



From Olivia Wenger, MD

We are happy to share our Summer 2015 news with you. In January 2015, I shared goals for New Leaf with our board, staff, and bishop

advisory council. After our meetings, I posted those goals on the wall of my office, just over the phone. When I am overwhelmed by the many tasks before me, the Clinic goals ground my work. The last six months have gone quickly enough. However, it is refreshing to stop and survey the progress we've made in the care of children with special needs.

One of the most difficult parts of caring for children with complex diseases is *choosing which one to fight first*. As a general pediatrician, I can care well enough for an earache, a cough, or constipation. However, as the physician at New Leaf, I see children with diseases that beg for attention. Who will find the cure for GM3 synthase deficiency, or Yoder dystonia? Who will organize the care of propionic acidemia? After working at New Leaf fulltime for two and a half years, I know there are diseases I need to leave for others to figure out. However, I want to be wise in choosing the ones that *could* improve with a little attention.

This year, we decided to focus on propionic acidemia (PA). PA is a problem with how the body uses protein to make energy. All children need protein from meat, eggs, and dairy in their diet. However, children with propionic acidemia cannot use basic protein building blocks in the proper way. Over years, during stressful times such as stomach flus or fasting, propionic acidemia damages the heart and brain. New Leaf cares for about 20 children and adults with propionic acidemia. There are many more people with the disease in the plain community. Drs. Kevin Strauss and Holmes Morton from the Clinic for Special Children in Lancaster both came to visit the NLC this spring. They work with diseases like propionic acidemia in the Pennsylvania Amish and Mennonites. I've asked them both to help us find the best way to care for this disease. Heart doctors from Akron Childrens and Cleveland have also agreed to help. We distribute the recommended supplements for propionic acidemia care

from our clinic. Martha Horst has gathered great information to help Moms cook low protein meals. Our nurses work hard to send blood and urine samples to labs. Parents worry with me in emergency rooms over seizures and fevers. This year, we will move from worry to thoughtful action.

The second goal on our list was shoring up our relationship with Akron Childrens Cystic Fibrosis Center. Like propionic acidemia, we follow about 20 children with cystic fibrosis. Unlike propionic acidemia, however, cystic fibrosis (CF) is well studied. Fifty years ago, children with CF might expect to live a few years. Today, children with CF can grow into young adults, have jobs and marry! This kind of fulfilling, productive life is only possible for people with CF when parents, doctors and nurses are willing to work together. I am proud of the special relationship we have cultivated with Akron Childrens CF doctors and nurses. It is really quite unique. We are a small staff operating out of a Mount Eaton basement, yet the National CF Foundation approves of our work. We see children with CF from the newborn period into young adulthood. In a CF baby's first year, frequent visits are needed. After that, our expectation is that families with CF will visit New Leaf and Akron Childrens every three months at alternate sites. This saves time, energy and money for parents. It also ensures that children are getting the best care possible. Over the past six months, we've streamlined communication to solidify our connection with CF specialists. Last week, we installed a donated telemedicine unit, a fancy phone with a video camera that will help parents talk to CF specialists who cannot travel to Mount Eaton.

I will close with a personal story. As I alluded to early, one difficult part of New Leaf's work is caring for children with diseases we will never cure. The tiny son of Adam and Lizzie Hershberger, Daniel, embodied that principle the most for me so far this year. Daniel was born with Microcephalic Osteodysplastic Primordial Dwarfism, or M.O.P.D. M.O.P.D. is very similar to Seckel syndrome. Several families in our community understand this disease. These children are only a few pounds when they are born. It is rare for them to live more than a year or two. Daniel was Adam and Lizzie's

first baby. However, Lizzie was not new to caring for children with special needs. She lost siblings to M.O.P.D as a young girl. Adam contacted us soon after Daniel was born. Despite all their hopes, they knew Daniel might not be with them long. Adam and Lizzie were clear that one of the main reasons they wanted my involvement was to avoid trouble with Childrens Services.

