortable waiting room, a hallmark of DDC Clinic, is a welcoming space, featuring an Amish quilt hanging on the wall and a collection of toys for children.

Our new DDC Clinic office is located at 150 W. Central Ave, Suite 1, in Titusville.

One of the exam rooms in the new clinic.



*Nurse Practitioner
Nicole Stevens
and Certified Medical
Assistant Vanessa Duke*





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.

A Time of Sadness

*"Blessed are those who mourn,
for they will be comforted."*

—Matthew 5:4



Recently at DDC Clinic, we mourned the loss of a few very special friends. One was among our oldest and longest patients. Others were of various ages, from infants to young adults. A few were our longest-standing, and most generous donors. Each one was special in their own way, and helped to shape DDC Clinic into the unique and special place it is today. We feel so blessed to have been a part of their life's incredible journey. The sadness and loss we feel is sweetened by the friendship and love they so freely shared over the years. Let's remember their families whose hearts are broken by their parting.

While we've experienced deep sadness, we've also been blessed. Because of such generosity from you, our friends, we were able to slightly lower some of our testing fees recently. While I doubt that we'll ever be able to provide free service, we strive to keep all our fees as low as possible, while still being sustainable.

GAP (Genetic Awareness Panel) continues to gain popularity for patients who need genetic testing. GAP is used for newborn screening, diagnosis of suspected genetic disorders, and to check for carrier status of genetic disorders. Recently, more young unmarried couples are using GAP to see whether they're at risk of having children with genetic disorders.

The Family Heart Center at DDC Clinic is open! And so is the new DDC Clinic medical office in Titusville, Pennsylvania! Much hard work went into these two expansions, and we're excited and grateful to provide specialized care for our patients, close to home.

Thank you to all our supporters — our community, volunteers, donors, board, and staff. You are all greatly needed and appreciated. Each of you is a blessing to DDC Clinic and the special children, families, and people we serve.

May you all be blessed,

Eli Miller, Executive Director

In Memoriam: **GORDON SAFRAN**

By Dr. Heng Wang

As we gathered to celebrate the latest achievements at DDC Clinic during our annual board meeting in April, our hearts were heavy with the absence of our dear friend, Gordon Safran, who passed away on March 25, 2024.

Gordon was more than just a founding member of DDC Clinic – he was a great leader with vision, a beacon of generosity, a devoted trustee, and a truly caring person who inspired many. His passion for improving the lives of special needs children with rare genetic disorders was inspirational.

I can still vividly recall the time I met Gordon over two decades ago during my first trip to Geauga County, Ohio. Gordon, then the owner of Red Maple Inn, accompanied me to an Amish home with several children suffering from a severe unidentified genetic disorder. “We need a doctor and we need a clinic here for these children,” said Gordon. He shared his vision with me about a future clinic, his eyes filled with compassion and determination.

When my family and I moved to Ohio, Gordon extended a surprising gesture of kindness. Before we had settled into our own home, Gordon offered us his second residence in Burton. This gesture of warmth and generosity left an indelible mark on my daughters’ young hearts; my oldest daughter Wendi even expressed her gratitude for Gordon’s kindness in an entry in her third-grade diary.

Gordon’s unwavering dedication was the cornerstone upon which DDC Clinic was built. Gordon played a crucial role in transforming that modest house into the inaugural home of DDC Clinic on Road 528 in 2003. His genuine concern for each child we served was palpable. At each board meeting after he listened to the patient stories I shared and the clinic’s positive impact on children and their families’ lives, Gordon would be eager to learn more about the progress we were making. His face would light up with hope and optimism upon hearing of treatable conditions, a reassuring encouragement amidst the challenges we faced.

When the need for expansion arose, Gordon spearheaded a capital campaign co-chaired with Mr. Chuck Fowler, navigating us through the storm of the 2007–2008 financial crisis with unwavering determination. I’ll never forget the evening Gordon and Evie welcomed my wife Jian and me into their home, offering reassurance and support in the face of uncertainty. This spoke volumes about Gordon’s character and the depth of his commitment, an unwavering commitment that ultimately ensured that our new, larger building became a reality in 2009.



Gordon Safran and his wife, Evie, at our Patchwork Benefit.

Among all the causes he championed, Gordon held a special place in his heart for DDC Clinic. Gordon’s tireless efforts and countless hours of service as a board member and lifetime director enriched the fabric of our clinic. We are forever grateful for Gordon’s vision, expertise, and leadership, which have shaped our clinic into the world-class institution it is today. His memory will live on, a guiding light in our hearts as we continue his legacy of kindness and service.

