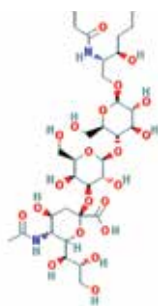


## A Twenty-Year Commitment to Special Children Affected by GM3 Synthase Deficiency

*In many ways, the story of helping to find answers for families with children affected by GM3 synthase deficiency is the story of our clinic.*

"We've been waiting 16 years for an answer... it may be too late for us but if we can help others with this center, we'll gladly do that." This quote from an Amish father with four profoundly handicapped children appeared on the front page of the *New York Times* in 2002. His children were suffering from GM3 synthase deficiency, and at the point of the *Times* article, the condition had never before been described in the medical literature. This family was one of a handful who gathered around a kitchen table in an Amish home in 1998 to found a clinic with the goal to help children with then unnamed, undiagnosed and sometimes devastating conditions. Most of these children appeared healthy when they were born, but then in the weeks and months that followed, many would suffer significant medical challenges and developmental disabilities.

### The Missing Molecule



Children with GM3 synthase deficiency lack an enzyme their bodies need to produce a type of fat called *ganglioside GM3*. The GM3 molecule is critical for normal brain development. (See

the *Understanding Genetics* column on page 3.) Affected children often appear normal at birth, but begin to develop symptoms just weeks later. Many of the children suffer intractable seizures and profound intellectual disability. Over time, most require wheelchairs and feeding tubes and become completely caregiver dependent.

After first discovering the mutation that causes this condition in 2002, DDC Clinic launched an international research collaboration to better understand the mechanism underlying the disease and to help illuminate the crucial function of gangliosides in the brain. We first reported on this condition in the journal *Nature Genetics* in 2004. Shortly after the publication, several children with the



*New York Times*, June 20, 2002.

disease were identified in other parts of the country in addition to the 10 children DDC Clinic had initially identified in Ohio.

With our early research on the function of gangliosides underway, we launched a now 16-year effort to identify a method to re-establish gangliosides in affected individuals whose bodies are unable to synthesize this critical molecule.

> PAGE 2



“We always believed that we could help these special children if we could just find a way to replace the missing gangliosides – the challenge was finding an available source,” according to Dr. Heng Wang, DDC Clinic’s medical director.

In 2013, we began a multi-year collaborative research project with Fonterra of New Zealand, one of the world’s largest dairy cooperatives. Fonterra scientists had found a way to extract and concentrate gangliosides from cow’s milk and we felt the product might help our patients. With the ganglioside supplement provided from Fonterra, we developed a clinical trial, orally supplementing GM3 and assessing its bioavailability to determine if the supplemented ganglioside might be detectable in patients’ bloodstreams. Our hope was to help relieve some of the symptoms of this most challenging disorder. This was the very first study to assess the metabolism of orally administered gangliosides in humans. A parallel research project, also a first, was launched in collaboration with Dr. Amin Zhou of Cleveland State University (CSU). The partnership with CSU led to the development of a quick and sensitive lab test to detect for the presence of gangliosides in patients’ blood.

## Reason for Hope

Much work remains, but the clinical trial outcomes to date give us hope. There is evidence of symptomatic relief for some patients and several findings in this area warrant continued study.

A subset of younger patients maintained normal or near normal body weight, body length and head circumference growth curves compared to non-supplemented GM3 children of a similar age that we have observed over the years.

Parents and caregivers reported a number of children who were “less fussy” while on supplemental gangliosides. Similarly, parents of the youngest patients on the supplement observed increased eye contact and other purposeful communication from their children. We were also able to demonstrate modest increases in cognitive measurements in several of the youngest patients.

