

Just Plain Values

Saving Lives, Learning Love: the DDC Clinic for Special Children



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By Denice Rovira Hazlett

“It was a very emotional experience,” JoAnn Leach-Brace says, her voice calm and steady. “You had the feeling there was something different about what we were doing.”

Neither she, her husband Don, nor any of the families who were first involved had the background necessary to pull this kind of thing together. They had no idea what they were getting into.

And there were trials. Big ones, she says. The kind that would throw even the most stalwart person off course.

“But every time we hit an obstacle,” Leach-Brace says, “an angel would appear. Someone would show up on our doorstep to solve the problem. We knew we were being guided. We were just instruments in making this happen. We believed that if it was meant to be it would happen. We knew it was not about us.”

Leach-Brace currently performs contract work with Amish schools part-time, providing assessments for placement. She also works with Amish special needs schools, helping to provide therapists and training teachers for special needs schools. But it was when she served as supervisor for the Early Intervention Center at Metzenbaum, the Geauga County Board of Developmental Disabilities (from which she recently retired), that the journey for the DDC Clinic Center for Special Needs Children began.

It was the early 1990's, and Leach-Brace had been working with several Amish families whose children had presented some troubling symptoms. These children had begun their development from birth fairly typically. But somewhere along the line, they developed severe complications. Seizures. Convulsions. Loss of consciousness. And, as they grew, their development became severely delayed, and they began to exhibit signs of significant brain damage. The families sought answers from several

major medical centers and were working closely with doctors but grew increasingly frustrated because there were no conclusive answers. There were two families in particular whose children all suffered from the same symptoms. Each week, a group of therapists would meet in one of the families' homes to work with the children, and the parents would express their frustrations with not finding answers.

During one of these meetings in November of 1998, a mother presented an article she'd come across in Reader's Digest and read it aloud. It was about a doctor in Lancaster, Pennsylvania, Dr. Holmes Morton, and included descriptions of situations experienced by Amish families there, situations very similar to what the families in Geauga County were experiencing. The article described Dr. Morton's clinic and how, because of low overhead, he was able to offer lower-cost screening tests specific to Anabaptist communities. Instead of spending 15 minutes with his patients, he would spend hours. And, even more importantly, he was able to provide answers.

The Geauga County families showed the article to some of their doctors who encouraged them to visit Dr. Morton's clinic. Leach-Brace picked up the phone to make the necessary arrangements. But when she spoke with Dr. Morton, he dealt her some disheartening news.

"You're too far away," he said. "I'm afraid I can't help."

When Leach-Brace conveyed the message to the parents, they weren't dissuaded.

"They were pretty insistent," Leach-Brace says. "They told me to call back and tell him they just wanted to visit."

Leach-Brace and her husband Don, along with four Amish families whose children had disabilities, traveled to Lancaster. When they arrived, they immediately knew this clinic was unlike any medical facility they'd encountered up until then. The clinic is a timber-frame structure crafted from donated materials and topped with a slate roof that had been salvaged from a 140-year-old barn. The building sits on a cornfield-bordered section of donated land. There are hitching posts in the parking lot.

Immediately, the families felt like this was more of a home than a clinic as they were greeted in German by Rebecca, an Amish receptionist, by Dr. Morton himself and his wife, Caroline. Dr. Morton pulled up a chair and spoke to the families. As soon as he saw the children, he closed his clinic for two days and dedicated that time to the

Geauga County families, bringing in specialists from Johns Hopkins and learning all he could about the children's symptoms.

At the end of those two days, he gathered the group into the waiting room and told them that, when they had arrived, he had hoped they would provide a few tidbits of information. Instead, because of their cooperation, he had come away with an entire meal.

“There's an answer for what you're dealing with,” he told them, “but it's going to take a lot of effort. A lot of work. And I'm too far away from you, so you're going to have to go back to your own community and find someone who can help you.”

