

Community Day for Heart Health Raises Awareness

DDC Clinic recently welcomed families to Community Day for Heart Health, the culmination of a three-day educational event designed to celebrate the opening of our new Family Heart Center, increase awareness of genetic cardiac disorders, and highlight our clinic's expertise in testing, diagnosis and treatment of genetic cardiac conditions affecting the Plain community.

The Community Day for Heart Health was part of our larger Cardiogenetics and Family Health Summit held October 10-12. The first two days were for physicians, scientists and other medical professionals, and the third day was reserved for members of our community.

"It was important to have a special community day because educating families is so critical to our mission," said Eli Miller, Executive Director of DDC Clinic. "Cardiogenetic disorders affect many in our community, and these diseases often go undetected for a long time, putting lives at risk. By teaching families about inherited heart diseases, we can save lives through early intervention and timely testing, diagnosis and treatment for these diseases."

Families who came to the Community Day for Heart Health toured our new Family Heart Center, and learned about heart health, diagnostic screenings, and how we care for patients with cardiogenetic disorders.

The event featured various education stations, each dedicated to a particular topic. At one station, families learned about how our Genetic Awareness Panel (GAP) is used to diagnose rare genetic diseases. At another station, DDC Clinic staff explained how echocardiogram machines use ultrasound to check the heart and how an EKG (electrocardiogram) machine analyzes heart rhythms.

Families also learned about a new gene therapy for rare heart disease from representatives from Tenaya Therapeutics. Another station offered blood pressure screenings, and provided heart-healthy dietary and exercise information.



Blood pressure checks were part of our community day.

Nursing students from Ursuline and Lake Erie colleges gave demonstrations and explained how cardiopulmonary resuscitation (CPR) and automated external defibrillators (AEDs) are used to treat someone whose heartbeat has stopped.



The echocardiogram room in our new Family Heart Center.

Besides enjoying lunch and refreshments, families were also given cards which they could get stamped at each station, making them eligible for a raffle to win a free echocardiogram or genetic testing.

"We were grateful for the families who came to our Community Day for Heart Health," said Eli Miller. "More importantly, we were pleased that we generated greater awareness of genetic heart disease, and in doing so, maybe we even saved someone's life that day."





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 Year of Growth



*"Thou preparest a table before me
in the presence of mine enemies;
thou anointest my head with oil;
my cup runneth over."*

— *Psalm 23:5*

This has been an exceptional year for DDC Clinic's growth, thanks to you! Our Family Heart Center, the Titusville, PA office, and three-day educational event for medical providers and families are three giant steps we took. Our innovative Family Heart Center is a first-of-its-kind initiative which has set a new standard for adult and pediatric providers working side-by-side, offering affordable diagnostic and treatment services for the whole family.

Our record-breaking benefit auctions left us greatly humbled, reminding us again of our generous friends in dozens of communities across the country. This year's auctions raised \$650,000. Words can't describe what your support means to families who depend on DDC Clinic. Your ongoing generosity is the reason we can offer affordable, compassionate care for even more people in need.

Long-term sustainability and securing our clinic's future are critical. This year, we welcomed seven new staff members who can grow into long-term, dedicated team members who understand the unique challenges presented by rare genetic conditions. Developing compassionate caregivers today supports the children, grandchildren and great-grandchildren of tomorrow.

We'll soon celebrate 25 years of helping families. Whether you joined us years ago, or became a new friend this year, you're part of our family. You support the hard work and vision that gives families comfort through specialized care and diagnosis.

Thank you to 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

Scientific Summit Kicks Off Three-Day Cardiogenetics Event



Dr. Wang prepares to cut the ribbon at the grand opening ceremony for our new Family Heart Center.

On Thursday, October 10, a group of physicians, medical professionals and scientists from around the country gathered at the Cleveland Marriott East hotel in Beachwood for DDC Clinic's Cardiogenetics Scientific Summit, the first day of our three-day Cardiogenetics and Family Health Summit.

