

### CLINIC FOR SPECIAL CHILDREN

#### Reflections on Challenges and Blessings

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Bishop Advisory and Medical  
Advisory Committees also  
provide oversight.

Rolling hills, nurtured by Sugar Creek for countless years, offered their final hymn of autumn color as I drove from Mount Eaton to Legacy Christian School. The muted browns, oranges, and reds were soothing. I was greeted at the school's entrance by one of the special education teachers. After a short tour of special ed classrooms, we settled into a conference room. I was expecting just a few people, but quickly counted fourteen young teachers seated at the table with myself and Christopher and Zachary's parents, Chad and Erica.

Chad and Erica reflected on the challenges and blessings of loving Christopher and Zachary. Children with Brittle Hair syndrome, like children with autism, are easily overwhelmed when relating to other people. They do not understand spoken or written words in the same way many of us do. It is hard for them to recognize emotions. As a parent,

I was filled with admiration for Chad and Erica's desire to accept their boys, while challenging them to reach their full potential. This is a difficult balance to strike in parenting! I was also refreshed by the open attitudes of the teachers and teacher aides in the room. What a challenge it is to manage a child with special needs when 21 other children are also in your classroom! Yet these young people wanted to learn what they could about two special young men. I am grateful for staff and teachers at schools throughout Ohio who care for children and young adults with special needs. From the 18-year-old tending a parochial classroom down a country road to the nurse working at a large, publicly funded training center, people working in education need our encouragement. They spend hours with our children that are often unseen yet can make or break a child's attitude toward learning and growth.

At New Leaf, we are not always busy or productive based on usual measures of healthcare success or economics. We still have days without a single patient scheduled. Does this mean we are doing something wrong? For me, these can be days to do our best work - our deepest reflection on the intangible and unmeasurable parts of life. We write educational materials and programs, follow up with parents, connect with new providers, develop useful research questions, and support systems that loop back to enable the days when we are packed full of patient appointments. I believe that time spent caring or talking to a child is never wasted time. Thankfully, my grandparents, parents, and teachers knew this before I did, and were willing to bear with me until I realized it for myself. I am glad for the opportunity to work at New Leaf in this moment and thank you for your support of all aspects of our work.

-Olivia Wenger, MD



Chad, Erica, Zackary, Christopher, Ariana and Mia Wengerd

Chad and Erica Wengerd of Wilmot had never heard of Brittle Hair Syndrome when they started their family. They have four children, Zackary (9), Christopher (6), Ariana (5), and Mia (18 months). The three oldest share the diagnosis of Brittle Hair Syndrome.

The family was visiting a church and a lady they had never met before came to Erica after the service, and in a very kind way asked if some of their children had Brittle Hair Syndrome. Through that conversation they discovered there was a clinic in Mt. Eaton called New Leaf Center, that could help them by doing a blood test to find out for sure and give them information.

The Wengerds are so thankful for the ability to have had testing done and receive a diagnosis, especially at a clinic so close to home. In Erica's words, "New Leaf provides so much more than we expected. The care and the love they have for their patients is felt with every interaction we have. They provide quality care and a listening ear. Each encounter with New Leaf and Dr. Wenger gives fresh hope and inspiration, with the realization that we are not on this journey alone and have so many wonderful people caring for us and our children."

*\*See page 3 for an explanation of Brittle Hair Syndrome.*

## Catherine Yoder Joins the Team

We welcomed new staff member Catherine Yoder in July. She works part-time at the front desk answering phones, scheduling appointments, answering questions, entering data, and doing many other tasks.

Catherine grew up near Mt. Eaton and has four siblings. She enjoys working with people and has experience as a family helper, selling wholesale and retail, and teaching school. Training her two horses occupies some of her time as well as participating in a drill team. Being with family and friends, volleyball, and visiting coffee shops are just a few things she also likes to do. She is

ready for an adventure any chance she gets!

Speaking Pennsylvania Dutch has been a big asset as Catherine relates to our families, especially the youngest patients, who do not yet speak English. The children are immediately more at ease when Catherine speaks to them. Her ready smile and cheerfulness are uplifting to all of us.



## Disease Specific Brochures Ready to Print

Our physicians and patient services coordinator have been working over the past several months to write disease specific brochures. These contain easy to understand, helpful information about our community's most common inherited disorders. They can be easily printed and distributed and will be shared with other special clinics across the country.

## UPDATES FROM DR. ETHAN SCOTT

### Mental Health Sometimes Not Visible

Over the past several months we have seen an increase in mood issues including depression and anxiety. Mental health concerns are serious and can lead to suffering that is not always visible even to close family members. These concerns can be difficult to discuss and sometimes go untreated for several years. We appreciate how brave some of our new and established patients have been in their

willingness to share their struggles. Several patients have responded well to medication, or counseling, or a combination of both. We encourage all families to reach out to us if your special child or young adult is struggling with mood issues such as depression and anxiety so we can get them feeling better.

### Congenital Hypothyroidism Patients Being Seen

New Leaf started this year to treat patients with Congenital hypothyroidism. So far, we have seen four patients with congenital hypothyroidism, and expect to see more. Congenital hypothyroidism is the disorder when a baby does not produce enough thyroid hormone. This can lead to poor growth and significant developmental delay.

Newborn screening can detect if a baby has low thyroid so that treatment can be started quickly. We expect babies with congenital hypothyroidism to do well and have normal development if they have regular lab work, check-ups every few months, and follow the treatment recommendations.

