

NEW LEAF CLINIC

UNRELENTING LOVE TO CHILDREN WITH SPECIAL NEEDS

It had been six months and Olivia Wenger had not heard a thing. Not one word. Shouldn't they have contacted her by now? She couldn't move forward without their support. At the meeting, she'd presented a compelling case, and she'd had backing from key folks who agreed this was not only a good idea, but a necessity.

"So why aren't they talking to you?" the Akron doctors asked.

She didn't have a good response except the one Scott Brace, superintendent of the Holmes County Training Center, had offered. "They're going to take their time deciding," he said, "but once they've decided, they'll be in full support."

And now, six months had passed, and no decision had been made.

And then one day, she received a call from Atlee Raber.

Olivia Wenger can't point to a specific day where she had some lightning-bolt experience, some "aha" moment or deep revelation telling her she'd be doing the work she does today. Instead, it came about the same way she purposes to live her life--day by day and one step at a time.

The first step began with her mother, Linda Stoltzfus.

"I saw how smart my mom was," Wenger says, "and how hard she worked to manage our house. She had five kids--I was the oldest--and she encouraged all of us, girls and boys, to do our best at school, told us we could be anything we wanted to be."

Wenger's mother loved to read and shuttled them to the Public Library for Union County in Lewisburg, Pa., every week, where young Olivia borrowed adventure stories and the Laura Ingalls Wilder series.

"My mom had a big influence on teaching me that it was okay to be a girl and to enjoy learning."

Unlike other children in her church community, Wenger attended public school, garnered a diverse group of friends, and developed a further love of learning and a goal of attending college. She considered nursing and midwifery, but what she really wanted was to become a doctor. Wenger discussed

her thoughts with her childhood physician who also happened to be her uncle, Elam Stoltzfus, a general pediatrician in Lewisburg, Pa.

"He's a compassionate, caring person," Wenger says. "I talked to him about my dreams, and he was encouraging, never dismissive of the idea of a woman being a doctor."

Dr. Stoltzfus told her that, to become a physician, she'd have to take pre-med. She enrolled at Sharon Mennonite Bible School in Western, Pa. for a short time where she met Matthew Wenger, who would eventually become her husband, the person she now credits with being a quiet support and keeping her faith going. She then attended college in Mid-

"Children of all abilities are a gift from God."

~ Dr. Olivia Wenger



Olivia Wenger, MD (left) and Kathy Troyer, RN (right) proudly standing in front of the New Leaf Center.

dletown, PA., majoring in biology and minoring in English. *“When it came time to apply for medical school, I decided to go ahead, and, step by step, I was accepted to schools in Hershey, Pa., and New York City.”*

She chose New York for the opportunity to live in a different kind of environment.

On graduation day, the commencement speaker was Holmes Morton, a doctor specializing in genetic disorders affecting Old Order Amish and Mennonite children, and founder of the Clinic for Special Children in Strasburg, Pa. Morton spoke of finding a patient you carry with you, one who drives what you do every day.

After graduation, Wenger married, and the couple welcomed their first child. They left the city and moved closer to her husband’s family in Ohio. Wenger pursued pediatrics, taking a residency at Akron Children’s Hospital (ACH). It was her first exposure to the Holmes County Anabaptist community. Until then, she’d thought Lancaster County held the highest concentration of Amish.

During her residency, Dr. J.R. Bockoven, MD, Associate Clinical Director of the Heart Center of Cleveland and Director of Outreach Education in Cardiology at ACH, took Wenger on a tour of the DDC Clinic in Middlefield, Ohio, a non-profit 501©(3) primary care and research facility serving people with special needs caused by genetic disorders.

“It was a very cool concept,” Wenger says. *“They were bringing high-tech solutions to a population-specific local setting.”*

It sparked Wenger’s interest, but, at the time, there wasn’t a community ready to organize around her as a physician, and it was time to make career and location decisions. Wenger and her husband pow-wowed over dinner at Matsos Family Restaurant in Wooster, Ohio, to determine their next move.