*“Four generations of my family made the six hour trip to DDC Clinic today. We are so grateful that we now have a diagnosis. I finally have an answer to why I lost four children decades ago and reason for hope for my grandchildren and great-grandchildren. We are very fortunate and blessed to have found this special clinic.”*

— Mrs. A. Shrock, September 2018

*An Amish family member from northern Michigan who recently had two great-grandchildren diagnosed with GM3 synthase deficiency.*

In summary, we have shown that oral ganglioside supplementation improves growth and development in patients with ganglioside GM3 synthase deficiency. For reasons not yet completely understood, the observed improvements were transient and gradually diminished after twelve months of supplementation. We theorize that the metabolism of gangliosides is fairly active and the potential need for replacement gangliosides in the GM3 synthase deficiency patients is substantial, perhaps greater than what can be established with oral supplementation alone. As we continue to search for effective therapies for this disorder, we now have established evidence that increasing ganglioside supplies in affected individuals can help treat the disease. The results from this recent clinical trial were just published in *JIMD, the Journal of Inherited Metabolic Diseases*. Future areas of study, including gene therapy, are currently being considered.

## A Continued Commitment

Since discovering the disorder in 2002, we have provided diagnoses and medical care for nearly 100 GM3 patient families from Amish and non-Amish communities across the country. By sharing our research and diagnostic expertise with other clinicians, we have helped further the care of both today’s and tomorrow’s GM3 patients. Our study of ganglioside synthesis and metabolism not only helps families with GM3 deficient children, but also contributes to the research base underlying some broad-based health care concerns including Parkinson’s and Alzheimer’s.

Twenty years after the founding of DDC Clinic, our commitment to and hope for GM3 families remains the same – that some day all of their children will grow up to lead healthy, happy and productive lives.

## Scientific Contributions

Over the last sixteen years, DDC Clinic’s research commitment to this disorder has led to seven major publications including:

“Oral Ganglioside Supplement Improves Growth and Development in Patients with Ganglioside GM3 Synthase Deficiency.” *JIMD*, February 2018.

“Early Growth and Development Impairments in Patients with Ganglioside GM3 Synthase Deficiency.” *Clinical Genetics*, 2016.

“Quantification of Monosialogangliosides in Human Plasma through Chemical Derivatization for Signal Enhancement in LCeESI-MS.” *Analytica Chimica Acta*, April 2016.

“A New Liquid Chromatography/Tandem Mass Spectrometry Method for Quantification of Gangliosides in Human Plasma.” *Analytical Biochemistry*, March 2014.

“Cutaneous Dyspigmentation in Patients with Ganglioside GM3 Synthase Deficiency.” *American Journal of Medical Genetics*, November 2012.

“Etiology of Vision Loss in Ganglioside GM3 Synthase Deficiency.” *Ophthalmic Genetics*, 2006.

“Infantile-onset Symptomatic Epilepsy Syndrome Caused by a Homozygous Loss-of-function Mutation of GM3 Synthase.” *Nature Genetics*, October 2004.

# Understanding Genetics

## What is GM3 Synthase Deficiency?

*GM3 synthase deficiency, also called **ganglioside GM3 synthase deficiency**, is a rare and serious genetic condition. Approximately 100 children have been diagnosed with this condition, and many, but not all, are from the Amish community.*

GM3 synthase deficiency is an inherited condition caused by a faulty gene. Children with this disorder lack an enzyme their bodies need to produce a type of fat called **ganglioside GM3**. Gangliosides are present in every cell in our bodies, but the greatest concentration, more than half, is found in our brains.

In GM3 synthase deficient children, those whose bodies are unable to synthesize this special fat, the brain fails to develop and function normally. Affected children often appear normal at birth, but begin to develop symptoms just weeks later. These symptoms include irritability, muscle weakness, poor eye contact, poor feeding and failure to grow at normal rates.

Within their first year, most GM3 children begin to have seizures. The children may become stiff, have convulsions and lose consciousness. Individuals with GM3 synthase deficiency do not develop the same way as other children. Affected children are not able to reach for objects, speak, sit on their own or walk. Over time, many of these special children require wheelchairs and feeding tubes.