### Vaccine Study Highlights

We conducted a survey across multiple Amish church affiliations to compare vaccine acceptance to a similar study done ten years ago.

Some of the survey findings are:

- Vaccine acceptance among the Amish has decreased in the last decade. This is similar to trends seen in the general population.
- Parents of special children are more likely to give vaccines than those with only healthy children.
- The Amish are less likely to accept a COVID-19 vaccine than the general population.
- Wives, more often than husbands, said their spouse was the most influential person when deciding about vaccines.

**\*Brittle Hair Syndrome explained (from page 1):**

Brittle Hair Syndrome is an inherited condition that causes brittle hair, short stature, mild learning problems, and anxiety. Children are born with Brittle Hair syndrome and do not outgrow it. There is no cure for Brittle hair syndrome, but symptoms can be managed. Children can benefit from support in school and understanding from their loved ones. Despite learning difficulties, most people are able to work outside the home and get married.

**Subspecialty Clinics Going Strong**

As our patient needs continue to grow, we are always excited when we have the chance to partner with area pediatric hospitals to hold subspecialty clinics at New Leaf Center. Due to restrictions caused by COVID-19 in 2020, several of our spring clinics had to be cancelled and rescheduled. We are very happy that each cancelled clinic was able to be made up over the summer and fall.

We have partnered with providers at Akron Children's Hospital to see our patients at New Leaf Center in Mt. Eaton for Cystic Fibrosis (CF), Propionic Acidemia (PA), Neurology and

Ophthalmology. Cleveland Clinic providers are seeing children at New Leaf with Glycogen Storage Disease (GSD). As of this writing, 119 children have been seen at a subspecialty clinic this year, with several more clinics to go in 2020. These clinics help reduce the number of trips to the larger hospitals and allows our patients to see a sub-specialist in a more familiar environment. We always strive to look at additional needs for clinics and lining up the providers who so generously help us care for our patient population.

-Carole Frye, RN, Nurse Manager

**Flu Shots Are Important**

There has been ongoing concern this year as fall and winter approach, about both Covid-19 and influenza cases impacting the community at the same time. We hope with additional hand washing, social distancing and use of facial coverings, that an increase in cases can be kept to a minimum.

Another step you can take to protect your child from influenza is to have them receive a yearly flu shot. Our doctors

recommend all children 6 months and older receive a flu shot this year. Without being tested, it will be very difficult to distinguish one illness from the other, as most COVID-19 symptoms mimic influenza. New Leaf Center has a good supply of the flu vaccine this year and we are taking appointments for your child to receive one. If you are interested in your child receiving the flu shot, please call our office at 330-359-9888 and ask to schedule a nurse visit.

-Carole Frye, RN, Nurse Manager

**Propionic Acidemia (PA) Paper Published**

The PA paper (Biochemical phenotype and its relationship to treatment in 16 individuals with PCCB c.1606A>G (p.Asn536Asp) variant propionic acidemia) was published in *Molecular Genetics and Metabolism* in September 2020.

It reinforces that our PA patients can have cardiomyopathy and serious neurologic complications. It also gives doctors across the country an idea of what to be thinking about and watching in their PA patients of Amish/Mennonite background.

**Midwife's Meeting to be Held in November**

New Leaf is hosting a midwife's meeting November 20, 2020. This will be the first use of the community room for an educational event.

The newborn assessment and newborn screening will be reviewed. A guest speaker will share how high blood pressure in pregnant Moms can cause growth problems in babies before birth.

Masks will be required, and social distancing will be practiced.

**Volunteer Driver Program Update**

Thank you to the volunteers who faithfully provided transportation for some of our families to Akron Children's Hospital for appointments. Due to COVID-19, we cannot offer the service at this time.

**"Never be afraid to trust an unknown future to a known God." – Corrie Ten Boom**



## CLINIC FOR SPECIAL CHILDREN

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After Hours Phone: (330)263-8500

**When uncertainty keeps you up at night, close your eyes and think of something that is certain – God’s love.**

### Year-End Giving is Needed to Meet Budget

New Leaf Center needs your support! Be sure to read the letter enclosed with this newsletter. We know New Leaf has an impact on those with special needs. Our work is a direct result of the generosity of the community. Service fees are kept low, so care is affordable to the families that come here. However, this covers only about 11% of the operating budget. We rely heavily on the support of churches, businesses, and individuals to provide the rest of the budget. The new building is providing more opportunities to serve and grow. Your giving matters!

**Thanks in advance for your gifts.**

### 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.

### Upcoming Events

The Bishop Advisory Committee/Church Contacts/ Board/Staff Meeting date has not yet been determined. Those involved will be contacted.

**April 20, 2021**

6th Annual Fundraiser Dinner at Heritage Community Center, 3558 US 62, Millersburg, OH 44654.

**Note this is subject to change depending on COVID-19 restrictions at the time.**

### Team Members

Barb Reinford  
*Executive Director*  
Olivia Wenger, MD  
*Medical Director*  
Ethan Scott, MD  
*Pediatrician*  
Carole Fry, RN,  
*Nurse Manager*  
Angela Zuercher, RN, BSN  
*Clinic Nurse*  
Janice Rufener, RN  
*Office Assistant/Nurse*  
Jennifer Hershberger  
*Patient Services Coordinator*  
Valerie Schaffter  
*Office Coord./Bookkeeper*  
Catherine Yoder  
*Office Assistant*

New Leaf Center is a 501(c)(3) non-profit clinic. We depend on the assistance from businesses, churches, hospitals, and friends in the community.