



CLINIC FOR SPECIAL CHILDREN

New Home is Complete

We moved into the new building at the end of May, with the help of many volunteers and the staff. It is truly a blessing to have more space for clinic operations. The large upstairs community room is perfect for meetings. And, we want to have educational events and share this with the community in the future.

Fundraising began in early 2019. The old house on the property was torn down in July 2019 and footers were poured in August. Despite the COVID-19 outbreak, construction steadily continued, and in less than a year, New Leaf has a new home!

The Building Committee comprised of James Troyer, Delbert Yoder, Gid Yoder, Dannie Hostetler, and Uriah Hostetler was involved the entire time. They did a spectacular job of coordinating, offering insights, and helping with construction.

Over 70 businesses and individuals were involved with the construction process. Both labor and materials were contributed.

Without these gifts, the building would have cost several hundred thousand dollars more. We are humbled by the response and so grateful for the support! If we fail to personally thank you, please accept our apologies and know that we are grateful.

We hope to have an open house in late summer or early fall so people can tour the facility. The building was built by the community and we want everyone to see it.

Thanks again to everybody who helped make this project a success!



Board of Directors

Atlee Raber, Berlin

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Bishop Advisory and Medical Advisory Committees also provide oversight.



NURSES STATION



RECEPTION DESK



DR. SCOTT'S OFFICE



EXAM ROOM

Dealing with COVID-19

COVID19 set me squarely down and helped me realize how much I take teachers, co-workers and church support for granted. At New Leaf, we saw half the usual number of patients in person through March, April and May. Some routine visits were handled by phone. As we learned more about the virus, we found plenty to do, prepping for our move next door, and revisiting neglected projects and questions.

New COVID infections are happening at a manageable rate for Ohio hospitals, which has given us confidence to open our new building's doors. We encourage patients to come in person, because nothing is better than hands-on care. We

are smiling underneath our masks, soaking up the chance to work in a space designed with special people in mind.

COVID is a real disease. I respect our state leaders, and leaders in the Amish community who had to grapple with its unexpected entry. As we go forward, it is difficult to balance the need to protect our patients from COVID with the need to protect them from other, very real problems (isolation, anxiety, and lack of access to quality medical care). How can we show support to a mother who has been at home with an autistic preschooler for four months?

As a pediatrician, I encourage each of us to carefully think about the real risks of any germ or virus to our most fragile loved ones. We must reach "faith over fear" with wisdom as a ladder. Could we consider getting the whooping cough vaccine if it kept a single infant out of Intensive Care? Could we consider washing our hands more frequently and limiting the size of our gatherings if it protected Grandma and Grandpa, our special needs individuals, and our respected community leaders?

We will keep "plowing ahead" here in Mount Eaton, at New Leaf Center. We covet your prayers for wisdom as we continue to see patients and families.
- Dr. Olivia Wenger

Cystic Fibrosis Nutrition Education Program

Patients with cystic fibrosis (a serious lung condition) need extra nutrition and calories to grow well and keep their lungs healthy. Over the past year, New Leaf Center has developed a nutritional education program for patients with cystic fibrosis. Families receive education twice per year and receive a weight measuring scales to help keep a close eye on their child's growth at home. Dr. Ethan Scott and Carole Fry, RN, Nurse Manager are leading the project and seeing encouraging results. Many of our cystic fibrosis patients have improved in growth and we have received positive feedback from our families.



Dr. Scott and Carole Fry with nutrition poster

5th Annual Fundraiser Successful Without a Dinner

Across the nation and world, the pandemic caused plans to change. New Leaf Center's Fundraiser Dinner was no exception. The dinner was cancelled but a letter was sent asking for support for Capital Expenses. The response has been

wonderful, and we exceeded our goal for a total of \$164,500! With these funds, we are able pay for paving the driveways and parking lots, landscaping, new signs, and some other miscellaneous items that were not covered in the initial

fundraising for the building. While the monetary goal was reached, we all missed gathering. Sharing food, fellowship, and stories can't be replaced with a letter! We hope to continue the dinner tradition in April of 2021.

Cartilage-hair Hypoplasia and Risk for Severe Combined Immunodeficiency Paper Published

Cartilage-hair Hypoplasia (CHH) is a common type of dwarfism that can be associated with severe combined immunodeficiency (SCID) and lead to serious, life threatening infections. Some people with CHH may need a bone marrow transplant to help their immune system fight off infection. It

is difficult to know which people with CHH are at highest risk for severe infections. Newborn screening in Ohio can now identify babies who may be at increased risk for SCID.