### How does a person develop GM3 synthase deficiency?

Ganglioside GM3 synthase deficiency is caused by two genetic changes in the gene **ST3GAL5**. This gene helps the body to make the enzyme that builds the special fatty molecules called gangliosides which are so important for normal brain development and function.

If a person has only one genetic change in the **ST3GAL5** gene, then his or her body can still help build gangliosides and the person has no symptoms. However, if a person has two genetic changes in **ST3GAL5**, his or her body has a much harder time building gangliosides. This leads to ganglioside GM3 synthase deficiency.

This disorder is inherited in a recessive manner, which means that both parents must carry at least one genetic change in **ST3GAL5** in order for their children to be at risk. If both parents carry a genetic change in **ST3GAL5**, there will be a 25% chance that their child will have the condition. Simply put, your child would have to inherit the genetic change from both you and your partner in order to have GM3 synthase deficiency.

### Understanding genetic changes

Think of a gene as a sentence that tells the body what to do. Sometimes there are misspellings in sentences, and it can be

hard to understand what the sentence is trying to say. A genetic change is like a misspelling in a sentence that makes it difficult for the body to understand what the gene is trying to tell it to do. Just like sentences, the body can still understand some genetic changes. Other genetic changes are too difficult to understand and can cause a genetic disorder.

Everyone has many genetic changes. Genetic changes are what make us unique. Some genetic changes will affect our health, and some will not. It's normal to have genetic changes, and most of us will never know which genetic changes we carry. It's important to remember that we have no control over what genetic changes are passed on to our children, and likewise, we have no control over what genetic changes we inherit from our parents.

Many genetic changes are treatable, especially with early diagnoses. DDC Clinic is dedicated to researching genetic changes that cause rare conditions, such as ganglioside GM3 synthase deficiency. Our hope is that through our research, we can help to find better treatments for patients and families affected by rare conditions.

## Meet Our New Genetic Counselor



**Our Molecular Diagnostics Laboratory is pleased to introduce our new genetic counselor, Sarah Ossler, who joined our staff in June.**

Sarah, who received her genetic counseling training at University of Cincinnati, worked at Aultman

Hospital (oncology) and most recently with the genetics lab at University Hospitals in Cleveland.

As our genetic counselor, Sarah provides genetic testing consultations and education services to patients, families and healthcare providers. Serving as the liaison between our laboratory and outside clinicians, Sarah provides information and technical support on appropriate test use, interpretation of results and reporting. She's also involved in research and new test development.

After several months without a genetic counselor, we're pleased to have Sarah onboard to further our lab's operations and development.

## Recent Publications and Presentations

Our work has a big impact not only on our patients, but also on our fellow clinicians. By sharing the knowledge we gain from our research, diagnoses and treatments, we can help children and families around the world.

Dr. Wang, our clinic's medical director, and Dr. Xin, our laboratory's technical director, recently authored or co-authored these articles and presented these talks at conferences close to home and abroad.

### PUBLICATIONS

To view the full manuscripts, go to [www.ddcclinic.org](http://www.ddcclinic.org).

#### *Journal of Inherited Metabolic Disease*

"Oral Ganglioside Supplement Improves Growth and Development in Patients with Ganglioside GM3 Synthase Deficiency" (June 2018).

#### *Blood*

"The Clinical Spectrum of Pyruvate Kinase Deficiency: Data from the Pyruvate Kinase Deficiency Natural History Study" (March 2018).

#### *Haematologica*

"Prevalence and Management of Iron Overload in Pyruvate Kinase Deficiency: Report from the Pyruvate Kinase Deficiency Natural History Study" (September 13, 2018; online ahead of print).

#### *Ophthalmic Genetics*

"Bilateral Angle Closure Glaucoma in a 28-year-old Cohen Syndrome Patient" (July 9, 2018; online only).