The group was there to hear about advances in cardiogenetics research, gain a deeper understanding of genetically-based heart diseases, and learn about diagnosis and treatment of cardiogenetic conditions in the Plain community and beyond. The day-long program also served to introduce them to our new Family Heart Center and to showcase our clinic's expertise in cardiogenetic diseases.

Cardiogenetics has become an exciting field of medicine, due to significant research breakthroughs and rapid growth in the understanding of the genetic basis of cardiovascular diseases such as inherited cardiac arrhythmia and inherited cardiomyopathies.

"Our clinic has first-hand experience with treating various cardiogenetic diseases as many of these diseases are prevalent in our community," said Dr. Heng Wang, DDC Clinical Medical Director. "Our summit enabled us to share our knowledge with fellow medical professionals, as well as provide an opportunity to hear from other experts in the field."

The summit attracted a wide range of attendees including clinicians, research scientists, cardiologists, internists, pediatricians, geneticists, genetic counselors, nurse practitioners and physician assistants.

The program opened with remarks by Dr. Wang, who also gave a presentation and delivered closing remarks. Among other DDC Clinic staff who spoke were Dr. Baozhong Xin, Research and Technical Director, and Dr. Vince Cruz, Geneticist and Internist.

The robust program also featured distinguished speakers from respected medical centers, universities and institutions, including Cleveland Clinic, University Hospitals, Central Pennsylvania Clinic, Michigan State University, Children's Cardiomyopathy Foundation, Le Bonheur Children's Hospital, University of Maryland School of Medicine, and Tenaya Therapeutics.

"Having these reputable healthcare providers and institutions together enabled everyone to hear about the latest discoveries, discuss ways to improve diagnosis and treatment of cardiogenetic conditions, and explore possibilities for future scientific collaborations," said Dr. Wang.

The day's program ended with attendees traveling to DDC Clinic for a grand opening celebration and tour of our new Family Heart Center.

Bus Tour Provides a Look at Amish Life

On October 11, a group of physicians, medical students, faculty and researchers boarded a bus for an Amish Cultural Tour that took them to an Amish schoolhouse, businesses, historical library and more.

The tour was on the second day of DDC Clinic's three-day Cardiogenetics and Family Health Summit, and many group members had also attended the first day, learning about advances in cardiogenetic research and rare genetic disorders in the Plain community.

Eli Miller, DDC Clinic Executive Director, said the tour was designed to provide an opportunity to see first-hand the many aspects of Amish life in Geauga County and gain insights into Amish culture.

"It's our hope that by learning about our beliefs and way of life, these healthcare

professionals will provide culturally-sensitive and compassionate care to the Amish patients they treat," he said.

The tour began with a visit to the Sunshine Training Center, where Amish adults with disabilities perform light tasks while receiving training to enter the general workforce. Next, the group visited Rainbow of Hope, which provides daycare and therapy for Amish children and adults with severe mental and developmental disabilities.

The group also observed class-time at a two-room Amish schoolhouse, learned about the Amish parochial school system, and visited a historical library with bibles, Anabaptist history books and artifacts while listening to a presentation on early Anabaptist history.



Lunch at an Amish restaurant was one of the stops on the tour.

After lunch at an Amish restaurant, the tour continued with visits to two Amish businesses – a wood mouldings company and a lithium battery distribution and sales center.

"This was one of my absolute favorite days EVER!" said a member of the tour group. "I learned so much and genuinely had such an amazing experience. I'm so glad BioMarin was able to support such a great event!"

Understanding Genetics

WHAT IS LONG QT SYNDROME?

Many things in life require good timing: telling a good joke, the rhythm of music, the planting of crops. All these things and many more depend on good timing to work smoothly. When it comes to your heart, timing is also essential. Every minute of every day, your heart is beating to pump blood throughout your body to ensure each part gets nutrients and oxygen. In fact, the average person's heart will beat over two billion times during their lifetime!