“We each wrote where we would like to go, then shared the papers with each other.”

Both Wenger and her husband had scribbled the same thing: Pennsylvania. So Wenger went into general practice with her uncle and, while the two years spent there were good, it was too fast-paced for Wenger--seeing too many patients in a day, and too briefly. She decided general pediatrics wasn’t

for her, that she wanted something more specific, with a more personal connection. She thought of Dr. Morton and wrote to him, saying, *“I remember your talk about meaningful work as a physician, and I was wondering if you could help me sort through this first year of practice.”* It took a while, but she received a reply inviting her to a conference focusing on diseases common in the Anabaptist population.

“Top researchers from their field were there with parents of affected children,” Wenger remembers. *“It was a down-to-earth meeting where, instead of lofty science, information was connected to real patient problems.”*

Dr. Morton invited Wenger to spend one day a week for a year at the Clinic for Special Children where Morton, his wife, and partner Kevin Strauss work together to bring quality care to local families. It was a great marriage of genetics, public health, and pediatrics, and it germinated an idea in Wenger’s mind.

At the end of that year, Wenger didn’t renew her contract in Lewisburg. She returned to Akron Children’s Hospital to serve as general pediatrician and found that ACH wanted to help the Amish community with its special needs, but didn’t know how to go about it. Wenger and her mentors proposed that the hospital support a

clinic in Holmes County, Ohio, where 19,000 of the area’s 40,000 residents are Amish and experience genetic disorders such like cystic fibrosis, Down syndrome, blue eye delay syndrome and more. These disorders often require special treatment, intense therapy, and costly medication. Issues of transportation and lack of commercial health insurance presents challenges for Anabaptist families seeking care from places like ACH. By now, Wenger had witnessed functional models of clinics that were resolving some of those issues, bridging the gap between Amish families whose children need care and medical facilities that provided that care.

Wenger approached her supervisors at ACH with a question: if there would there be one open door--just one--would they support a clinic in Holmes County? In response, ACH granted Wenger one day a week away from her practice to investigate, pursue the possibilities, and convince the powers-that-be that such a clinic was not only possible but beneficial to all parties.

Story cont. on page 10 >>

"I had an office out of my house, and some days I did nothing but send emails to make network connections, to convince the hospital to support a clinic, that it was in their best interest economically. The physicians needed to know that, although they might not be seeing them because of cultural issues, there are diseases in this community that are common and need better attention."

Wenger sent feelers out in the Holmes County community to see who, if anyone, would be interested in getting such a clinic off the ground. She found Scott Brace from the Holmes County Training Center; a group called Windows of Hope out of Walnut Creek; Dr. Elton Lehman, who was retired but active in the medical community; Dr. DJ McFadden from the Department of Health. They held a meeting with Amish families at the Holmes County Training Center outlining the mission for a non-profit, community-supported clinic for special children and asked for their support.

And then she waited.

For six months, Wenger heard nothing. Not a word. And then one day, her cell phone rang. It was Atlee Raber, who Wenger describes as a mover and shaker in the Amish community.

"Atlee works with the best interest of the church and community in mind," Wenger says. "He has a lot of compassion for kids with special needs, though he doesn't have children himself. He knows a good idea when he sees it." He has a passion for bringing progress without compromising their intention. He does what makes sense."

Raber knew about the proposal for a clinic in Holmes County. He knew about Dr. Morton's clinic, because of friends in Lancaster, Pa. who benefited from Dr. Morton's clinic. Raber understood that the Anabaptist population encounters unique, inherited diseases that require a specialist who is familiar with those diseases. He also knew that couples with special children were becoming frustrated and incurring mounting medical expenses due to extensive and sometimes superfluous testing by medical professionals who didn't have knowledge of the community's genetic disorders.

