

CLINIC FOR SPECIAL CHILDREN

Isabelle's Family Story

Isabelle Kaufman has endured more in her short life than most of us will ever experience even if we live a very long time. At New Leaf, the staff has been inspired by Isabelle and her family and we asked if they would share their story. While it is a story of disappointment, frustration and sadness, it is also one of commitment, hope, and faith. It is their desire that sharing this will be an encouragement to other families.

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Advisory Committees also
provide oversight.

Isabelle's mom, Laura, wrote, "Our precious daughter was born January 25, 2016. She was transferred to Aultman NICU with breathing problems which resolved overnight but she was kept for 16 days with feeding difficulties. During that time, they found a heart problem.

They referred us to Dr. Wenger at New Leaf Center as they suspected a genetic disorder. It was heart-breaking to hear this, but I knew no matter what we would always take the very best care of her. The summer of 2016 was difficult as we faced the fact that Isabelle was not growing and developing like babies normally do. But the doctors could not give us answers. When she was seven months old she got very sick and was admitted to Cleveland Clinic. They decided to insert a feeding tube so she could grow. Her lungs collapsed, and she went to the PICU on a ventilator, but they were able to put the g-tube in the next day.

The next eight weeks were spent trying to take out the breathing tube, but she failed four times. The doctors were puzzled and couldn't find the problem. We could hardly bear to see her go through so much distress over and over and we begged for a tracheostomy. They finally put one in, but it was scary to think about taking her home. However, the Lord tells us not to be afraid and promises never to leave us, so we had peace instead of fear.

We transferred care to Akron Children's for Isabelle's rehab and the training we needed to take her home. Right away they told us her lungs were ruined from aspirating and that's why she needed the ventilator. Thankfully, we were told that lung tissue can regenerate up to seven years old.

After 99 days of hospital life we brought her home by ambulance and had nurses from Akron along with two family members to help care for her at night. As a mom, I had to 'let go' a little bit and let others care for Isabelle. I could do that knowing there was no way we could do it alone. There was the scary possibility of the trach plugging or coming out and being sure we would

do as we were trained. My prayer at home has always been, 'Dear Jesus, please help whoever is with Isabelle in the event of an emergency, guide their hands and help them.' That prayer has been answered many times.

Isabelle was weaned from the ventilator over the next 10 months. We were told she could get rid of the trach by spring of this year. But instead we were met with the very disappointing news that she has a lot of scar tissue in her airway and would need reconstruction before the trach could come out. This is major surgery. She had three balloon dilating procedures done as an outpatient before the reconstruction in August 2018. It was wonderful – no more trach! About three weeks later we took her home with hearts full of gratitude. It was awesome; there were no home nurses, no suction machine wherever she was, and we could all sleep in the same bedroom!

But a week later she was back in the hospital with respiratory distress and the doctors were again puzzled. We went through the agony of her coding five times before we decided to put a trach in again. We wanted answers, so transferred her to Cincinnati Children's. They said she is aspirating her saliva and secretions which inflames her lungs. She will likely need another airway reconstruction. This was disheartening to hear but we finally know why she can't do without the trach.



After 66 days in the hospital we are very grateful to have our sweet little Isabelle at home again to care for, and for our Lord's protecting hand over her. She has a trach and feeding tube and is on the ventilator most of the time. As of now, she is doing quite well. Kaitlyn, age 6, is Isabelle's big sister and has adjusted well to her sister's needs. She has been with us through the joyful times and has cried with us as we prayed, after Isabelle had another rough day. Isabelle adores her sister and always brightens up when she is in the room. It is hardest for Kaitlyn when Isabelle has a hospital stay and she has to stay home to go to school.



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Isabelle continued. . .

It is impossible to adequately thank family, friends, our church, and the community for all they have invested in us - prayers, visits, paying bills, tending to things at home, etc. We are especially blessed to have my two sisters and a neighbor lady to take care of Isabelle at night, which eliminates the need for nurses in our home. We are not sure what the future holds for Isabelle. Our 'normal' life is not the same as we anticipated, but we are in this together as a family."