It was a profound honor to count Gordon, Evie, and their family as dear friends. Jian and I were privileged to visit Gordon’s basement, where we saw firsthand the treasures that held special meaning to him. Among them were photographs of the children whose lives he touched and the heartfelt letters he received from those whose lives he had forever changed. We were thrilled to see a copy of Wendi’s third-year diary among what he treasured.

What I never had the chance to fully express to him directly is the monumental impact he had on thousands of children’s lives through his dedication to DDC Clinic. His steadfast support transformed not only the clinic but also countless families, including my own. He instilled in us a sense of compassion and dedication that has made us better doctors and more caring individuals.

Gordon, your absence is deeply felt, yet your spirit remains ever-present within our clinic and beyond. Your legacy of compassion and service will continue to inspire us as we strive to uphold the standards of care and kindness that you exemplified. Thank you, Gordon!

Understanding Genetics

WHAT IS GENETIC COUNSELING?

Genetic counseling is often defined as the process of helping people to understand and adapt to the medical, psychological and familial implications of the occurrence, or potential occurrence, of a genetic condition.

In simpler terms, genetic counseling is an important conversation which helps people understand how genetic illness can affect them and their families. This conversation breaks down large complex medical terms into words that are simple to understand and is aimed at meeting the personal needs of individuals and their family members.

Genetic counseling can be provided by any person with advanced training and knowledge about genetics. This includes medical doctors and other members of healthcare teams including genetic counselors and specialty nurses.

What is a genetic counselor?

A genetic counselor, commonly called a GC, has specialized healthcare training in medical genetics, genetic testing and counseling. Most genetic counselors have a master's degree in genetic counseling which includes course work in medicine, genetics and counseling. Some also have degrees in related fields including psychology, nursing and social work.

Like a medical doctor, genetic counselors must take and pass a board exam. In our state, genetic counselors are licensed by the State Medical Board of Ohio. Most practice in large academic medical centers in larger cities but some work with specific communities such as the Amish and Mennonite populations.

How is a genetic counselor different from a medical doctor?

While both genetic counselors and medical doctors can educate patients and families about genetic conditions and help them to cope with their impact, only a medical doctor can make a diagnosis of whether a person does, or does not, have a genetic disorder.

Genetic counseling at DDC Clinic

At its core, genetic counseling is about education. Our clinic's genetic counselor provides pre-test and post-test genetic counseling to our patient families. Our GC meets with parents to discuss the genetics of their children's newly diagnosed conditions, explain the related issues that can exist with these conditions, and answer their questions.

Another important part of our genetic counselor's job is educating individuals about our Genetic Awareness Panel (GAP), which tests for 220 genetic disorders found in the Amish community. GAP is used for disease diagnosis, newborn screening, and identification of risk factors. Our GC meets with couples to explain how GAP testing can be used to determine if they're at-risk of having children with genetic disorders. Our GC also meets with expectant parents to explain the importance of using GAP for supplemental newborn screenings so rare genetic disorders can be detected and treated early.

Our genetic counselor also supports our clinic's new Family Heart Center by meeting with parents and families to

educate them about our Cardiogenetic Awareness Panel and to answer questions about how genetics may play a role in their heart health.

Much of our clinic's knowledge of rare genetic diseases comes from research. Educating patients and their families about our research efforts and explaining how they can participate in research studies or clinical trials is another component of our genetic counselor's job.

Trained in genetic disorders and genetic testing, our genetic counselor also reaches out to medical professionals in Plain communities outside our area to bring attention to the array of diagnostic testing we have available. By keeping doctors, nurses and midwives informed, our GC helps in the care of others who may be impacted by the same genetic conditions we see in our community.

Our GC may also assist with contributing to online medical resources and scientific publications aimed at the broader medical and scientific communities. Sharing our knowledge and discoveries increases awareness and global understanding of rare genetic disorders and helps to improve the care of special needs children around the world.

At DDC Clinic, genetic counseling is about providing information, caring and support to patients and families affected by rare genetic disorders. It's about helping parents to understand life-changing diagnoses and cope with the impact that these conditions can have on their children.

PATIENT STORY

Hypertrophic Cardiomyopathy – From Sorrow to Joy

This story was written by a husband and wife with two children affected by this serious genetic disorder.