It was later discovered that the children of two of those families had GM3 synthase deficiency, also known as Amish infantile epilepsy syndrome. GM3 synthase deficiency usually presents itself within the first few weeks after birth with symptoms of excessive fussiness, difficulty feeding, vomiting, and loss of weight. Within the first year, the baby begins to have seizures that worsen and are usually resistant to traditional anti-seizure medications. Brain development is disrupted, inhibiting intelligence and motor skills. Arms jerk and flail uncontrollably. Eyesight and hearing diminish. Sometimes, skin becomes discolored. And, because GM3 synthase deficiency is rare and affects mostly Old Order Amish families, with only around 50 cases being reported, it's incredibly difficult for traditional hospitals and physicians to diagnose. With these early families, diagnosis was particularly difficult because the disease was not yet known. Even now, without access to appropriate care, which, in the words of Dr. Morton, is geographically, economically, and culturally difficult among the Amish community, many children with these and similar treatable metabolic disorders become disabled or die.

During the eight-hour return trip from Dr. Morton's clinic, the families discussed what they would do next. That trip set the wheels in motion for the birth of Das Deutsch Center for Special Needs Children. A steering committee would be formed, half Amish and half English. More children with genetic disabilities of several types would be found. The community's Amish church bishops would be consulted. A mission statement would be created:

“Das Deutsch Center for Special Needs Children provides care to children who have complex medical needs, which may be

due to inherited, metabolic or genetic disorders. The clinic is open to all special needs children but will focus on the Amish community.”

JoAnn and Don Leach would be intrinsic parts of the process. Don Leach would become so impassioned for the cause that he would say to his wife during the ride home, “This is bigger than we are.” He would then serve as the center’s first president of the board. Amishman Bill Fisher would pass his hat to collect \$50 in seed money for stamps and envelopes. More seed money would come from the Amish community and the Cleveland Foundation. The local hospital and other organizations would offer their support. Little did that core group know the great strides—and the great struggles—they would encounter during the coming year.



One of the greatest struggles would first present itself during a meeting with Dr. Morton in one of the Amish homes in July of 1999 when Don Leach had to excuse himself to take a nap due to a terrible headache. It was just prior to a steering committee meeting that Leach experienced a seizure. His wife drove him to the hospital, but Leach insisted the meeting continue, so the group met at the hospital with

Leach joining the meeting in progress after his emergency room visit. The following week, Leach had yet another seizure, and this time was hospitalized and subsequently diagnosed with a brain tumor. Dr. Morton spoke to JoAnn Leach, telling her that it was going to be difficult to carry on with the center through this, but that she had to press on and help make it happen. The community rallied around the Leaches, and it meant the world to them both.

“Just before he passed in July of 2000,” JoAnn Leach remembers, “people came to our house on Sundays to sing for us. I would look down the driveway, and they were there with their lunches, sitting and singing German hymns in English so we could understand.” School children would come and sing. Neighbors would come and sing. And when Don Leach died, those same people came to his services and sang. Bill Fisher, whose hat had been passed to collect the center’s seed money, performed Don Leach’s eulogy. And after the services when JoAnn returned to her home, a whole community awaited her with a meal they had prepared.

“I really felt embraced,” she said. “The whole community had their arms wrapped around us.”

By then, the center had formed a 501c3 nonprofit status, had established a vision, and was conceived as a gathering place “—a place of love, compassion and caring where children and family are respected; a place where people take the time to listen and share; a place of faith and hope. The vision included a clinic that would serve as a world-class medical home which would be family-centered and improve the health, welfare, and potential abilities of all people with special needs. It would be a model of science and technology that would focus on treatment, intervention, research, and education for individuals with complex medical needs. It would serve as a pioneering research facility to achieve groundbreaking outcomes by partnering with the local community and with an ever-widening network of support and world-wide collaborations. All of this would be done while providing affordable care to those in need and would operate as a financially sound, non-profit, independent clinic.

The next piece of the puzzle was to find a qualified physician up to the task at hand, so they put out the word that they were on the lookout for a unique person.

“We needed our own Sherlock Holmes,” says Leach-Brace (who has since remarried). “A good pediatrician and researcher, someone to treat patients but to come up with answers, too.”

