Connor Goes the Distance – Again!

The following is an update on a patient story last shared in 2010.

Please picture in your mind, a young boy in a wheelchair with an ear-to-ear smile despite a steady loss of motor function. This boy’s name is Connor Teare and he grew up just a few miles from our clinic. Though born healthy, Connor began to suffer progressive loss of motor control and muscle weakness as a toddler. Soon no longer able to walk nor fully support his own body weight, he went to elementary school each day in a wheelchair. For years, despite many doctors, many tests and many hospitals, he and his family had no answers – no diagnosis nor treatment for his condition which continued to worsen.

Now flash forward and picture Connor again, not as a five-year-old boy in a wheelchair but 13 years later as a young man, now 18, still smiling and standing confidently next to Dr. Wang!

Just this past spring at our annual Patchwork Benefit, Connor walked from his family’s table to join Dr. Wang at the podium to share his story of healing and his heartfelt future plans. Everybody in the room stood and spontaneously applauded. More than a few tears of joy were shed as Connor made his way to the front of the room and told the hundreds of people in attendance that thanks to the faith and hope of his mom, of DDC Clinic and collaborating doctors, he is now a healthy young man. Connor shared that after high school his plans are to study nursing so that he can someday provide care for others.

Long QT syndrome, at the heart of the matter...

At DDC Clinic Molecular Diagnostics Laboratory, we have discovered many genetic disorders through research involving our Amish patients. For many of these disorders, the discoveries have improved our knowledge of a disease and this knowledge has been very useful to many non-Amish patients. Disorders such as Cohen syndrome, Prolidase deficiency, GGM and GM3 synthase deficiency are seen more frequently in our Ohio Amish population, but our growing expertise is helping affected children around the world.

This process of discovery and sharing of information continues.

Long QT syndrome is a heart rhythm condition cause by a malfunction of the heart’s electrical system. It can be inherited and known as congenital Long QT, or it can be acquired as a result of medication use, or it can be a combination of inherited and acquired. About half of individuals known to have a Long QT gene change will have...
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 more than 800 patient families in 30 U.S. 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 and 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.

Cohen Syndrome Family Gathering

Families from all over the world were represented as they came together to celebrate the lives of people with Cohen Syndrome at the 6th International Cohen Syndrome Meeting.

Awareness of Cohen Syndrome and diagnosis rates continue to increase and this year’s event, held at Highbrook Lodge of the Cleveland Sight Center in Chardon, Ohio, was attended by approximately 100 people from across the United States, Canada, England and Australia, including 38 people with Cohen Syndrome. What a change from the first small gathering held at DDC Clinic in 2004, that was attended primarily by members of the local community.

The event was a perfect opportunity to meet with families and friends and learn from the professionals who came to speak on various subjects relevant to the lives of those with Cohen Syndrome. Camp counselors arranged for activities for the Cohen Syndrome participants each day and Amish caregivers assisted the counselors on Friday and Saturday. Beautiful weather was enjoyed all weekend long!

Presenters at the event in order of appearance were: Lisa McElhinney, President-Cohen Syndrome Association; Blake Andres, Executive Director-DDC Clinic; Patti Gallagher, Business Manager-DDC Clinic; Christine Wensel, Genetic Counselor-DDC Clinic; Meghan Marino DeBenedictis, Genetic Counselor of the Cole Eye Institute of the Cleveland Clinic; Dr. Heng Wang, Medical and Lab Director-DDC Clinic; Dr. Dennis Weiner, Orthopedic Surgeon-Akron Children’s Hospital; Shannon Leslie, Registered Nurse-Akron Children’s Hospital; Sherri Riccardi, study coordinator-University of Colorado; Suzy Harper, parent of a Cohen Syndrome child; Dr. Lawrence Boxer, Pediatric Hematologist-University of Michigan.

The highlight of day two was a presentation by Allen Wargo and his “Best Buddy” Amy Davies of Best Buddies Maryland. Best Buddies International is an organization that creates opportunities for one-to-one friendships, integrated employment and leadership development for people with intellectual and developmental disabilities.

Everyone enjoyed the time together and plans are already underway for a meeting in 2018!

For more information on the Cohen Syndrome Association and Best Buddies International, please visit:
BELIEVE IN MIRACLES, MY FRIENDS….CONNOR IS WALKING….however dim the situation may seem, there is always HOPE. When you least expect it, you could turn the corner in that tunnel of darkness and find yourself at the end…looking at the LIGHT...