Hypertrophic cardiomyopathy has affected our family more than once. When we lived in Pennsylvania, our second child, Lavern, was delivered by a local midwife. We had a blood kit from DDC Clinic so we could take a sample of cord blood at birth. We collected the sample and hired a driver to deliver it to DDC Clinic for testing.

When he was just nine days old, I knew Lavern was very sick. He was hardly nursing and having severe crying spells. Soon after, we were devastated to learn from DDC Clinic that our baby had hypertrophic cardiomyopathy.

We made the trip to DDC Clinic, where Dr. Wang saw our baby after office hours, and prescribed a medication to keep him comfortable. That same evening, our dear baby Lavern quietly passed away from my arms to Jesus. Just the evening before, he laughed out loud twice.

Years later, we were living in Michigan when our fifth child, Wyman, was born in the month of October. He appeared perfectly healthy at birth, but maybe slightly pale. As we had done before, we shipped the cord blood sample to DDC Clinic. Ten days later, we got the heart-wrenching news that he also had hypertrophic cardiomyopathy. By then, Wyman started turning blue sometimes when he cried.

I called for an appointment with a pediatric cardiologist in case Wyman needed medication to keep him comfortable. Bless their hearts – they took him in the next day. The doctor prescribed two medications, but the pharmacy didn't have either of them on hand, so we had to wait a day to start the prescriptions.

We could see Wyman filling up with fluid. At one point, he was very listless. But after he took his medication the next day, we could see his fluid starting to go down. At one point he was very

listless, but much to everyone's surprise he started waking up and eating a little as the day went on.

Our doctors spoke to us about a heart transplant for Wyman. We reached out to family and folks from church with transplant experiences, and a few days later we let the doctors know that we wanted to go ahead with transplant plans.

The next day Wyman grew worse and was passing blood. We went to Ann Arbor, knowing that it was all in God's hands whether Wyman would get a new heart. In no time, they were taking ultrasound pictures of his heart. The doctors at the hospital were amazed to see Wyman breathing on his own considering how sick his heart was. They gradually increased his medications, and with time he looked almost like a healthy baby.

After 2½ weeks, Wyman was placed on a transplant list in the state of Michigan. In order to try to get his HLA antibodies down, the doctors tried blood transfusions but because of his heart they needed to push it in manually, very slowly, as the machine wouldn't give it slow enough.

On December 12th, after five blood transfusions, he was placed on a nationwide transplant list. On January 9th, he received a sixth transfusion. Wyman grew very sick, and the doctors inserted a breathing tube. He was supposed to get a Berlin heart pump on January 14th, but two days before, doctors said he was improving enough to hold off.

On January 13th, all four heart transplant doctors came into Wyman's hospital room and gave us the wonderful news – they had a heart for Wyman! It took some time for us to register that this was actually happening. Two weeks after the transplant, we were filled with overwhelming joy and gratitude, heading back home with our sweet baby. We felt so blessed.

David and Erma Mullet

Family Heart Center Holds Echocardiogram Days

The new Family Heart Center at DDC Clinic is now providing regularly scheduled echocardiogram days twice a month. Echocardiograms, which use ultrasound to check the heart muscle and valves, are used to diagnose a variety of conditions such as cardiomyopathy, valve disease, blood clots and more.

Nineteen patients had echocardiogram tests during the center's first three echocardiogram days – March 25, April 10 and April 22. Our certified technician, Laurie Moore, performed the echocardiograms. Based in Erie, Pennsylvania, Laurie will travel to DDC Clinic twice a month to perform echocardiograms, which are available to our patients by scheduled appointment.

DDC Clinic's Family Heart Center focuses on the diagnosis and treatment of genetic cardiac conditions in children and adults. Providing much-needed cardiology services to families in our area, the center offers affordable testing, early diagnoses and onsite treatment for genetic heart diseases. Future plans call for additional specialized cardiac care to be provided by visiting cardiologists from nearby medical centers.

DDC Clinic will host a special 2-day Cardiogenetics Summit on October 10-11, followed by a community open house on October 12 at the Family Heart Center. Visit ddclclinic.org/ events for additional information.



Bridging Two Cultures

At DDC Clinic, we're committed to furthering personalized medicine and increasing understanding of genetic diseases. Our efforts are "closing the gap" by building bridges between the Plain community and the healthcare system; between research on broad-based health concerns and the study of rare genetic diseases; and even between different cultures.