Five finalists applied for the position. The steering committee brought in three for interviews. One of the three was Dr. Heng Wang, a physician whose grew up in China, and, at the age of 20, became one of his country’s youngest doctors, graduating in the top 3% of his class from Anhui Medical College.

Dr. Heng Wang believes that everything happens for a reason. That includes the day he saw in the *Journal of Pediatrics* an ad from a center in Ohio that was looking for a physician. Dr. Wang was living in Little Rock, Arkansas at the time, finishing up his residency training. He had already been offered several jobs: one from his mentor in Tennessee; one in a large Chinese community in Houston, Texas; and one right where he and his family were living in Little Rock. He had no reason to seek anything else.

But this ad intrigued him for two reasons: first, the journal literally jumped out at him, falling to the floor while he was looking at a different magazine at the academic library. It flopped right open to the ad from the group in Geauga County; second, he had seen this ad before during his third year of residency and had filed it in the back of his mind. He had since forgotten it, what with the other options he had available. But now the ad had fallen directly into his path for the second time. He knew he had to look into it, so he sent an email to the clinic asking for more information. When they replied, he read about Dr. Morton’s work in Lancaster, PA, and especially about Dr. Morton’s speech at the 125th Year Celebration at Boston Children’s Hospital where Dr. Morton had talked about meaningful work, where he had said, “These special children are not just interesting medical problems, subjects of grants and research. Nor should they be called burdens to their families and communities. They are children who need our help and, if we allow them to, they will teach us to love. If we come to know these children as we should, they will make us better scientists, better physicians, and thoughtful people.”

On the first visit, Dr. Wang arrived alone. His interview process began at 5:30 in the morning at an Amish home and lasted through the rest of the day. He met with children, family members, Amish farmers, doctors, therapists, volunteers, and community members. Leach-Brace recalls that, though language issues made things a

little difficult due to Dr. Wang's first language being Chinese and half of the steering committee's first language being Pennsylvania Dutch, he immediately made everyone feel comfortable. When he walked into an Amish home, he welcomed the children into his arms. When the interview was over, the community had decided.

"We want him," they said. "His heart is pure. We'll work through problems with language."

A lot of the process, JoAnn Leach Brace admits, was determined by emotion. She forced herself to be analytical, checking into Dr. Wang's history. What she found confirmed their decision.

After medical school, Dr. Wang had earned his PhD and had worked in the field of medical research for 16 years, but then decided he wanted to do more.

"Sometimes in the lab you feel that your work is meaningful," Dr. Wang says, "and sometimes you don't. You don't always see how the work you're doing can be applied to the children."



He had decided to return to school for pediatric training in Arkansas. It was that combination of research and pediatric training that both he and the steering team recognized as the perfect fit for DDC.

“I felt my training, particularly my research, wouldn’t have been used the way I wanted with the other offers. Here, I could help the Amish children, and my research expertise could be used, too. Most importantly, I feel very much attracted to serving a special population—working with the Amish, working with children with special needs.”

So, in 2002, Dr. Heng Wang became DDC’s medical director, thanks in part to that ad that had fallen into his hands. What he later discovered was that the DDC Clinic had only run that ad in the *Journal of Pediatrics* twice, several months apart. And Dr. Wang had seen it both times.

In the beginning, the clinic didn’t have a building. For the first year, Dr. Wang worked out of his vehicle doing house calls. Then, they bought a small residential home that served the center’s basic needs. In 2009, they moved to the present clinic where they diagnose, research, and treat genetic conditions and metabolic diseases among 700 patients from 30 different counties, other states, and some who have come from as far away as Australia and Canada.

“We see more than 70 diseases,” Dr. Wang says. “With a lot of the diseases, there’s not much we can find in medical literature.”

In fact, some diseases seen at the clinic have been researched and named there. So far, DDC has identified three new diseases. They are also helping to establish more clinics to serve other communities, clinics like New Leaf Center in Mt. Eaton, Ohio.

