

CLINIC FOR SPECIAL CHILDREN

New Leaf Center & Windows of Hope Merge

Board of Directors:

Atlee Raber, Berlin

Brian Kempf, Apple Creek

Dan Miller, MD, Walnut Creek

Dannie Troyer, Fredericksburg

James Troyer, Baltic

Jason Miller, Millersburg

Myron Troyer, Sugarcreek

Shannon Stutzman, Dundee

Stephen Steiner, Dalton

Titus Dutcher, MD, Sugarcreek

Bishop Advisory and Medical
Advisory Committees also
provide oversight.

Some things just go together. Peanut butter and jelly. Hugs and Kisses. Milk and cookies. And now, New Leaf Center (NLC) and Windows of Hope Genetic Information Center (WHGIC).

NLC's mission statement reads as follows: "Our mission is to provide medical care to Anabaptist children with inherited disorders." The mission statement for WHGIC was: "Windows of Hope Genetic Information Center shall provide information and resources for families and professionals to aid in the diagnosis, treatment and care of individuals with inherited disorders." With two mission statements that are so similar, it's almost as if these two non-profit organizations were meant to join forces.

Serious discussions of a possible merger between the two centers began early in 2017. Board members from both organizations were given the opportunity and time to process what such an alliance would look like. With representatives from both boards, a committee was formed to work out the details. Effective October 1st, 2017, the WHGIC board voted to dissolve their standing as a non-profit organization and transfer all their assets to NLC, who in turn, voted in agreement of this decision.

Windows of Hope Genetics Information Center began as an extension of the Windows of Hope Project (WoH) out of Exeter, England. The idea of establishing a genetic study in Holmes County first came to Dr. Andrew Crosby when he ran across genetic research that had been accumulated by Dr. Har-

old Cross in the 1960s. Being of an Amish background, Dr. Cross became interested in genetics research as a student at Johns Hopkins University when several of his cousins were diagnosed with a rare genetic disorder. That seed of interest led him to seek out a genetics professor who helped him with a research project focusing on genetic diseases within Holmes County. He completed a thesis named "Genetic Studies in the Amish".

Several decades later, while studying genetic diseases within several British families, Dr. Crosby discovered the research by Dr. Cross and found similarities of those diseases in Holmes County. Through a series of events the two gentlemen came together and in January of 2000, Windows of Hope officially began.

In 2009, wanting to provide a place where people could ask questions, and gain a better understanding of genetic health conditions, WHGIC was established in Walnut Creek, Ohio. As an extension of the original research project, WHGIC helped families through education, testing and research. Though some of these disorders were not curable, WHGIC also helped families find physicians, health clinics, and individuals who would be helpful in understanding and dealing with the diseases. Windows of Hope, since its inception, has defined and published the genetic basis of 13 new inherited conditions that are present in the surrounding communities.

Research is such an important piece of the puzzle for diagnos-

ing certain conditions. Dr. Wenger states that families have often expressed the feeling that their children were "guinea pigs" for doctors and hospitals who were simply looking to learn about a disease and didn't truly know how to help their condition. "I'm hopeful New Leaf's absorption of WHGIC will ground the questions we face as a community. I'm hopeful that research, as a merged entity, will provide us with insight into how best to identify children with inherited disorders before they are admitted to the hospital, instead of after they have been there for a week. I'm hopeful that research will help us find a few affordable, useful treatments for a few disorders in time. Even when a treatment cannot be found, research gives parents and doctors the assurance that everything has been done that should be done."

Since NLC opened its doors in 2013, Dr. Wenger has regularly collaborated with Dr. Andrew Crosby, a Molecular Geneticist, and Dr. Emma Baple, a Clinical Geneticist, both from Windows of Hope. They will continue to offer their assistance with diagnostic testing, especially the more difficult cases. By merging their expertise, the doctors have been able to give 50% of their patients a diagnosis. Both doctors share the vision of the NLC team, stating, "The merger is the logical consequence of the ever-closer working relationship that developed between our groups. We are convinced that the best way to achieve this vision is to bring together clinical care with research. Clinical needs direct research questions, and research provides answers that improves clinical care."



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This and That

New Staff Member Joins New Leaf Center



We are so pleased to welcome Becky Miller, RN, as our newest staff member. Becky started her full-time position as Research Coordinator in early November. She has been a nurse for 10 years and most recently worked in a local doctor's office.

Becky was attracted to New Leaf because she wanted to work with the Plain community and more specifically with special children.

She resides in Sugarcreek, and in her spare time, she loves to be outdoors, biking, hiking, and reading.

As Research Coordinator, Becky will provide support to administrative staff and patients through a variety of patient care management and educational efforts. The position includes coordination of research efforts related to community genetics, therapeutic trials, and newborn screening.