Cynthia Teare, Connor’s mother

Connor Goes the Distance – Again! > from page 1

and his family the knowledge and confidence to keep trying. In this case, a drug intended to help Parkinson’s patients provided Connor an almost complete cure. Connor began receiving the medicine and experienced what was described by everyone at the time as a miracle. Within days of starting the medication, after four years completely dependent upon a wheelchair, Connor could feel his muscle strength returning. Within several weeks, he began “furniture-walking” around his home, and on Friday, September 14, 2007, less than three months after beginning treatment, Connor walked through the front door of DDC Clinic, independently, for the first time in his life! As the months and years passed, Connor grew to be able to do all the things his schoolmates enjoyed, including playing basketball and running on his school’s cross-country team.

This newsletter comes to you in the Fall of 2016 and we are happy to share that Connor is now in his first year of college, studying to be a nurse — his way of someday giving back to others facing medical challenges.

The patients and families DDC Clinic has the privilege to serve come from many places and backgrounds. Our founding families always believed that what we would learn together, serving special children in the Amish and Mennonite communities, should and would help all the world’s children. Connor’s story is one of a number of examples of our founders’ vision coming to be.

Many of the disorders our clinic treats are indeed rare, but diagnoses should not be.

Our special clinic has experience with many hundreds of children with many rare conditions.

But in all cases, early diagnoses are key for us to help these children and their families. Many of the conditions are treatable, some highly so. Our doctors, nurses and staff are always working with those we serve to comfort, to support, to heal and sometimes cure.

Please continue to help spread the word about our privileged work. Encourage the hesitant family who has a special child, but no diagnoses, to reach out. Oftentimes we can help provide a long-awaited diagnosis, help limit further disability, improve the quality of life for the children and provide support for their families.

Most important of all, please remember that the work we do together provides hope for tomorrow’s special children.

Recent Publications

Patient-oriented research advances diagnoses and ground-breaking treatments, bringing relief to children and hope to their families. Sharing what we learn in serving children with special needs benefits all the world’s children.

**Cell:** TMCO1 Is an ER Ca²⁺ Load-Activated Ca²⁺ Channel

**Gene Reviews:** Cohen Syndrome

**Clinical Genetics:** Early growth and development impairment in patients with ganglioside GM3 synthase deficiency

**Clinical Genetics:** Novel DNMT3A germline mutations are associated with inherited Tatton-Brown-Rahman syndrome

**Journal of Clinical & Cellular Immunology:** Mutations in ELANE and COH1 (VPS13B) Genes Cause Severe Neutropenia in a Patient with Cohen Syndrome

**Analytica Chimica Acta:** Quantification of monosialogangliosides in human plasma through chemical derivatization for signal enhancement in LCESI-MS

**International Atherosclerosis Society:** SAMHD1 Gene Mutations Are Associated with Cerebral Large-Artery Atherosclerosis

To view the full manuscripts go to www.ddcclinic.org
symptoms, usually at younger ages. Some of these individuals experience symptoms such as fatigue and unexplained or sudden fainting or seizures. For other individuals, the first symptoms of Long QT may be severe and tragic, resulting in SIDS or sudden death of an adolescent or young adult. Long QT was once thought to be an uncommon disorder affecting perhaps 1 in 20,000 individuals. Now, the number of affected individuals is estimated to be up to 10 times higher or 1 in 2000. Improved recognition of the disorder along with confirmation by means of genetic testing led to this increased estimate.

Early diagnosis of Long QT syndrome is important as medical management is possible. There are medications which can be used for treatment as well as medications that should be avoided. There may also be activities which should be avoided by individuals who have Long QT syndrome.

Work done as part of our genetic research program has shown that the frequency of Long QT in the Amish population is at least as high as in the non-Amish population, if not higher. Most patients with Long QT syndrome have a single copy of a disease-causing mutation or variant in one of the Long QT genes. The Long QT gene most common in the Amish population is KCNQ1 known as Long QT syndrome type 1, which is also the most common type of Long QT in the non-Amish population.

Long QT syndrome can also be associated with additional medical problems, such as hearing loss, neurodevelopmental issues and finger or toe abnormalities. Amish children with profound hearing loss and Long QT have a double dose or two copies of the gene change in KCNQ1, one copy inherited from each parent.