When a person has a problem with the regular beating of their heart, they're said to have an **arrhythmia**, or irregular heartbeat. A common genetic condition that can cause arrhythmia is **long QT syndrome**. An easy way to think about long QT syndrome is that it causes your heart to take longer to re-charge between beats. This can cause arrhythmia.

Symptoms of Long QT Syndrome

The symptoms of this condition can be sneaky. The most common symptom of long QT syndrome is fainting or passing out. Sometimes doctors or medical providers use a different word for fainting and call it **syncope** instead. Before a person with long QT syndrome faints, they might experience light-headedness, blurred vision, or may feel like their heart is racing.

Other times people may not experience any symptoms at all and can go their entire life without knowing they have long QT syndrome. In some people, the condition can be more serious and may cause their

heart to stop completely. When this happens, it's called **sudden cardiac death**. Cases of sudden cardiac death can be surprising when they happen, especially for families and loved ones who didn't know about long QT syndrome before a death happens.

Diagnosing Long QT Syndrome

Medical care for patients with long QT syndrome often focuses on preventing cases of sudden cardiac death. When a person is diagnosed with the condition, their doctor may recommend that certain medications (like certain antidepressants or some antibiotics) should be avoided because they can make long QT syndrome worse. The doctor might also order tests like an EKG (also called an ECG) or have the patient wear a special monitor to evaluate the heartbeat and help them decide if additional treatments such as medications, surgical intervention, or a defibrillator are needed.

What Causes Long QT Syndrome?

Long QT syndrome can be caused by genetic changes in several different genes, however a gene called KCNQ1 is a common cause. Genetic changes in KCNQ1 that cause long QT syndrome are more common in the Plain community, and through genetic testing, our clinic has found many patients and families who have a genetic change that can cause this condition. Genetic testing has helped many patients and families learn about their genes and be proactive about their care.

Long QT syndrome due to changes in the KCNQ1 gene follows **dominant inheritance**. This means having just one change in the KCNQ1 gene can cause the condition. A person with one change in the KCNQ1 gene will have a one in two chance of passing on that change to their children. Usually, a person inherits this change from one parent, so testing for a person's parents or siblings would also be recommended.

If both parents have one change in the KCNQ1 gene, their baby might inherit two changes (one from each parent). When this happens, the baby is often born with hearing loss in addition to long QT syndrome. This is called **Jervell and Lange-Nielsen syndrome**. Genetic testing through our Genetic Awareness Panel (GAP) can help patients and families to understand if they have Long QT and help them get care. This is especially important because this condition is treatable when found early.

Expanding Our Knowledge

Our knowledge of long QT syndrome is still incomplete. We still don't understand exactly why some people with the condition have episodes of fainting or even sudden cardiac death, while others don't. Through our clinic's Family Heart Center, we hope to learn more about how arrhythmias like long QT syndrome affect Plain populations.

Our team of physicians, imaging technicians, nurses, genetic counselors, laboratory and administrative staff have one goal: to ensure the patients and families we serve get exceptional heart care.

One Man's Personal Journey of Giving

I've often hesitated to share my story of giving. One late night, over a cup of coffee with an Amish friend who has since passed, I was reminded of the teachings from Matthew 6:1-21. To paraphrase, it speaks of how good works should remain humble and unseen, for if we are rewarded in this world, we forfeit our reward in heaven.

This conversation brought clarity to an experience I had during the ribbon-cutting of our first clinic. I had expressed my gratitude to a friend and his family for their contributions, but he seemed embarrassed, even upset. Now I understand why.

My journey of giving began modestly, around a kitchen table on an Amish farm. A few families had been traveling around the Amish settlements in Geauga and Holmes counties, seeking support from bishops to build a clinic for Amish children suffering from genetic metabolic disorders.

