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SPRING / SUMMER 2019

NEW LEAF CENTER CONNECTIONS

CLINIC FOR SPECIAL CHILDREN

5th Annual Fundraiser Held in April

The fifth annual fundraiser for New Leaf Center (NLC) was held on April 30, 2019. Approximately 500 people were offered delicious food, wonderful company, and a chance to hear firsthand the difference NLC has been making in the lives of families. This year, in addition to the program and auction, plans for a new building were unveiled.

After everyone was well fed, board member, Atlee Raber, started off the program with a brief history of the clinic's beginnings. He also acknowledged board members, the bishop advisory committee, and church district contacts. Each of these groups play a significant role for NLC.

Barb Reinford, executive director, introduced staff members, and interviewed two families. David and Rhoda Weaver, who have three children with Glycogen Storage Disease, and Aden and Malinda Yoder, who have two children with MASD, shared their stories. They reiterated the importance of New Leaf Center, and shared their appreciation, not only for the treatment their children have received, but even more so for the love and care that has been shown to them.

Part of the growth of the clinic has been to add a second physician to the staff. Dr. Ethan Scott will be joining the team full-time in July. After being formally introduced, he shared a brief history about himself, his experiences, and his excitement of joining the New Leaf team. "It's humbling to be here," he stated, "to be part of an organization with so much trust and support from the community." Dr. Scott's passion for helping the children and their families was evident, and the staff at NLC is excited to welcome him aboard.

Medical director, Dr. Olivia Wenger, spoke about the center's mission statement: "New Leaf Center strives to improve the quality of life for people with special needs caused by inherited disorders through cost-effective medical care, education, research, and advocacy." She went on to speak about each point more in depth, favoring the idea of advocacy. Being an advocate means giving a voice to those who cannot speak for themselves, and that is important for the children who need diagnosed to receive the proper treatment.

Being a non-profit organization, NLC relies heavily on the generosity of the community and to that end holds an annual fundraiser dinner. These funds are used for capital expenses and Brian Kempf, board treasurer, explained what these funds cover and that operating funds are raised from the Amish churches at a separate time. Board Treasurer, Steve Steiner, put to rest any doubts as to whether a new building is necessary, and gave the statistics of the Building Campaign and what will be needed to make the dream reality. Of the $700,000 needed, $550,000 had already been raised. Both men noted that the initial amount does not include items such as furnishings, paving, technology, or landscaping.

Every person who spoke expressed gratitude to be living and working within a community that is so full of generous people. A community that takes care of their own. A community that reaches out to those in need. A community that understands the importance of selfless giving.

THE HUMAN SPIRIT IS ONE OF ABILITY, PERSEVERANCE, AND COURAGE, THAT NO DISABILITY CAN STEAL AWAY.

NLC Receives Austin-Baily Grant

NLC has received a $13,000 grant from the Austin-Bailey Health and Wellness Foundation. The grant will be used to support the research coordinator position in assisting with research efforts of NLC and Windows of Hope Project researchers, as well as patient assistance programs.

Other grants have been received from Austin-Bailey in past years for assistance with Propionic Acidemia, research, the physician's salary and the purchase of a generator. We are so grateful for their aid in our endeavors.

Austin-Bailey supports programs that promote the physical and mental well-being of the people residing in Holmes, Stark, Tuscarawas, and Wayne counties. The Foundation emphasizes healthcare affordability concerns of the uninsured and underinsured, the poor, children, single parents and the elderly.

The Foundation was established in late 1996 with proceeds from the sale of Doctors Hospital, Inc. of Stark County, Ohio. Since its inception, it has approved over $8,600,000 in grants through 2018.

Dr. Ethan Scott to Join New Leaf Team

Dr. Ethan Scott will begin employment as a pediatrician at NLC on July 1st. Ethan has become a familiar face at NLC over the past couple of years and we warmly welcome him as an official member of the team.

The first 18 months will be spent in a community genetics fellowship. While not an officially recognized fellowship, this time will help Dr. Scott with foundational skills and insight for management of complex patients with developmental delay/epilepsy, growth failure, and inherited disease in the Amish/Mennonites. He will spend time in other genetics clinics, specialty areas at Akron Children's Hospital, as well as begin seeing patients at New Leaf. Ethan grew up in Akron, the oldest of three children. He attended Northeast Ohio Medical University (NEOMED) and did his pediatric residency at Akron Children's Hospital. He will complete his residency the end of June.

Ethan said this about his call to work at New Leaf, "During my first year of training to be a children's doctor, at Akron Children's I started to notice a curious pattern to quite a few patients I was taking care of - it felt like most days I was taking care of an Amish or Mennonite child with special needs. At first these meetings were intimidating - often the child was quite ill, and possibly had a condition I had never previously heard of. But this forced me to really take time and listen to these parents, who knew what their children needed. These meetings challenged me to be a better doctor, they kept me thinking, learning, and most importantly listening. I was inspired by the examples of numerous families who were filled with love, compassion, and complete dedication to their loved ones with special needs. In addition to talking with the families, I started to get calls from Dr. Olivia Wenger when one of her patients was admitted to the hospital. She was the most dedicated primary care physician I had heard of. At the end of my first year of residency I was able to spend a few days at New Leaf learning and seeing patients with Dr. Wenger. The work was challenging, complex, nuanced - it was like no other place I had seen during residency. I was hooked. I wanted to spend as much time as I could at New Leaf. The pull in my heart to work at New Leaf grew. I could tell New Leaf was not only a great place for patients and families, but it was a great place to be a doctor. The staff made me feel so welcomed; right from the beginning they made me feel like family."