--- Ernest, Laura, Kaitlyn, and Isabelle Kaufman

Ernest and Laura are totally dedicated to Isabelle but sometimes you can see the tiredness in their eyes. At New Leaf, we know how exhausting it can be to care daily for children with special needs. Ernest and Laura say there is no way they could travel this journey alone.

We are grateful for how Isabelle's family faces uncertainty with courage. Drs. Wenger, Baple and Crosby will continue to work on finding a diagnosis for Isabelle. In the meantime, Dr. Wenger and the staff will advocate for and encourage the family the best we can.

"The Lord will give strength to His people; the Lord will bless His people with peace." Psalm 29:11

Introducing New Nurse Manager



Welcome Carole Fry, who started at New Leaf Center in early July as nurse manager. She earned her R.N. degree from Cuyahoga Community College. Prior to becoming a nurse, she worked for many years in the business office of a manufacturing company. For a long time she wanted to become a nurse and so went back to school. Her most recent nursing position was

"home" to me. I love being able to spend time getting to know each child and their family and being able to help them through their healthcare journey. These special children have so much to teach me and I humbly welcome each new learning experience they bring. I have truly been blessed with the opportunity to come to New Leaf Center as the Nurse Manager and hope to provide nursing care to these children for many years to come!"

Carole is married and has two grown children. In her spare time, she loves to garden, spin and weave wool, do 18th century reenactments, and play the fiddle, mandolin, and dulcimer.

with LifeCare Hospice as a registered nurse case manager.

Carole said, "Since my start at New Leaf Center, I have been so warmly welcomed, not only by staff, but also by our patients and families, making this truly feel like

We are so pleased that Carole has joined the team here at New Leaf as she brings excellent experience in home nursing and loves pediatrics.

Important Notices

- If paying bills by mail, please note the patient's name on the check.
- When mailing a church donation, please note the district number on the check.
- When requesting medication refills, please allow a 24-hour notice from call in time, for all refills to be sent to your pharmacy.

Holiday Hours

Christmas Eve and Christmas Day:
CLOSED
New Year's Day:
CLOSED

Flu Vaccine is Especially Important for Children

Influenza (the flu) is an infection of the nose, throat, and lungs caused by influenza viruses. Each year, millions of children get sick with seasonal flu; thousands of children are hospitalized; and some children die from the flu. Flu is more dangerous than the common cold for children.

Flu illness can vary from mild to severe. The flu can be especially dangerous for young children and children of any age who have certain long-term health conditions, including asthma, neurological and neurodevelopmental conditions, chronic lung disease, heart disease, blood disorders, endocrine disorders (such as diabetes), kidney, liver, and metabolic disorders, and weakened immune systems due to disease or medication.

Symptoms of the flu can include fever, cough, sore throat, runny or stuffy nose, body aches, headache, chills, fatigue and sometimes vomiting and diarrhea (more common in children than adults). Some people with the flu will not have a fever.

To protect against the flu, the first and most important thing you can do is to get a flu vaccine for yourself and your child. Vaccination is recommended for everyone 6 months and older. It's especially important that young children and children with long term health conditions get vaccinated.

New Leaf Center offers the flu vaccine for children. Please ask about it.

From Dr. Wenger



One of my favorite moments after a specialty clinic day is the quiet, dark time after 5:30 p.m. I walk down the hall to get my

lunch bag, or one last cookie in the conference room. During the day, the place is bustling. Angela peers out from the medication room to clarify an order. Parents check out at the counter and chat with Janice. A pulmonologist “gowns up” to enter the room of a cystic fibrosis patient. Then, the space gradually quiets. I am alone with my thoughts and more than one neglected task. I think of six years ago, when we didn’t have a place for specialty doctors and parents to meet close to home. In those moments, I am proud and grateful.