I had the privilege of driving them to some of these visits, which gave me precious time to learn more about their values, their deep connection to family, and their hopes for their children. As I listened, I realized that their hopes were the same as mine for my own children. *This clinic wasn't just a building; it represented a dream for the future of their community.*

Since those early days, I've been fortunate to continue giving—both time and money—to DDC Clinic. Whether it's making pie runs for an auction or helping to plan the many steps that have led us through the last 25 years, I'm proud to have played a part. As the clinic has grown and expanded its ability to serve more families, I've remained committed, often digging a little deeper when needed.

Even now, as I reflect on all that's been accomplished, I know I can—and will—continue to give more, as the clinic's mission and the community it serves continue to inspire me.

– Anonymous Donor

WAYS TO GIVE

To our non-profit clinic, every dollar counts and every gift is important. There are multiple ways you can support our clinic, and no matter how you give, your donation makes a real impact.

One-Time Donation

Your one-time gift helps to provide medical care, support and resources that are critical to families with special needs children. Donate online, by mail or by phone.

Planned Giving – Wills and Trusts

Leave a lasting legacy by giving to DDC Clinic through your will or trust. Your thoughtfulness will ensure life-changing care for tomorrow's special children. Consult with your attorney to make your bequest.

Gifts of Securities

Support our clinic through gifts of stocks, bonds, mutual funds and other financial assets. Your gift will help sustain our mission, bring relief to children and provide hope to families. To make arrangements, consult with your broker or financial advisor.

Memorial or Honor Gifts

Celebrate the life of a loved one who has passed or honor a living person by donating to our clinic in their name. Your generosity can create a brighter, healthier future for a special needs child.

Matching Gifts

Before making a gift, check to see if your company has a matching gift program for charitable contributions. If so, your employer will match the amount of your donation, making your gift go twice as far.

Fundraising Events

Our Patchwork Benefit and community benefit auctions provide essential operating funds for our clinic. By attending these annual fundraisers, you support our mission to enhance the quality of life for people with special needs.

DDC Clinic – Center for Special Needs Children is a non-profit 501 (c) (3) organization. Your donations are tax deductible to the full extent allowed by the IRS. For more information on donating to our clinic, contact us at 440-632-1668.

CLOSING THE GAP



Dr. Heng Wang

Gaps Are Closing – My Reflection

By Heng Wang, MD, PhD

As we recently celebrated the grand opening of our Family Heart Center with other healthcare professionals, researchers, families and the local community this October, I feel a great sense of hope for the future.

Twenty years ago, when I first came to Middlefield, infantile hypertrophic cardiomyopathy was one of the first diseases that local physicians and Amish families asked me to study and find an answer for. At the time, the community had lost so many children, even before DDC Clinic was started, but nobody knew the cause of the disease.

I recall the difficult time I had as a doctor when DDC Clinic lost three children with cardiomyopathy in a very short period of time. I have kept this reflection I wrote in 2007, the day after I had a house call in the middle of the night:

“On my way to their house, the faces of these children and parents often jumped into my mind. I thought about an old saying ‘to cure sometimes, to relieve often, to comfort always.’ It was such a privilege for us to serve these children and their families and to be there while they needed us.

However, when I left their houses, I often felt a deep sense of failure as a physician – we knew so little about the disease, and we could only do limited things for them.

More than once, I had to stop my car at a crossroad to figure out where I was and where I should be going. Looking at the dark sky, I had brief moments of doubt – was there any hope for these children and families? And where was the hope?

These doubts fortunately never lasted long. I realized that this work was definitely going to be an uphill battle, and that

it would not be an easy one for any of us. But I truly believe it will be a journey filled with hope.

Those children who died before we could conquer those lethal diseases are, in fact, often the very source of inspiration and hope. They have taught us love, strength, hope, courage, humility, and faith.”

Indeed, we have since put in countless hours working with other medical teams across the country and around the globe to study and research this devastating disease. I’m excited that significant progress has been made and that we can finally feel some real hope.

New drugs developed in the last couple of years or currently under development will likely be very helpful for this condition. I’m particularly excited about gene therapies in ongoing clinical trials.