"Someone like Dr. Morton or Dr. Wenger, just by the nature of the child and their genetic background, can make a diagnosis and avoid frustrations for the couples and costly tests. They can go into the home and see how it's functioning, see what the dietary plan is. All of those little details make a big difference for the children."

To Raber, what made sense in this community with genetic isolates was to have a local doctor who focuses on genetic disorders, but during a meeting for the Ohio Crippled Children's Fund where he serves as board member, Raber heard

that the proposed Holmes County Clinic wasn't moving forward.

"Maybe it was because the community didn't fully understand how beneficial a clinic could be. Maybe they thought taking their children to facilities in bigger cities was their best option. Or maybe," Raber says, "the timing hadn't been quite right."

So he posed the question: Why isn't this clinic happening?

"I told them this would be a clinic like Dr. Morton has, and they said, 'Who is Dr. Morton?' I realized I had a contact and connection that the others didn't have."

That's when Raber decided he needed to get on the phone with Dr. Wenger and make something happen. The fact that Raber doesn't have children with special needs--in fact, he doesn't have children at all--didn't matter.

"Regardless of whether they were our children or someone else's children, this was our responsibility," Raber says.

So, six months after that initial meeting, Atlee Raber made the phone call to Wenger. *"We need to make this happen,"* he

Story cont. on page 13 >>



Justina Rohr, RN (left) with Kate and Kristen (twins) Troyer and mother, MaryEtta Troyer (right).

told her. *“We have a doctor, and now we need to build a clinic around her.”*

Raber remembers the long silence on the other end of the line. He wondered if maybe Wenger had moved on, if she was no longer interested in serving a clinic. But then he heard her say, *“I can’t believe it. I can’t believe it.”*

Raber organized a steering committee and searched for several months for the right leadership. They found Steve Steiner, a local businessman who knew how to set up the corporation, find personnel, and organize a structure of the right people around Olivia.” The steering committee turned into a board. The board negotiated with Akron Children’s Hospital who endorsed the clinic, allowing Wenger to transition to a full-time position in Mt. Eaton. They also agreed to underwrite half of her salary. The balance would come from the Amish community she would serve, to whom the clinic would belong.

And so, in January 2013, New Leaf Center, a clinic for special children, became a reality. Supporters sprang into motion. Financial backing came from ACH, Amish families, generous sponsors, and board members, resulting in the complete coverage of the entire first year’s operating expenses. A space was secured--a vacant dental clinic in the basement of a Mt.



Kathy Troyer, RN (left) and Martha Horst, RN (right). Two of the nurses that are on staff at the New Leaf Center.

Eaton building owned by Dr. Elton Lehman, who donated the first year’s rent. Board members and volunteers swept in and transformed the dingy, dark basement into a bright, child-friendly clinic. Colorful mobiles, inspiring quotes, and calming artwork found homes in each examination room. A staff was hired, including two nurses, Martha Horst and Kathy Troyer. Wenger and Troyer wrote and received grants for things like generator backup to keep vaccines refrigerated during power outages, necessary office and exam equipment, and more. Troyer worked with patient assistance programs and negotiated with pharmaceutical companies to receive free and discounted medications, like enzyme replacement therapy necessary for treatment of children with cystic fibrosis--therapy that would otherwise cost self-pay families thousands of dollars per month. Aside from simply providing excellent care to children with special needs due to inherited disorders, New Leaf’s goal is to decrease healthcare costs for those already shouldering a significant burden. New Leaf’s printed brochure states: *“We will always work to keep our fees affordable for self-pay families. We do not want cost to be a barrier to visiting us.”* No child, regardless of ability to pay, will be turned away.

Martha Horst is a retired nursing instructor from Malone University and a nurse at New Leaf. She says their primary goal is to alleviate some of the stress and anxiety associated with caring for a child with special needs.