Ethan is married to Elizabeth and they are expecting their first child this summer. In his free time, he enjoys taking drives and exploring new areas with his wife, spending time with family, going to church, working out, and reading about medical history.

Rare Genetic Condition Diagnosed

Recently, a family was given a diagnosis for their 19-month old son. Named Foxg1 syndrome, it is a rare (about 300 individuals in the world have this), severe genetic condition. Dr. Wenger initially tested the child for some of the more common disorders we see but the results were all negative.

Drs. Emma Baple and Andrew Crosby from Exeter University, who continue to work with NLC in finding a diagnosis for children whose conditions remain a mystery, were finally able to pinpoint the disorder. The parents were so relieved to know what is wrong with their child, and to learn more about the nature of the condition which does not run in families. While the knowledge of the diagnosis does not correct anything, it does provide great peace of mind and information to know what can be expected.

Emma and Andrew are a vital part of the work at NLC. They work tirelessly to find diagnoses; about 50 percent of the mysteries at NLC have been diagnosed by the researchers.

NLC Launches Building Campaign - *Continue the Mission and Build for the Future*

Since opening its doors in 2013 NLC has become a trusted and respected clinic in the community, specializing in providing medical care to children and families who suffer from genetic diseases. Starting with 30 active patients and now treating over 400 per year, the clinic has seen much growth and development over the last six years. Awareness of what NLC does, and the success in diagnosing difficult cases have both been contributing factors to this growth. Along with the growing number of patients, staff members, and specialty clinics comes the need for more space, as every inch has been utilized in the current basement location.

Seeing the need for additional room, the Board made the inevitable decision that the time had come for NLC to find a way to accommodate the growing numbers. For that purpose, a building committee was formed. They recommended building from the ground up rather than expanding the current structure.

With a great deal of input from the staff, plans for a new facility were drawn up, figures were run and thus began the Capital Building Campaign. A Capital Campaign Committee assisted with making contacts for lead donations. This gave a wonderful head start when announcing the project to the public.

The new facility, with the front facing north, will be located to the east of the current building. The two-story structure will have clinic space on the lower level and a large community room on the upper level. The house and garage on the site are slated to be torn down, and excavation is set to begin late June.

The cost for the building alone will be $700,000, and the goal has nearly been met.

Contact NLC at 330-359-9888, or PO Box 336, Mt. Eaton, OH 44659, or www.newleafclinic.org to support the campaign, or for more information. *Thank you for continuing the mission and building for the future.*

GM3 Synthase Deficiency Receives Special Attention

The disorder, GM3 Synthase Deficiency, received special attention in May. On May 14, nearly 200 doctors, researchers, educators, and families gathered at Amish Door in Wilmot to learn more about GM3 Synthase Deficiency.

Topics included the GM3 natural history survey results, an overview of treatment strategies, home care, and the GM3 experience in Geauga and Holmes counties and Indiana. Two families shared about their children's experiences - one with a liver transplant and the other with a bone marrow transplant.

A science symposium was held the previous afternoon at NLC. The meeting room was packed full with 30 providers and researchers, who shared about their work and conversed together. That evening a special pizza meal was provided for the affected families, providers, and staff.

From responses received, it was clear participants felt positive about the various events and input. Costs for the events were underwritten by the Northwest Genetics Network, a part of MPHI, and the Holmes County Board of Developmental Disabilities. These grants allowed more families and their affected children to attend.

GM3 MEETING, 2019

GM3 Synthase Deficiency is an inherited metabolic disorder that affects mostly the Amish. It is caused by a defect in the gene which makes GM3 synthase, an enzyme which is important for normal brain development.

Affected infants often appear normal at birth but within a few months exhibit irritability, poor feeding, vomiting and general "failure to thrive". Many babies are floppy and lack muscle tone and may develop seizures within the first few months of life. Affected children seldom achieve the usual childhood developmental milestones such as sitting, head holding, walking, and talking and are generally unresponsive to environmental stimuli.

At this point, there is no cure for GM3 Synthase Deficiency. The various symptoms of the disorder may be managed, such as medications for seizures and a feeding tube to assist proper nutrition and ensure adequate hydration and caloric intake. New Leaf Center sees several patients with GM3 Synthase Deficiency.

New Leaf Center

CLINIC FOR SPECIAL CHILDREN

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After Hours Phone: (330)263-8500

My child is NOT a statistic, NOT a number, NOT a diagnosis, but a person with different abilities taking on a difficult world. He proves every day that he is a miracle and that he will never give up. I am his voice and he is my heart. ***– Parent of a special needs child***

Our Mission

New Leaf Center strives to improve quality of life for people with special needs caused by inherited disorders through cost-effective medical care, education, research, and advocacy.

Note for Patients:

Please call New Leaf for medication refills. We do not honor pharmacy refill requests. Please remember that we need 24-hour notice for processing.

Volunteers Needed:

Volunteer Drivers are needed for appointments at Akron Children's Hospital. This entails picking up the family at their home, taking them to the appointment and returning them home. The family pays drivers a small stipend for the service. Call Janice at 330-359-9888 for more information.

Team Members

Barb Reinford
Executive Director
Olivia Wenger, MD
Medical Director
Arie Troyer, LPN
Office Manager
Carole Fry, RN,
Nurse Manager
Angela Zuercher, RN, BSN
Clinic Nurse
Janice Rufener, RN
Office Assistant/Nurse

New Leaf Center is a 501(c)(3) non-profit clinic. We do not receive state or federal grants but depend on the assistance from businesses, churches, hospitals, and friends in the community.