Today, I have a great sense of accomplishment as our Family Heart Center provides services to our community. It’s so fulfilling to see state-of-the-art diagnostic testing and procedures such as GAP testing, echocardiogram and e-Patch, personalized treatments, and even future gene therapies being done at our Family Heart Center. It’s equally fulfilling to let the community know that all these can be done affordably and close to home. We’re closing gaps!

Let’s remember the children we have lost during this special time. Although they were with us very briefly, for days or months, they were here for a purpose. We lost them, but we never lost hope, the hope for future generations. We are getting there.

Meet Our New Staff

We extend a warm welcome to these new staff members who recently joined our team.



John Tumbush, DO
Staff Physician

A life-long member of our board of directors, Dr. Tumbush has practiced medicine for 32 years. He now treats patients with genetic heart disorders at our Family Heart Center.



Vanessa Duke, EMT, CCMA, CPT
Administrative and Medical Assistant

Vanessa works in our Titusville, PA office. She has 10 years of experience as an emergency medical technician, certified medical assistant and phlebotomy technician.



Nicole Stevens, FNP, CRNP, DNP
Family Nurse Practitioner

Based in our Titusville, PA office, Dr. Stevens earned her Doctor in Nursing Practice degree from Johns Hopkins University, from where she'll soon receive her doctorate degree.



Theresa Miller
Medical Assistant

Theresa has 25 years of experience, mainly in the area of Family Medicine. Most recently, she worked at University Hospitals Evans Middlefield Medical Center.



Garrett Edinger, MS, CGC
Genetic Counselor

Garrett is a board certified and licensed genetic counselor and recent graduate of the Case Western Reserve University School of Medicine Genetic Counseling Training Program.



Erma Troyer
Receptionist

A member of the Amish community, Erma taught at an Amish school for five years before coming to DDC Clinic. She enjoys working with our patients and their families.



Rebecca Terrill, MPH
Research Associate

Becca recently earned her Master of Public Health in Public Health Genetics from the University of Pittsburgh School of Public Health.

FAREWELL TO PATTI



As we prepare to say farewell to a cherished member of our team, we want to honor Patti Gallagher, who will retire at the end of this year. Since joining DDC Clinic in 2005, Patti has held multiple job titles, most notably serving as our Operations Director. Beyond her official role, she has also been the heart of our office, lovingly known as our "Office Mom."

Patti's contributions over the years have been invaluable. Her leadership, expertise, and warm demeanor have created a supportive environment for everyone at DDC Clinic. Whether tackling operational challenges or providing a listening ear, Patti has always gone above and beyond for colleagues and patients alike.

MARK YOUR CALENDARS!

MONDAY, DECEMBER 16 | 1 – 5 p.m.

Please drop in and join us in our lower-level community room for an open house celebrating Patti's many years of dedication to our clinic and community.

Dr. Heng Wang, our Medical Director, shared, "Patti has been integral to our team. Her compassion and caring toward patients and families have made her naturally connected with everyone. Her dedication and commitment are immeasurable, and she'll be greatly missed by all of us."

While we'll miss Patti's familiar face and exceptional skills, we're excited to hear that she's already considering ways to stay involved through volunteering. It's a testament to her generous spirit and commitment to making a difference.

Thank you, Patti, for everything. Here's to many happy years ahead!



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ddcclinic.org

SAVE THE DATE

Patchwork

2025 BENEFIT

Special Children Deserve Special Care

APRIL 5, 2025

Join us for a delightful evening and support
our mission to help special needs children.
Details coming in early 2025.

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

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GIVING TUESDAY

December 3, 2024

*For more than 20 years, we've
provided children like Daniel with
life-changing medical care.*

On this Giving Tuesday, will you please
make a donation to DDC Clinic to help a
special needs child?

To make a gift, use the donation envelope
inside, visit ddcclinic.org or call
440-632-1668.