One of the important ways we've helped to close the gap is through our Genetic Awareness Panel (GAP), a diagnostic tool which can simultaneously test for 220 rare genetic conditions found in the Amish population, including Cohen syndrome.

It was actually Cohen syndrome which brought a group of nurses from Japan to DDC Clinic on March 21. Although rare, Cohen syndrome is not confined to our Amish community; it also affects people in Japan and other parts of the world. The nurses came from across the globe to learn how our clinic diagnoses and treats children and adults who have the condition.

The group's leader, Ms. Kaori Kuraishi, discovered DDC Clinic and our work with rare genetic diseases three years ago when she attended an online Cohen syndrome conference. After learning that Dr. Wang is a leading expert on Cohen syndrome, Ms. Kuraishi made it a goal to visit DDC Clinic and learn more about the condition. In Japan, her work focuses on rare diseases as well, and she has a specific interest in working with older adult Cohen syndrome patients.

Ms. Kuraishi and the other nurses, who specialize in pediatric nursing, spent the day by meeting with Dr. Wang, listening to presentations from DDC Clinic staff, learning about diagnosis and treatment of Cohen syndrome, and touring our in-house laboratory. As part of their three-day trip, the group also visited the Sunshine Training Center for Amish handicapped adults, Rainbow of Hope which provides daycare and therapy service for Amish special needs children, the Middlefield Amish birthing center, and University Hospital's Geauga Medical Center.

"It was a wonderful three days," said Ms. Kuraishi. "It was a great pleasure to meet the team at DDC Clinic, who know so much about Cohen syndrome... I will tell Cohen syndrome families in Japan about what I learned at DDC Clinic."

Gifts Come in All Shapes and Sizes

Our donors support DDC Clinic for a variety of reasons and in different ways. Dr. Yin An, a pediatric dentist, was so moved by working with our patients that she became a regular donor. Read about her experience and the unique way she supports our clinic.

When I was a pediatric dental resident in 2017, I hopped on the Ronald McDonald Care Mobile to DDC Clinic. I spent three weeks on the bus treating Amish children and teenagers. This was my first interaction with the Amish, and it was absolutely surreal for me, a Chinese immigrant, to get to know this community.

I became connected to the people and sparks of passion filled my heart. Parents were grateful for the care we provided to their children, and I felt a deep sense of fulfillment. Seeing the Amish community desperately in need of a local pediatric dentist and understanding the challenges they faced accessing dental care pushed me toward a decision.

By 2021, I completed my residency training and became a faculty member at Case Western Reserve University. I became convinced that I could use my knowledge and skills to improve the oral health and overall wellbeing of the Amish, particularly the special needs population. The first person I shared my idea with was Dr. Wang at DDC Clinic. He and his colleagues welcomed me with open arms, gave me encouragement and helped me to shape my vision.

My practice, Sunflower Pediatric Dentistry, opened in nearby Burton in July 2022. I felt a huge responsibility to take care of the community that I fell in love with in 2017, and I knew the best way to show gratitude was to give back.

That's why I became a regular donor. For every new patient that we see, our practice makes a donation to DDC Clinic. In this way, we help the clinic continue to provide trusted care to our community's special needs children.

Dr. Ying An, Sunflower Pediatric Dentistry

Patchwork

2024 BENEFIT

Please join us as we gather to celebrate our clinic's achievements, give thanks, and remember the many special children and families we've helped.

Enjoy a buffet dinner, drinks, live and silent auctions, and a special program by Dr. Heng Wang.

Get details at ddcclinic.org/events.

Purchase tickets online with Zelle or PayPal, or call 440-632-1668. This event will sell out!

Your support helps to provide life-changing care to special needs children affected by rare genetic disorders.

Report to the Community

Reflections on 2023

As we look back at 2023, we're grateful for the many blessings that have touched our clinic. Our supporters continued to bestow their generosity upon us, and their enduring belief in our mission enabled us to move forward with plans for the future expansion of our clinic's services.

Thanks to generous support that year from our donors and grants from The Elisabeth Severance Prentiss Foundation and the Cleveland Foundation, we were well on our way to establishing a new Family Heart Center and a much-needed satellite clinic in western Pennsylvania.

In 2023, Eli Miller began his third year as our executive director. Through his dedication and perseverance, he raised awareness of our Genetic Awareness Panel (GAP) within our Amish community. Because of his efforts, GAP testing increased and more patient families found long-awaited answers for previously undiagnosed genetic conditions.