### PRESENTATIONS

#### **4th Annual Conference of the Chinese Stroke Association and Tiantan International Stroke Conference 2018 (TISC 2018) – Beijing, China**

Dr. Xin was invited to present "Genetic Testing in Plain Populations: A Clinical Laboratory's Experience" (June 29 – July 1, 2018).

#### **University Hospitals Geauga Medical Center**

Dr. Wang was invited to present "Becoming an Expert on Genetic Diseases in the Amish Community" (May 16, 2018).

#### **Cleveland State University**

Dr. Wang was invited to present "Solving Medical Mysteries – From Rare Diseases to Common Pathways, From Gene Discovery to Novel Therapies, From Amish to Chinese" (September 7, 2018).

#### **6th Annual Translational Medicine in Plain Populations Conference – University of Wisconsin**

Dr. Wang was invited to present "SAMS Association – From Bedside to Benchside, From Gene Discovery to Novel Therapy" (July 30-31, 2018).

## COMMUNITY PROGRAMS

### *Programs for Mothers with Special Children*

We invite mothers of special needs children to these upcoming programs at DDC Clinic where you can visit with other mothers, share information and enjoy time together.

#### **MOM'S COFFEE BREAK**

Wednesday, November 14 • 9 a.m. – noon

#### **GRAB & GO GIFT EXCHANGE WITH LUNCH**

Wednesday, December 12 • 9 a.m. – 2 p.m.

#### **FEELINGS OF MY HEART TALK**

Wednesday, January 9 • 9 a.m. – noon

Additional programs are scheduled for February, March and April. For more information, please call DDC Clinic at 440-632-1668.

### DDC Quilting and Craft Club

The ladies of the DDC Clinic Quilting and Craft Club invite all interested ladies to bring a lunch and join them on the first Wednesday of each month from 9 a.m. to 1 p.m.

Now in its seventh year, the group enjoys working together on quilts and other projects and spending time visiting. The ladies donate their work to benefit auctions and to Christian Aid Ministries.

The group's next meeting is Wednesday, December 5 at DDC Clinic.



### Teacher In-Service Day

Sunny Hope and Sunny Acres school teachers gathered at DDC Clinic on August 22 to participate in an educational in-service day focusing on occupational, physical and speech therapy for special needs students. We appreciate the partnership and services provided by the Early Intervention team at the Bessie Benner Metzenbaum Center.

## Sunshine Training Center Rebuilds



*Framing and roofing of the Sunshine Training Center were almost complete before the tornado struck.*



*The Sunshine Training Center took a direct hit from the tornado which leveled the building.*

*A destructive tornado roared through Middlefield on the afternoon of Thursday, September 20, devastating the new 6,000-square-foot Sunshine Training Center which was under construction.*

Neighboring DDC Clinic, the Sunshine Training Center took a direct hit from the EF-1 tornado, which completely flattened the building's walls and lifted its roof, carrying it 33 feet away from its foundation. Thankfully, there were no injuries as no one was at the construction site at the time.

DDC Clinic also sustained damage, although much less severe, to its building and solar panels. Our staff took shelter in the clinic's basement during the tornado, and everyone made it through safely.

The clean-up effort for the Sunshine Training Center began on Saturday, September 29, thanks to the help of community

volunteers. Ray Miller, president of Sunshine's board of directors, expected about 15 people to show up that morning. To his surprise, nearly 50 dedicated volunteers came to work on the clean-up. In just three and a half hours, the hardworking crew salvaged what materials they could, disassembled what remained of the structure and cleared the area.

Rebuilding of the Sunshine Training Center is underway, and volunteer crews are working tirelessly to get the structure weathered-in before winter. The facility, which will be a workplace for special needs Amish adults, is scheduled for completion in spring 2019.