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.**

Excerpts from CDC
Kathy Troyer, RN, Nurse Manager

Year-End Giving is Appreciated

WE NEED YOU! Please be sure to read the letter that was enclosed with this newsletter. Especially important are the three, real-life stories of how New Leaf impacts special children and their families. This impact is a direct result of the generosity of the community. Fees for services are kept low so care is affordable to the families we touch, but this only covers about 15% of the operating budget. We rely heavily on the support of churches, businesses, and individuals to provide the rest of what is needed. Your giving matters! Thank you in advance for your gifts.

Notice to Parents Regarding Medication Refills



We have switched to electronic medication ordering. This process takes us a bit more time. Due to this, we are requesting 24 hours notice for medication refills.

We appreciate your understanding and apologize for the inconvenience.

Kindness can transform someone's dark moment with a blaze of light. You'll never know how much your caring matters. Make a difference for another today.

From Dr. Wenger

Our recent merge with Windows of Hope Genetics Information Center (WHGIC) deserves front page in this newsletter. The WoH board, staff and physicians have worked hard to teach doctors (like me) about the importance of research and education. When I cannot diagnose a child, but suspect they may have an inherited disorder, I lean on the experience and passion of Drs. Emma Baple and Andrew Crosby. Over the past four years, we have seen 75 patients together. Half of those patients received a diagnosis. We hope to meet many more families together.

Barb never sings her own praises, but she has worked hard over the past several months, in the background, to make our merger a success. This leads me to mention, in follow up to our last

newsletter, the other services New Leaf provides in addition to seeing patients for medical needs.

First, we often serve as advisors to families faced with massive hospital bills. Barb, again without making a fuss about it, meets regularly with parents struggling to navigate the complex billing process that follows an extended hospital stay.

Second, we host educational events for various disorders. Our most recent family day was for cystic fibrosis. Parents and doctors shared a meal, enjoying a safe place to chat about priorities for children with CF. Our nurses spend extra time connecting newly diagnosed families to other families with the same diagnosis. They write many letters per week, following up on test

results and delivering updates.

In addition to specific disorders, we endeavor to be a safe place for midwives to bring their questions. In September, we hosted a midwives meeting in our newly remodeled conference room. Nine midwives attended along with staff from the Ohio department of Health and local birthing centers. We talked about common diseases seen in our community's newborns. Together, we made plans to improve accuracy of newborn screening results. We look forward to these meetings, feeling inspired by the day's end.

When we are not seeing patients, we are working to raise awareness of the common disorders in our community. As New Leaf's Medical Director, I am often asked to speak to



special needs teachers, outside hospitals, and institutions such as hospice about how best to diagnose and care for special children. I sit on Ohio's newborn screening committee as a representative of the plain people. Finally, I attend our Amish Medical Ethics Committee with Akron Children's and various Amish leaders. This group of highly motivated men (with one admiring Lady Doctor) stands ready to help parents and doctors who are feeling frustrated with shared decisions around a child's healthcare.

From the Executive Director



We continue to grow! Assuming the assets and functions of Windows of Hope is yet another way we are stretching.

It takes effort to bring together two organizations, and the journey is just beginning. However, we are all committed to this work. When we can give parents a diagnosis for their child, it is because

many people have been involved in an often-complex process of evaluation and testing. The collaborative efforts only enhance the work we both do.

Part of our continued commitment to research is the hiring of Becky Miller as Research Coordinator. She will assist Dr. Wenger, Dr. Baple, and Dr. Crosby. Becky

will certainly be an asset to New Leaf and the community.

We are also pleased to welcome Dr. Titus Dutcher, Myron Troyer, and Shannon Stutzman to the board. These three served on the previous WHGIC board and we look forward to the contributions the new board members will bring.

- Barb

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When families are faced with unknown conditions, it is often a scary feeling, not knowing what to expect or how to help their loved one. The NLC team shares the vision and commitment of ensuring that the power of medical research is used to

improve the lives of special children and their families. Often, simple and more cost effective genetic tests can be done *before* undergoing expensive and sometimes painful tests. Both organizations were founded with the purpose of trying

to alleviate suffering of those affected with inherited genetic disorders. There is no denying that, separately, both have made an impact on the surrounding communities. Now imagine what we can do as one.

NEW LEAF CENTER



CLINIC FOR SPECIAL CHILDREN

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*It was only a little smile,
and little it cost in the giving,
but like morning light it scattered the night
and made the day worth living.
— F. Scott Fitzgerald*



OUR MISSION

Our mission is to provide medical care to Anabaptist children with inherited disorders.

The four elements of our care:

- cost effective
- culturally appropriate
- cutting edge
- locally accessible

UPCOMING EVENTS

Bishop Advisory Committee & Church
Contacts Meeting :

**Thursday
January 25, 2017**

6:30 p.m.

Information will be mailed to all involved.

TEAM MEMBERS

Barb Reinford
Executive Director
Olivia Wenger, MD
Medical Director
Arie Troyer, LPN
Office Manager
Kathy Troyer, RN, BSN
Nurse Manager
Angela Zuercher, RN, BSN
Clinic Nurse
Janice Rufener, RN
Office Assistant/Nurse
Becky Miller, RN
Research Coordinator

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.