It was a year in which we saw steady growth in the area of patient care. Families continued to travel from out of state and across the country to bring their children to our clinic. We had 168 new patients, and 1,164 total patient visits, a 10 percent increase from the prior year.

Turnout for our major fundraising events of the year exceeded our expectations. Our three community benefit auctions were a resounding success, and our Patchwork Benefit was a record-breaker, raising more money than in any previous year. We were amazed by such loyal and generous support.

On another front, we continued to make progress in research and education. In 2023, Dr. Wang, Dr. Xin, Dr. Cruz and nurse Valerie Sency contributed to three prestigious scientific journals and online resources, sharing our knowledge of rare genetic diseases with physicians and researchers around the world.

We also hosted our second Hypertrophic Cardiomyopathy Family Gathering. The event brought together specialists from regional medical centers, representatives from our research partner Tenaya Therapeutics, and Amish families affected by MYBPC3 gene-related cardiomyopathy. The gathering provided important information to families, and also gave them a sense of hope and optimism.

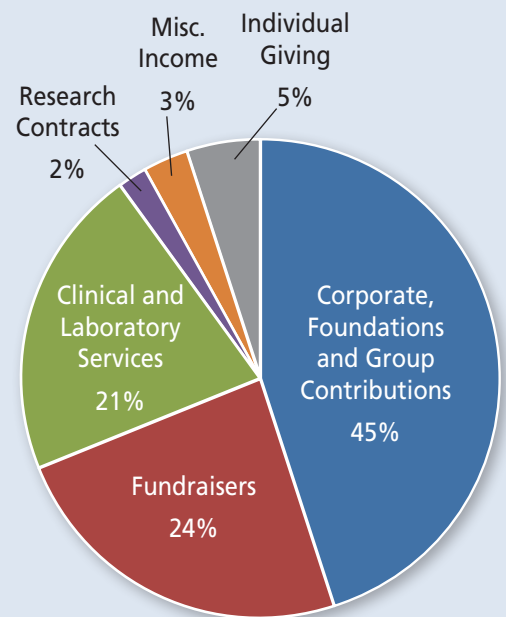
Our advances in patient care, research and education were possible because friends like you were there to help. With your support, we were able to provide answers to parents and life-changing medical care to their special children.

We're truly grateful to all of you. It's because of you that our clinic, which started as a humble medical practice, has grown into a respected world class medical and research facility. Together, we can continue to make a difference in the lives of special children in our community and around the world.

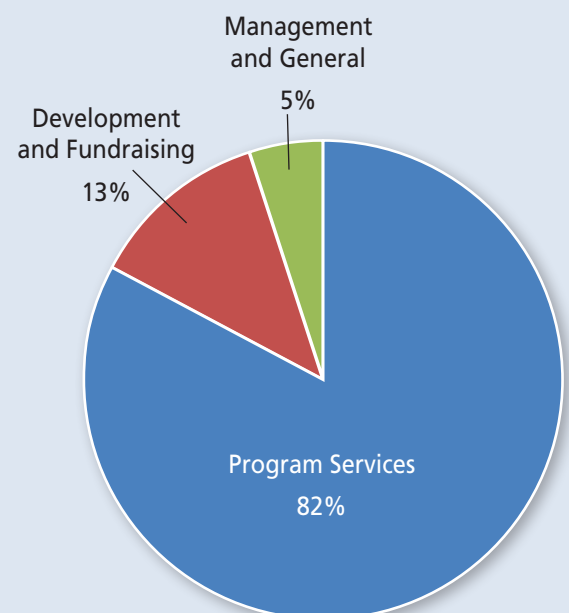
Thank you for putting your faith and trust in us.

2023 Financial Report

Revenue



Expenses





14567 Madison Road
Middlefield, Ohio 44062
440-632-1668
ddcclinic.org

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

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Chuck Fowler
Joe Weaver

In Perpetuity

Gordon Safran

COMING SOON

Community Benefit Auctions

Don't miss the fun of a live country auction. 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 DDC Clinic's mission and help us to provide life-changing care to special needs children.

Shiloh Community Auction
July 13, 2024
Shiloh, OH

Spartansburg Community Auction
August 2, 2024
Spartansburg, PA

Geauga Benefit Auction
August 23, 2024
Middlefield, OH

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