In January 2020, New Leaf Center published a research paper in the

Journal of Clinical Immunology that will help families and doctors know which babies with CHH will be at high risk for SCID. It helps identify which CHH patients would most likely benefit from a bone marrow transplant and which ones need careful monitoring.

Introducing Newest Team Member



We welcome Valerie Schaffter who started employment as Office Coordinator/Bookkeeper in February. She holds an associate degree in Business Management Technology and brings many years of experience in book-keeping and banking/credit unions. She most recently worked at Everence as a member service representative. Valerie jumped right in to help with the building project and spent a lot of time researching and ordering supplies and equipment.

She is married to Mike and they have two adult children. When not

working, Valerie loves spending time with her family. She also enjoys being outdoors taking walks, running, bicycling and throwing ball with her dog. Reading is another favorite pastime.

When asked what she likes about working at New Leaf, she answered, "The people I work with and the patients. I grew up and went to school in the Mt. Eaton area and it felt like coming home when I started at New Leaf. I feel I am contributing something important working for a non-profit."

Study on Amish & Mennonite Opinions on Baby Shots

Baby shots are an important way to prevent serious illness, hospitalizations, and large bills for our patients and families. Dr. Ethan Scott is currently completing a study to understand why some families decide to get baby shots and others do not. We anticipate this study will help us discuss concerns that families have about baby shots and help educate our families on the importance of baby shots. We will share the results with the community when the study is complete.

Several Patients Lost in Twelve Month Period

In the months of May 2019 through May 2020, several of our special people have died. These names are usually shared at the Fundraiser Dinner but that was not possible this year. The special person and their family are listed below. Each one of them was a precious gift from God and we know the families are still grieving the loss of their loved one. New Leaf Center misses them as well.

Whitney Amstutz, parents Aaron & Verna
Anita Burkholder, parents Paul & Ada Mae
Hannah Hershberger, parents Jacob & Rebecca
Maria Hershberger, parents Ezra & Lydia
Hosanna Hostetler, parents Joel & Helena
Sarah Hostetler, parents Joe & Emma
Katie Mast, parents Dennis & Amanda
Connor Raber, parents Mark & Ina
Ivan Slabaugh, parents Jerry & Elsie
Leah Swartzentruber, parents Gideon & Sarah
Sara Rose Troyer, parents Allen & Rosanna
Abigail Weaver, parents Timothy & Louise
Daniel Wengerd, brother and friend to many
Aaron Yoder, parents Melvin & Ella
Clara Yoder, parents Rudy & Lizzie
Mary Beth Yoder, parents Aaron & Linda
Emma Zook, parents Jonas & Mary

Prayer for Comfort

Bring comfort to those coming to terms with the unexpected loss of a loved one. Bring healing to those alive but broken by serious injuries and related trauma. Bring unity to those working for peace and understanding between communities. Bring your warmth to those whose hearts are cold and empty, and bring your blessing on all who in such times are there to share your love.

Newborn Screening Explained



As children's doctors in a clinic specializing in inherited disorders, Dr. Scott and I are often given the responsibility of delivering upsetting results to parents as they hold their newborns. I dread this part of my job. However, new parents who face the future with courage, faith and humility strengthen my resolve.

Listen to the notes of heartbreak and hope from the parents who faced traumatic news about their newborns:

"Newborn screen...you vaguely recall hearing about it at the birth of your first child, but it does not mean a thing to you— until one day you are on the receiving end of a call about an abnormality in your baby's newborn screen. It would have been easy to resent the life-changing message that our tiny two-week old daughter, who was fussy and struggling to gain weight, quite possibly had cystic fibrosis. Yet we were grateful...grateful to be made aware of the issue and to move ahead in dealing with it...grateful to be spared months of searching for answers while our baby suffered. In that way the newborn screen is a benefit. Normal tests are a blessing we no longer take for granted."

- Andrew & Maribeth Miller
(used with permission)

"We as parents would encourage anyone who is unsure about the newborn screen to go ahead with it. Our son was diagnosed with propionic acidemia through the newborn screen. Although it was heartbreaking to receive the news that something is wrong with him, it has been a blessing to us. We feel that with early detection and treatment he has been given a better start than if we would have waited until the symptoms occur to have him diagnosed and treated."