“Couples get married and hope to have children who can walk, run, jump, play, and learn like every other child,” Horst says. *“What do they do when their child can’t do those things? We’re here for them, to help them find the resources they need, or to assist them in whatever way possible.”*

Horst gives the example of one child in an Amish family diagnosed with cystic fibrosis at a year old. The visit to the local hospital left the family with a huge bill. Wanting to be financially responsible, they chose not to return until the bill was paid off; in the meantime, the child went without treatment. New Leaf was able to intervene, and the child is now receiving necessary care.

Another way New Leaf is working with families is by seeking solutions through research for genetic syndromes like GM3 synthase deficiency, a severe infantile-onset epilepsy associated with developmental delay and blindness. It can be identified through genetic testing, and when treated during infancy, seizures can be stopped, but there’s currently no cure. New Leaf is working with researchers to uncover one.

“We need to find out what will cross over the brain’s special barrier to deliver the missing enzymes,” Horst says. *“There are researchers at National Institutes of Health in Baltimore, MD,*

Story cont. on page 14 >>

and the Clinic for Special Children who are doing research to find solutions.”

Wenger says the most pressing goal, in her mind, is prevention.

“We need to stop mopping up floods and start turning off faucets,” Wenger says. “A doctor can manage crisis situations, or they can work with communities to discover what is causing the crisis in the first place and prevent it from happening.”

To help parents, medical professionals, and researchers connect, New Leaf invites specialists to luncheons where they share what’s available for specific genetic conditions and what research is being done.

New Leaf Center now sees 150 patients. Those patients travel from 17 surrounding counties, stretching from Marion to Jefferson, Medina to Muskingum. Just last week, multiple families from Hardin County spent an entire Tuesday at the clinic, each receiving the standard hour-and-a-half initial consultation. Families are finding support for more than 22 conditions, things like glycogen storage disease, Amish brittle hair syndrome, Down syndrome, and Mennonite microcephaly. They’ve established a 10-member advisory board of

HERE’S WHAT FAMILIES HAVE TO SAY ABOUT THE NLC

“Two years ago our son, Jared was born with a chromosome disorder. We made numerous trips first to the pediatrician, then usually on to the hospital. Now we have the opportunity (close to home) to receive professional care for Jared in a warm and friendly atmosphere at the New Leaf Center. What a Blessing!”

~ David & Betty Hochstetler

“The opening of New Leaf Center (NLC) was the best thing that could have happened. Dr. Wenger was the first person to discover that our five week old daughter, Mari Ann had liver problems. She was there to help us all along the way for Mari Ann to be diagnosed with biliary atresia and set up for a liver transplant at seven months of age. Local doctors and emergency centers are often afraid to treat Mari Ann because of her complicated medical history. Dr. Wenger treats her locally when possible. We love the homey and friendly atmosphere at NLC. People like Dr. Wenger are few and far between. We are fortunate to have NLC close by.”

~ Reuben & Naomi Raber & children

“The staff at New Leaf took the time and effort to understand and patiently work with our daughter in a way that we have never experienced before. We were amazed at how well she responded to the staff. We highly recommend Olivia and the New Leaf Clinic to anyone with special needs children as we know they will be treated with the utmost respect and highest care.”

~ Marlin & Lisa Miller

“A caring, kind, and compassionate atmosphere can be found at the New Leaf Clinic. We can call in at any time and Dr. Wenger will answer our questions. It is so different from what we were used to. Usually we had to call and talk to an answering service, then a nurse would call back and often we had to go to Akron to see the doctor again. We really appreciate the effort and compassion. It feels like family and they really care. Our son is not just another patient to see. Dr. Wenger and staff have chosen a high calling and May God Bless Them.”