## Cohen Syndrome Family Gathering

*From Geauga County to faraway New Zealand, 160 people from all over the world came together for the seventh International Cohen Syndrome Gathering held June 21-23 in Beachwood, Ohio.*

Presented by the Cohen Syndrome Association, the gathering is held every two years and provides families an opportunity to meet other families affected by Cohen Syndrome, a rare genetic disorder affecting fewer than 1,000 people worldwide.

With 40 cases of Cohen Syndrome in our community, DDC Clinic has become a resource for parents and medical professionals seeking information about the disorder. This year's program featured several presenters from our clinic including medical director Dr. Heng Wang; executive director Blake Andres; business manager Patti Gallagher and genetic counselor Sarah Ossler.

Additional presenters included specialists in ophthalmology, orthopedics and hematology from Cleveland Clinic, Akron Children's Hospital and University of Michigan Medical Center.



Nearly a third of the families at this year's gathering were first-time attendees, and all were grateful to share their experiences with other families and to speak to Dr. Wang and other medical professionals about managing and treating Cohen Syndrome.

The next International Cohen Syndrome Family Gathering will be held in summer 2020.

# Patchwork 2018 BENEFIT

## Patchwork Benefit A Huge Success

*Thanks to our enthusiastic supporters, we raised \$89,474.*

A record-breaking crowd of 290 guests enjoyed a celebratory evening of food, fellowship, music, auctions and Amish hymns at this year's Patchwork Benefit on April 14.

The evening began with a special tribute to Frann R. Zverina, who served on our board of directors for seven years. We're grateful to Frann for her generosity, dedication to our mission and unwavering commitment to improving the lives of special children.

After dinner, Dr. Heng Wang, our clinic's medical director, presented a program about our work with patient families affected by SAMS Association, a rare condition that puts children at risk for early-onset stroke.

We extend a heartfelt thank you to all those who generously supported our Patchwork Benefit. Your contributions enable us to further our clinic's mission and help children grow up to live healthy, happy and productive lives.



### *Save the Date*

*We look forward to seeing all of you again at our next Patchwork Benefit on Saturday, April 13, 2019.*



## THANK YOU TO OUR SPONSORS

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### NON-PARTICIPATING SPONSORS

Dr. Robert Gavazzi, D.C.

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# 2018 Community Benefit Auctions

*We're so grateful to our friends in the Amish and Mennonite communities who held benefit auctions again this year to support our clinic's work with special children.*

The Shiloh, Spartansburg and Geauga benefit auctions were a success. The steadfast commitment of these three communities to our mission and our families is truly humbling. We thank those who donated goods, time and labor and helped set up, tear down and work during the auctions. Your valuable contributions ensure that we can help to improve the lives of special needs children in our community and beyond.

## Shiloh Auction

The 12th annual Shiloh Mennonite Community Benefit Auction was held on July 14 in Shiloh, Ohio. This auction benefits both DDC Clinic and the Clinic for Special Children in Lancaster, Pennsylvania. This year's highlights included an expanded silent auction area, larger food service menu and extended hours for the second outdoor auction ring. The event was well-attended and raised \$38,713 for our clinic.

## Spartansburg Auction

The 6th annual Spartansburg Auction was held at the fairgrounds in Spartansburg, Pennsylvania on August 10. This western Pennsylvania community holds a yearly auction to benefit DDC Clinic as a number of its families travel to our clinic for their children's care. The interest and turnout for this community auction continues to grow. This year, proceeds from the event totaled \$65,670, nearly double last year's total.

## Gauga Auction

Our most recent auction, the 18th annual Geauga Benefit Auction, was held on October 13 at the John "Buster" Miller farm in Middlefield, Ohio. We had strong attendance for this event which included live and silent auctions, a basket raffle, a full menu of breakfast and lunch offerings and train rides and games for children. Popular auction items included a 24 x 32-foot garage, 16 x 20-foot timber frame pavilion, Amish quilts, antiques, horses and one day's labor from an Amish work crew. The event raised \$170,117 for our clinic.