Those of you who know me well know that I have a competitive streak. I confess that one of my main reasons for responding to Adam and Lizzie's call was to prove that a doctor might be able to help them with more than just avoiding Childrens Services. I was immediately impressed by the two of them. They were younger than Matthew and I were when we married, yet they were already immersed in the care of their special baby. Lizzie tended to Daniel's every need for four months. Daniel was generally happy and responsive, but developed fevers and fussiness that brought Adam and Lizzie to the doors of a children's hospital. It quickly became apparent that little Daniel had developed a stroke. He didn't have long to live. After difficult phone conversations and consultations with their family, Adam and Lizzie took their four month old son home to die. The following three evenings were precious. Matthew cared for our children while I went to Adam and Lizzie's to wait by Daniel's crib. Poets describe death as a trip to unknown shores. Anyone who has watched a child die sees a terrible mystery unfold. Daniel passed quietly, without much of a struggle, surrounded by his family and friends. I cherish the conversations we had over his crib, and how Adam and Lizzie and their parents welcomed me into their home. This is the best kind of parent-doctor relationship--when doctors and parents stop avoiding each other to embrace over the bed of an ailing child. Later, Kathy and I visited the house. Lizzie took us to see where Daniel was buried. Even the pebbles in the soil over his tiny grave were chosen carefully. A few weeks later, we received a handwritten copy of the story of Daniel's life. The stories I gather from my work don't always end perfectly, but thanks to parents like Adam and Lizzie, they end well.

NEWS

Website: The website is up and running. Visit www.newleafclinic.org. Thank you to Matthew Wenger and Cassel Bear Graphic Design for all of your time and effort to make this a professional and meaningful website for NLC.

Hiring of 2nd Doctor and Executive Director

We are still in need of qualified applications for the Executive Director position. The position description for the 2nd doctor is in the process of being published.

2015 Winter/Spring 'HIGHLIGHTS'

Annual Fundraiser Dinner

The First Annual Fundraiser meal and auction was held at the Mt. Hope Auction on April 9th to both raise awareness for New Leaf Center, as well as to start raising funds for an electronic medical records system. We are happy to announce that we raised \$45,785 that night! Thank you to everyone who attended and to those who donated toward this project. We really appreciate it.

The food was provided by local churches working together to provide a low key evening of touching topics by Dr. D. Holmes Morton and Dr. Olivia Wenger. The statement that is worth remembering: "These Special Children help us all become better people". Auction items were: a quilt, an inlaid checker board table with 2 stools, and a wall plaque. Featured this year were families affected by cystic fibrosis and propionic acidemia.

Brian Kempf, Atlee Raber & Martha Horst

Subspecialty Clinics

Every two months we have Specialists come to New Leaf Center, who focus on an area of special need for our children. This year we had the following Specialists and Focus Clinics: Dr. Morton, Propionic Acidemia, Dr. McBride, neuro-developmental disorders, Dr. Weiner, Cartilage Hair Hypoplasia, and Dr. Baple, undiagnosed special needs.

Usually our little waiting room is busy with siblings of the children who have appointments, but on 'focus days' parents often meet each other in the waiting room. Here are some of the interactions that I get to hear (names are not the real names of patients). Linda gets very anxious in the doctor's office, especially when she has to wait. After pacing for a while she decided to rest on the floor by the door. Mom was apologetic and ready to move her but the dad of another patient said, "Let her rest, we can step over her". They exchanged other words of understanding and care. Another day I heard the mom of Sara, obviously handicapped, ask Harvey's mom, "What is wrong with your child he looks like a healthy 2 year old." Mom replied, 'he has Propionic Acidemia and recently started having seizures.' Sara's mother explained what was wrong with her little one and added, "but she is a blessing to us".

I like to see cultural barriers broken down and parents reaching out to each other with a spirit of care and understanding. They KNOW what it is like to love a child that will always need them and they know what it is like to try everything to make these children's lives as good as possible. Arie Troyer LPN, Office Manager.

Amish Inherited Disease Conference

On April 25 we hosted our first educational seminar on Amish inherited disease, entitled "Practical Approaches to Amish Inherited Disease." The event was held at the Pier, in Mt. Eaton, and was done in collaboration with, and funded by, Windows of Hope. The day was full of presentations about various genetic disorders, in which speakers provided us with a wealth of information about these conditions and how to approach them, often with the use of case studies. These case studies helped us to relate the disease with a patient, which in turn helped us to understand how to put all this information into practice. Topics discussed included neurodevelopmental disorders such as Brittle Hair Syndrome, GM3 Synthase deficiency, and Cockayne Syndrome; orthopedic-related disorders, such as Cartilage Hair Hypoplasia (Dwarfism); Cardiac disorders such as Hypertrophic Cardiomyopathy and long QT syndrome; and Spastic Paraplegias such as Troyer and Mast syndromes. Presenters included Dr. Emma Baple from England, Dr. Kevin Strauss from the Clinic for Special Children in Lancaster, PA, Dr. Zahka, a pediatric cardiologist, Dr. Weiner an orthopedist, Dr. McBride, a pediatric neurologist, and others. Dr. Olivia Wenger did a great job of facilitating the discussion and adding her own expertise as well.