- Parents of children
with propionic acidemia

"To find out our baby has cystic fibrosis through newborn screen was a real shock, although we now see it was to her benefit to be diagnosed at such a young age. We feel newborn screening is

- Paul & Fannie Miller
(used with permission)

Across the nation, disorders are added to the newborn screen each year. This can create uncertainty for parents and doctors who don't deal with rare diseases. I hope the following information will deepen our appreciation for the newborn screen. We will look at what newborn screening is, why it is important, how the tests are chosen, and then answer the question, "What happens if my baby's screen is not normal?"

What is Newborn Screening

Newborn screening can protect your baby's health and potentially save his or her life. Newborn screening attempts to find diseases and conditions that cause serious problems like brain damage, learning problems, lifelong disabilities, and death. The newborn screen used to be called the "PKU test" because it screens for phenylketonuria (PKU), a treatable cause of mental retardation. The doctor who started low cost testing for PKU had a special son, and a niece with delays from PKU. Since 1960, most US states offer low cost PKU screening in combination with a few other treatable diseases.

In 2020, newborn screening has three different parts:

Blood screening uses a few drops of blood from a heel prick to check for a growing number of disorders. The results are most useful if a baby is at least 24 hours old. In Ohio, dried blood is sent on paper to a central Columbus lab run by the Department of Health. About 130,000 babies are born in Ohio each year.

Hearing screening painlessly tests to see if a baby can hear sounds as quiet as their parent's voices. This test is done when a newborn is sleeping and is most accurate before two weeks of age.

Heart screening painlessly checks oxygen levels in a baby's blood. This is best done when the baby is 24 to 48 hours old. The results are available within seconds.

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Why is newborn screen important?

Blood screening finds health problems early. About 1 in every 800 non-Amish babies is born with a disorder that can be discovered by a blood screening test. However, some of these disorders, like cystic fibrosis, propionic acidemia, and severe combined immunodeficiency are more common in plain communities. Babies benefit from treatment right away, even if they first appear healthy. Finding the illness early and treating babies before they show signs of sickness can help prevent serious life-long problems or even death. Babies may have these problems even if their siblings are healthy.

Hearing screening is important because treating hearing loss when a baby is young helps prevent speaking and learning delays. Babies need to understand clear differences between words to learn how to speak. A baby with hearing loss may react to louder sounds without hearing his mother's words.

Heart screening can detect certain types of heart problems in a baby before the baby becomes ill and needs emergency care.

How are disorders chosen for the newborn screen?

Some babies are born with defects that are easy for a parent or midwife to see. The newborn screen checks for diseases that do not change the way a baby looks or acts until it is too late to prevent suffering. The newborn screen does not typically check for diseases unless good treatment is available.

What happens if a baby's screen is not normal?

Some babies will need to have repeat or further tests to confirm results. If your baby does not pass the blood, hearing or heart test, your midwife or doctor will help you with the next steps. It is very stressful for parents to get a call about an abnormal screen. Often, midwives and doctors feel anxious about the news as well.

Because it causes suffering and expense to miss a treatable disease, newborn screening is sometimes *too sensitive*. Sometimes new parents are asked to get more tests only to find out that their baby is healthy. This is very confusing. There is no way to avoid this difficult experience for one family without putting another family at risk of a missed diagnosis. Parents, doctors and nurses who decide which disease to check on newborn screening must balance this risk carefully.

The Ohio Crippled Children's Fund helps with treatment costs for all disorders found on the newborn

screen, but parents often pay for the first set of tests after an abnormal screen. If your baby has one of the disorders on newborn blood screening, there is help. Treatment may include hearing aids and learning to use sign language at home. Babies with heart defects can have surgery or medications to help avoid suffering.

At New Leaf Center, plain people and healthcare personnel work together. If you are concerned about an abnormal newborn screen in your newest family member, give us a call.



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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.

TEAM MEMBERS

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Jennifer Hershberger
Patient Services Coordinator
Valerie Schaffter
Office Coord./Bookkeeper

THANK YOU TO VOLUNTEERS!

Volunteers and team member, Valerie Schaffter, prepared the annual Amish church mailing in June. Packets were mailed to the district contacts (31 couples) who distribute them to the Bishops in their group. Each Bishop receives a letter, response card, and handouts with information about New Leaf for every family. The churches' support provides a large portion of the operating budget for a year. We are so grateful for volunteers who help in many different ways!



Maggie Wenger, Valerie Schaffter, Nigel Wenger, Elam Wenger, Lauren Hershberger, and Lyric Wenger