There are many types of Long QT syndrome, each associated with a different gene. Three genes including KCNQ1 result in the majority of inherited Long QT, and more than a dozen other genes have also been associated with Long QT. DDC Clinic Molecular Diagnostics Laboratory is using this genetic information to offer genetic testing for Long QT syndrome. We tailor the testing, such that those of Amish ancestry have the option of targeted mutation testing and those not of Amish ancestry have the option of a full panel of genes, or testing specific to a gene change already known in the family. Our goal in offering Long QT testing is to prevent a catastrophic event in gene-positive individuals prior to onset of any symptoms and allow early treatment options.

By Christine Wensel, DDC Clinic’s Genetic Counselor
We’d like to extend our sincere appreciation to those who attended our annual Patchwork Benefit on Saturday, April 16th.

This year’s event was a huge success. Thanks to the generosity of our supporters, we raised $93,000, surpassing our goal. Your enthusiastic support enables us to further our mission of enhancing the quality of life for children with rare genetic disorders.

More than 200 Patchwork guests enjoyed a celebratory evening of food, drinks, music and auctions. The highlight of the evening was a special presentation by DDC Clinic Medical Director, Dr. Heng Wang, who was joined by one of our patients, Connor Teare, who shared his personal story of strength and healing.

Thank you to our many supporters for making it possible for us to continue our work of helping special children in our community and beyond. We look forward to seeing you at our next Patchwork Benefit on April 8, 2017.

We are grateful to the businesses and individuals who supported this year’s Patchwork Benefit.

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**Community Groups**

**DDC CLINIC CRAFT CLUB** continues to meet once a month at DDC Clinic. Started in 2011 with just a handful of ladies, the group has grown to more than twenty women! On the first Wednesday of the month from 9:30am until 2:30pm the ladies get together to work on a variety of projects, including quilts, tie comforters, cards and of course, to visit! All of the projects are donated to fundraising events in the community. One of their beautiful quilts is always a hit at each of the DDC Clinic events every year!

“I encourage other ladies to come and join us. It’s my favorite day of the month!” said Katie D. Miller, who coordinates the monthly gathering.

Bring a lunch with you. DDC Clinic will provide coffee, tea and water. Currently babysitting is not available.

**MOM’S COFFEE BREAK** is a new group meeting on the 2nd Wednesday of each month from 9:30am to 12:00pm. This is an opportunity for mothers of special needs children to get together to visit, share ideas and have a little time to relax! Coffee is provided and ladies are asked to bring a light snack. Babysitting is not available, but you are welcome to bring your preschooler with you!

**MOM’S HEART TO HEART CIRCLE AND FAMILY ACTIVITIES GROUP** meets monthly for a variety of fun activities. From Feelings of the Heart talks, family fun nights, mystery shopping trips and more, this is a great opportunity for families of special needs children in the community to get together!

For more information call DDC Clinic at 440-632-1668.

**Patient Assistance**

Designed to help our patient families, the Patient Assistance Program at DDC Clinic for Special Needs Children helps provide lower or no cost medications, formulas and supplies to children with special needs. The staff at DDC Clinic recognize that by easing the financial burden created by these expenses and reducing the stress to the family, we enhance the quality of life for not only our patients but the families that provide their care.

DDC Clinic started the program in 2008 to help one such family that had five children with seizure disorders. Medications for their special needs children were costing thousands of dollars per year. Our staff was able to identify a program offered through a pharmaceutical company and enroll all five children. This family currently receives all of their seizure medication at no cost!

Our staff manages the program, starting with every office visit. Medications, supplements and supplies are reviewed and, if there is a program available, we begin the application process. Requirements vary from program to program but assistance is generally limited to families that are uninsured or underinsured. Once approved, the patients are added to a database that our staff monitors closely so no important dates for refills or re-enrollments are missed.

As of October 2016, we are serving over 150 children. We estimate that DDC Clinic is able to save the local community 1.5 million dollars!
DDC Clinic participates in The VFC Program

The Vaccines for Children (VFC) Program helps ensure that all children have a better chance of getting their recommended vaccinations on schedule. Vaccines available through the VFC Program are those recommended by the Advisory Committee on Immunization Practices (ACIP). These vaccines protect babies, young children, and adolescents from 16 diseases.