## Save the Dates

Our 2019 benefit auctions will be held in Shiloh (July 13), Spartansburg (August 9) and Middlefield (October 12).

# Recent Grant Awards

*DDC Clinic is grateful for support from the following friends:*

## Geauga County Commissioners – Community Development Block Grant

For their \$29,100 award towards the paving of our main parking lot.

## United Way Services of Geauga County

For their \$12,500 award in support of the Amish Rare Disease Panel.

## The Hemophilia Team at University Hospitals of Cleveland

For their \$5,600 donation in support of the clinics held at DDC Clinic throughout the summer months.

## CareSource Foundation

For their \$5,000 grant award for Personalized Patient Care for Special Needs Children.

## The Children's Guild of Cleveland

For their \$4,000 award in support of patient assistance programs.

## Youth Fund Distribution Committee of United Way Services of Geauga County

For their \$1,500 award in support of patient assistance programs.

# In Loving Memory

Frann R. Zverina, a dedicated volunteer to our special clinic, passed away October 19, 2018.

Frann joined DDC Clinic's Board in 2010 and served us most generously for seven years, including three as Board President. Frann was passionate and hands-on with all three parts of our mission – patient care, research and education. Whether helping to jumpstart a new research project with an equipment donation, chairing our Patchwork Event, or wielding a shovel to plant donated trees to enhance our landscape, you could count on Frann to both lead and entertain us all.

Following in the Zverina family tradition, Frann shared her time, energy and talents in service to many causes. She was active in a number of other organizations including Heidelberg College, Cleveland Sight Center, American Red Cross and Case Western Reserve University, to name a few. When not volunteering, *Franny* could be found on the golf course, watching "her girls" at Heidelberg play softball, or out on Lake Erie with her dearest friends – chasing the perch and walleye.

Frann was a tremendous volunteer, trustee, donor and dearest friend of DDC Clinic whose greatest joy in serving was interacting with our patient families. Frann's commitment is best summarized by a quote that accompanied the naming of the clinic's medical wing in her honor at April's Patchwork Benefit: *"Dedicated To The Children That Teach Us All, By These Children We Are Blessed."*

Goodbye to our special friend – your generous heart and spirit will be missed.





DDC Clinic – Center for Special Needs Children is a non-profit primary care and research facility serving patients with complex medical needs. Located in Middlefield, Ohio, we have 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 nearly 1,000 patient families in 30 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 70 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.*

# Report to the

## *Dear Friends,*

It is with tremendous gratitude that we reflect upon another year of service to families affected by rare genetic disorders. Since our founding nearly twenty years ago, our commitment to providing transformative medicine for children with complex medical needs remains the hallmark of our center.

The stories we share in this publication reflect the daily work of our clinic, the journeys our patient families take, and the journeys we take with them. The work of our committed staff is only possible through our many volunteers and supporters – people like you.

Over the last year, our research collaborations led to the discovery of nearly two dozen new conditions for formerly undiagnosed patient families. With just 50 steps between our laboratory and patient care rooms, we continue to advance translational medicine, moving these new discoveries to personalized treatments for patients. Our Molecular Diagnostics Laboratory now offers testing for more than 1,000 rare conditions, helping to fulfill our founders' vision that DDC Clinic's work is leveraged to help all the children with special needs around the world.

Through partnerships with regional medical centers, we are able to continue our commitment to serve as a medical home, hosting regular and low cost subspecialty clinics in neurology, hemophilia, dentistry, and immunization programs. More than 2,000 were served by these clinics in the last year alone. Additional community collaborations allow us to provide education and support services including adult day programs, mothers' groups, and family gatherings. It is only with such good partners and friends that we can fulfill our mission.

On behalf of our staff, board and many patient families, we thank everyone who helped spread the word about our services, participated in a benefit auction, collaborated on a special project, or helped to support our clinic in a myriad of other ways. Your help plays a big part in our continued ability to make a difference in special children's lives. Thank you for demonstrating our collective power to provide hope to parents and an improved quality of life for their children.