“Dr. Morton helped us set up our clinic,” Dr. Wang says, “So this is our way of paying Dr. Morton back.”

And because DDC has its own laboratory and is intimately familiar with the diseases and disorders affecting the Anabaptist community, they are often able to diagnose within the first visit, and for a fraction of the cost of major medical centers.

“People don’t know much about the conditions in Amish populations,” Dr. Wang explains. “Major medical centers do a series of standardized tests that, collectively, could cost hundreds, thousands, in some cases, for a patient with a rare disorder, millions of dollars to get answers. But they don’t get answers, because these medical centers are treating the Amish like they’d treat anyone else in the population. But we focus on the target mutations and diseases, knowing that we have 40 diseases that are more common in Amish population. We use our knowledge to focus on these diseases.”

The lab, Dr. Wang says, is state-of-the-art. In many cases, DDC’s is the only lab in the country performing tests for certain diseases, and at a fraction of the cost of other labs—just \$75 for each test—because they operate as a non-profit and are supported by the community.

“It’s a service,” Dr. Wang says. “We offer these tests at less than our costs because, with early diagnoses, we can help many of these children and their families. To be able to do these tests here at the clinic saves millions of dollars. We can use the tests to confirm what we see, then work with physicians to provide answers.”

As an example, Dr. Wang points to a condition called Cohen Syndrome, which affects only about 100 patients in the country and impacts motor skills, mental development, vision, immunity, physical appearance, and behavior. Out of those hundred patients, DDC has seen more than 80, about 40 of those being Amish. As a result, DDC hosts the National Cohen Syndrome Meeting and Family Gathering each year which draws people from Alaska, Hawaii, and Canada. In fact, most of the disorders that are addressed are not unique to the Amish populations so, their work can benefit others in need far beyond the local community.

Dr. Wang has now been with the clinic for 12 years, and he feels he’s part of the community. He learns so much from the people he meets, and his faith is boosted by the clinic and its growth

“I share with my friends and the church the testimony of how I know our clinic has been growing. When I started, we had a \$200K per-year budget, maybe less. Now it’s more than \$1 million each year. When we start a new year, we don’t know where the help will come from, but we know it will be there. You always pray for that, and you

always see that, by the end of the year, the clinic continues to grow, and our needs are met.”

And for a community clinic like DDC to be able to meet those needs makes a significant impact. Many genetic diseases are very treatable—some highly so. Dr. Wang says it’s a misconception to believe there’s nothing we can do for these children. Improved diagnostic rates result in healthcare savings, and this is particularly important to the Plain communities DDC serves.

But equally important is the feeling of emotional relief when a family finally finds the answer that has eluded them for years.

“Our mission is to improve the quality of life for families with special needs children with diseases caused by rare genetic disorders,” says Blake Andres, the clinic’s executive director. “We do so with the blessings of the community, and that enables us to provide early diagnoses, effective treatments, and culturally competent family support. By doing our work together in this way, we save families and community health funds many, many dollars.”

“We’ve learned so much,” Dr. Wang adds. “From a medical standpoint, we learn about a lot of diseases. We learn how to help other children. I get email from Europe—from France, Italy, Spain, Germany. A lot of requests, asking questions. We help others through the knowledge we gain. As a human being, we also learn so much: how to be humble; to admit there’s so much we need to learn; and to be faithful. To wait for the next year, to know you’re doing good work, and that you’ll be provided for.”

Over those 12 years, Dr. Wang has raised his own two daughters in the same community he serves. The youngest left for college this fall. In her college entrance essay, she shared about how much she has learned from living here, how it has formed her life.

“Both of them want to go into medicine,” Dr. Wang says. “They have a lot of Amish friends, and they want to help children with special needs. If we had worked in a major city or hospital, they would not have learned what they’ve learned. They’ve learned how to serve here. They’ve become better people by growing up here.”

And it's all because of the support of people who strongly believe it is our responsibility to help children with special needs, who believe that, when we do, they will teach us to love, will teach us to become better scientists, better doctors, and more thoughtful people.



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.