DDC Clinic began offering immunizations to the local community in 2009. The program continues to be a success and we are seeing our numbers increase every year! The number of newborns beginning the immunization process is especially encouraging! In 2015 we provided 1,027 vaccinations to 476 children and through September of 2016 we have already given 883 vaccinations to 372 children.

Immunizations are by appointment only. Please call DDC Clinic at 440-632-1668 to schedule an appointment for your child. Appointments are made between the hours of 9:15am and 4:00pm.

2017 DATES ARE AS FOLLOWS:

January 11th and 25th
February 8th and 22nd
March 8th and 22nd
April 12th and 26th
May 10th and 24th
June 14th and 28th
July 12th and 26th
August 9th and 23rd
September 13th and 27th
October 11th and 25th
November 8th
December 13th

A Child is like a butterfly in the wind.
Some can fly higher than others.
But each one flies the best it can.
Why compare one against the other?
Each one is different.
Each one is special.
Each one is beautiful.

Mobile Dental Unit Provides Services at DDC

The Ronald McDonald Care Mobile (RMCM) is a 42 foot mobile dental unit, equipped with three dental chairs and state-of-the-art dental equipment. The RMCM has the ability to provide routine dental cleanings, exams and x-rays and complete dental treatments, including fillings identified by the dentist during the routine cleaning.

By appointment only at DDC Clinic – Center for Special Needs Children, located at 14567 Madison Road, Middlefield. Treatment is available for children up to 21 years of age. Families interested in receiving dental treatment through the RMCM at DDC Clinic should contact Tina at 216-844-3084 or 216-870-8660 to schedule an appointment.
2016 Community Benefit Auctions

Each year, friends in several Amish and Mennonite communities hold benefit auctions in support of our work with special children. Many hundreds of local community members participate, all in support of our work at DDC Clinic. The Shiloh, Spartansburg and Geauga communities’ commitment to our mission and our families is truly humbling.

**Shiloh Auction**

This was the ninth year that our clinic has shared in the proceeds from the Shiloh Mennonite Community Benefit Auction. A record number of participants attended the July 9th event. This annual auction benefits both DDC Clinic and the Clinic for Special Children in Lancaster, Pennsylvania. This year’s proceeds for DDC Clinic were $38,750 and we are so grateful to this community!

**Spartansburg Auction**

On September 30th, the 4th Annual Spartansburg Auction benefit was held in Crawford County in Western Pennsylvania. A number of families from the region travel to our clinic for their children’s care. Several years ago the community came together and held this benefit to support our mission. In just four years, proceeds from this annual evening benefit have already grown to $37,000!

**Geauga Auction**

Thanks to the generosity of 2,000+ in attendance and the auction committee’s hard work and careful planning, the 16th Annual Geauga Benefit Auction was an unprecedented success! At the end of the night, more than $150,000 was raised for DDC Clinic! We are humbled by the support of so many.

If you’ve never been to one of our traditional Amish auctions, please consider doing so and bring your family and friends!
Total Revenue for 2015 – $1,470,511

- Grants and Research: $483,933
- Benefit Auctions: $271,495
- Clinical Services: $264,703
- Individual Giving: $394,062
- Miscellaneous Income: $56,318

Total Expenses for 2015 – $1,239,926

- Program Services: $1,031,383
- Fundraising: $128,289
- Management & General: $80,254

Statement of Financial Position

**Assets**

- Cash and Cash Equivalents: $539,588
- Accounts Receivable: $88,890
- Pledges Receivable: $108,492
- Grants Receivable: $30,968
- Prepaid Insurance: $21,868
- Property and Equipment: $1,781,643
- Cash restricted to Endowment: $381,388
- Pledges Receivable: $260,000

**Total Assets**: $3,212,837

**Liabilities and Net Assets**

- Accounts payable: $7,028
- Total liabilities: $7,028
- Undesignated: $2,287,223
- Board designated: $107,438
- Total unrestricted: $2,394,661
- Temporarily restricted: $277,198
- Permanently restricted: $533,950

**Total net assets**: $3,205,809

**Total Liabilities and Net Assets**: $3,212,837

*Reported less $92,478 depreciation.*
Thank you to our donors

Donor Recognition report from 1/1/2015 – 12/31/2015

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An evening to celebrate DDC Clinic for Special Needs Children

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Save the Date!

APRIL 8, 2017

Join us at
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