Blake Andres  
Executive Director

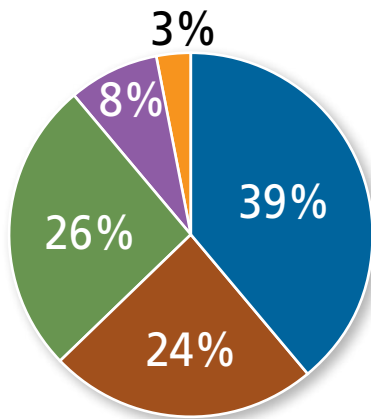
Dr. Heng Wang, MD, PhD  
Medical Director



# Community

## Revenue

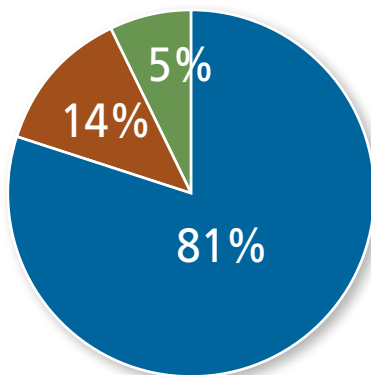
Total Revenue for 2017 – \$1,437,508



■ Contributions	\$ 561,349
■ Benefit Auctions	\$ 348,546
■ Clinical Services	\$ 375,430
■ Research Collaborations	\$ 110,010
■ Miscellaneous Income	\$ 42,173

## Expenses\*

Total Expenses for 2017 – \$1,337,966



■ Program Services	\$1,086,471
■ Fundraising	\$ 181,371
■ Management & General	\$ 70,124

\*Reported less \$97,972 depreciation.

## Statement of Financial Position

### Assets

2017

Cash and Cash Equivalents	\$ 550,053
Accounts Receivable	\$ 67,842
Pledges Receivable	\$ 5,020
Grants Receivable	\$ 184,498
Prepaid Insurance	\$ 30,532
Property and Equipment	\$ 1,674,266
Cash Restricted to Endowment	\$ 396,931
Pledges Receivable	\$ 250,000

### Total Assets

**\$ 3,159,142**

### Liabilities and Net Assets

Accounts Payable	\$ 82,392
Total Liabilities	\$ 82,392
Net Assets	
Unrestricted	\$ 1,995,605
Board Designated	\$ 109,697
Total Unrestricted	\$ 2,105,302
Temporarily Restricted	\$ 437,498
Permanently Restricted	\$ 533,950
Total Net Assets	\$ 3,076,750

**Total Liabilities and Net Assets \$ 3,159,142**

# Thank You to Our 2017 Donors



## **SUSTAINER** (\$25,000 and up)

The Cleveland Foundation  
The Fred A. Lennon Charitable Trust  
Geauga Community Benefit Auction  
Ohio Developmental Disabilities Council  
Mr. & Mrs. Gordon Safran  
Shiloh Mennonite Community Benefit Auction  
Spartansburg Community Benefit Auction  
United Way Services of Geauga County

## **PACESETTER** (\$10,000 - \$24,900)

Anonymous (2)  
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Dr. Susan & Mr. Jack Turben  
Ms. Frann R. Zverina\*

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## Together, We Can Change Children's Lives



*Thanks to you, we can make a difference in the lives of children like Michael who are affected by rare genetic disorders.*

Michael's family is just one of nearly 1,000 families with special needs children that we've helped over the years.

Individually, each condition that our clinic identifies, diagnoses and treats is indeed rare; but collectively, rare genetic disorders are not. One in 10 of us will have a family member affected by a rare genetic disorder sometime during our lives.

Rare genetic disorders are our disorders and working together, we can make a big impact.

Thank you for your continued interest in our work. If you know of a family who is in need of our services, please let them know that we're here to help.