There is a lot still to learn about the inherited diseases discussed during this education day and a lot of research is still being done so that we can continue to find ways to help children who are suffering from these conditions. One major theme that came from the day was that we should never say "there's nothing to be done". Whether or not there's a cure for a disease, there's always something we can do to support the child and the family in their situation.

It was encouraging to have such a great representation of doctors and staff who were either presenting or in attendance at the conference. It is our hope that together we can use the knowledge gained from this seminar to benefit the special children that we aim to serve. By the end of the day we each experienced feelings of fullness. Our heads had been filled to overflowing with information, our stomachs had been filled time and again with amazing food, and most importantly, our hearts were filled with compassion and a desire to do what we can to help these special children who are suffering in different ways.

Thank you to Windows of Hope who obtained a grant to sponsor this marvelous education day.

Angela Zuercher RN.

Kathy's Corner

Dental Awareness Program

Good dental hygiene is an important factor when striving for overall good health. New Leaf is conducting a dental campaign in 2015 to raise awareness in our families of the need for daily oral care and regular visits to the dentist. We recently received a grant from the Austin Bailey Foundation that provided funding to allow New Leaf staff to share a new toothbrush and toothpaste with each of our patients as well as educational handouts with proper tooth brushing techniques. New Leaf staff also compiled a list of dentists in the area where patients can go to receive pediatric dental care.



Hope:

- My hope is in you Lord. Psalm 39:7
- What gives me the most hope every day is God's grace; knowing that his grace is going to give me the strength for whatever I face, knowing that nothing is a surprise to God. Rick Warren
- Hope is being able to see that there is light despite all of the darkness. Desmond Tutu
- Hope is patience with the lamp lit. Tertullian
- Hope is like the sun, which, as we journey toward it, cast the shadow of our burden behind us. Samuel Smiles

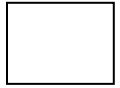
Financial Statement

During 2015 we have received donations of about \$16,000 through the end of May. We are so grateful for the generosity of our supporters, and could not do this without you. Please continue to consider us in your giving throughout the year as we rely on donations to keep our fees affordable for the families that we are here to serve. Brian Kempf

Board of Directors:

Stephen Steiner, Chair, Dalton
Scott Brace, Secretary, Chagrin Falls
Brian Kempf, Treasurer, Apple Creek
Dr. Dan Miller, Walnut Creek
Jason Miller, Vice Chair, Millersburg
Atlee Raber, Public Relations, Berlin
Dannie Troyer, Parent, Fredericksburg
James Troyer, Parent, Baltic

New Leaf Center is also under the direction of a Bishop Advisory Board.



“We aim to eliminate the useless suffering of children. History shows us that the suffering of children can deepen faith and broaden a community’s capacity to love. This is useful suffering. However, history also gives many examples of children who suffer uselessly. Useless suffering is destructive--creating deep, painful scars. When do our children suffer uselessly? Our children suffer uselessly when their parents and doctors cannot compromise. Our children suffer uselessly when the adults entrusted with their care act out of ignorance and pride instead of conscientious humility. Suffering children are not given the choice of whether their pain and loneliness will be useful. That choice rests only in the hands of the adults around them.” Olivia Wenger MD

Mission Statement

To provide medical care to Anabaptist children with inherited disorders through:

- 1. Access to population-specific diagnostic evaluation.**
- 2. Access to consultation for urgent medical issues (call coverage).**
- 3. Family-centered guidance regarding treatment options.**
- 4. Participatory research that focuses on immediate needs.**
- 5. Facilitation of productive discussion across cultures, disciplines, specialties and institutions about the needs of special children.**
- 6. Development of long-term sustainability through networking, fundraising, and recruitment.**

NLC is a non-profit 501(c) (3) tax exempt organization and a registered charitable organization in Ohio. Tax deductible receipts will be given for all contributions.

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