~ From a family whose child has a rare genetic disorder

“The past year has been somewhat of a nightmare for our family having two of our children diagnosed with a genetic metabolic disorder. Between doctor visits, dietitians, tests, and medications it all seemed like a never ending circle, and it was very confusing and tiring. Finding the New Leaf Center (NLC) was one of the huge blessings of the year! We have found Dr. Wenger and the staff at the NLC all to be very knowledgeable, helpful, and concerned with a true desire to help the special children of our community. Right in our home community at that! They have really made things a lot easier for us all. We would very highly recommend New Leaf Center to anyone who has children with special needs. For my God shall supply all your need according to His riches in glory by Christ Jesus. Philippians 4:19”

~ Steve & Sue Weaver

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Olivia Wenger (left) providing her nursing services to Kristen Troyer and her mother, MaryEtta Tryer (right).

Amish bishops as a liaison between the clinic's eight-member board and the Amish community to ensure effective communication.

New Leaf is also moving toward more effective communication with key healthcare providers. They're currently seeking funding to transition from paper to electronic charting, with a price tag of around \$10,000, that would expedite communi-

cation of important information to other doctors and health care facilities for enhancement of better patient care, especially during emergency situations.

The clinic needs funding, too, for respiratory vests and airway clearance systems for patients with cystic fibrosis. Those vests can be refurbished and reused by multiple patients, but cost around \$4,000 per vest and machine.

It's all in an effort to fulfill New Leaf's mission of providing cost effective, culturally appropriate, cutting edge clinical care to Anabaptist children with inherited disorders throughout the Holmes and Wayne county areas.

"We want to provide a good standard of care locally for a good price," says Dr. Wenger. "To make it happen is a challenge. It takes a lot of thinking on your feet."

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Story cont. on page 16 >>

Atlee Raber says, during the year the clinic has been in operation, it has made a major difference for the special children and their families.

“New Leaf Center is highly used and respected and has saved the community money,” Raber says. “And we have our own doctor. Really, she’s more than a doctor. She’s a medical caregiver. Her passion goes beyond the normal doctor, because she focuses on quality, not quantity. We don’t have to guess about hospital procedures and whether they should be done. We can fully trust her, because she is part of our community. She is part of us.”

For more information or to offer support, contact New Leaf Center, Clinic for Special Children toll-free at 1-888-559-5323 or by writing to PO Box 336, Mt. Eaton, Ohio 44659.

Denice Rovira Hazlett is a writer and library reference associate living in Charm, Ohio. Her feature articles have been published in national and local publications including the Bargain Hunter, The Budget, Farming Magazine, and Library Journal. She loves good stories--both hearing and telling them--and can be reached at write2denice@gmail.com.

CONDITIONS AND AREA OF SERVICE

Proposed area of service:

Wayne
Holmes
Ashland
Coschocton
Stark
Tuscarawas
Harrison
Knox
Guernsey
Muskingum
Richland



Crawford
Morrow
Marian
Medina
Carroll
Licking
Jefferson

New Leaf is currently seeing children with the following conditions:

- Amish Brittle Hair Syndrome
- Chromosomal Deletion Syndromes
- Cobalamin-C Deficiency
- Cockayne Syndrome
- Congenital Infantile Osteopetrosis
- Cornelia DeLang Syndrome
- Cystic Fibrosis
- Downs Syndrome/Trisomy 21
- Familial Absence Seizures
- Glycogen Storage Disease Type 1a
- GM3 Synthase Deficiency
- Hereditary Fructose Intolerance
- HERC2/ Blue Eye Delay Syndrome
- M.A.S.D. (Macrocephaly, Anxiety, Seizure, Developmental Delay)
- Mennonite Microcephaly
- M.O.P.D. (Microcephalic Osteodysplastic Primordial Dwarfism)
- Nephrocerbellar Syndrome
- Osteopetrosis
- Propionic Acidemia
- SAMS Association (Aicardi Goutieres)
- Trisomy 21
- Unknown causes of developmental delay/cerebral palsy/epilepsy

Other genetic conditions will also be considered for treatment at New Leaf.

NEW LEAF CENTER
CLINIC FOR SPECIAL CHILDREN

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