Moments like that also lead to the “What’s next for New Leaf?” questions. Children with disorders of brain development or facial bone growth usually need help with their eye sight at some point in their lives. When Dr. Richard Hertle, a pediatric ophthalmologist (children’s eye doctor), approached me about visiting New Leaf, we were

pleased! He and his partners, based at Akron Children’s Hospital, see children with many kinds of vision problems. We will be hosting our first “eye sight clinic” at New Leaf in March 2019. I’ve asked Dr. Hertle a few questions about his job, and his hopes for visiting our clinic.

1. How is pediatric ophthalmology different from optometry?

- Ophthalmologists are Medical Doctors trained in the diagnosis and treatments of diseases of the visual system with medicine and surgery. Optometrists are non-medical Doctors of Optometry who are trained in the evaluation of the visual system and non-surgical treatment of eye disorders with glasses/contact lenses, and basic medicines.

2. What is the earliest an eye doctor can do something to help a baby see better?

- We treat the patients as young as 16 weeks premature and as old as 90 years of age for congenital and childhood eye problems that remain into adulthood.

3. When is it too late to improve vision with glasses?

- It is never too late to treat, although the visual system becomes less responsive to treatment after a child turns ten years old. However, when a baby is born with cataracts or glaucoma, they need to be treated within the first 12 weeks of life to prevent blindness.

4. When do eye doctors worry most that a baby will have a vision problem?

- Premature birth, genetic or syndromic disorders (like Down syndrome), and some medications make it more likely that a baby will have vision problems. Babies whose close family members had childhood eye diseases are also more likely to need help from an eye doctor.

5. What do you hope to provide for our community’s children and families?

- We hope to provide a way for families to more easily access specialty vision care and consultation, so that only people needing more complex eye treatments will be required to travel to a larger hospital.

6. What else would you like to share with parents of children with special needs?

- Evaluation and treatment of the visual system is often a low priority in children who have many medical problems. However, early and continuously guided treatment of disorders of vision in infancy and childhood will insure the lifelong gift of vision.

Dr. Hertle’s first clinic at New Leaf Center will be in March 2019. If you are interested in scheduling an appointment with him, call New Leaf Center (330-359-9888). You do not need to be a current patient at New Leaf to see Dr. Hertle.

From the Executive Director



I struggled for days about what to write for this newsletter. Then this morning it came to me, or rather something happened to me. I was on

my way to work on a busy two-lane highway and hit a pipe in the middle of the road on a steep hill. I was unable to move my vehicle and had gotten out and was standing beside it. Very soon a co-worker, who was traveling the same

way to work stopped ahead of my car to see if I was okay. As she walked toward me, her vehicle started to coast backwards on the hill. I called to her and she ran but it was gaining momentum on the steep hill and rolled into my car. When the state trooper finally came, he was kind and gracious in every way. The tow service driver was very helpful and concerned for our safety. He told me how fortunate we were that there wasn’t snow and ice on the roads. Both of our vehicles suffered damage, but no one was cited and neither of us was injured. We both are so grateful as we

realize things could have turned out very differently!

So, you might wonder what this has to do with the newsletter. Well, my mishap reminds me of several things. Accidents happen despite our best intentions. Injured vehicles are not the same as injured people. There are kind people everywhere. And not having my car for several week is a very small inconvenient matter compared to what families with special needs children go through every day!

- Barb

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After Hours Phone: (330)263-8500

Year-End Giving is Appreciated

New Leaf needs YOU! Be sure to read the letter that was enclosed with this newsletter. We know New Leaf has an impact on those with special needs. This is the 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. Your giving matters! ***Thank you 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

Tuesday, January 29, 2019 -
Bishop Advisory Committee, Contacts,
Board & Staff at James and Mandy Troyer's
home, 2703 TR 190, Baltic, OH. Notices
will be sent to those involved.

Tuesday, April 30, 2019 -
5th Annual Fundraiser Dinner at
Heritage Community Center, 3558 US 62
Millersburg, OH 44654

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
Becky Miller, RN
Research Coordinator