



Parent's Note

"Accepting this as God's will for our child is a journey"



Family Days

Children connect and share their experiences



Attention Parents

Article about a program that is meant only for the adults in the family

Looking Back to See Ahead

by Raymond Fox, Board Chairman

Sometimes to see what the future might hold, it helps to take a step back in time and look at history.

It has been 30 years since Dr. Morton and the communities have opened the doors of the Clinic for Special Children in Strasburg, PA. Having gotten its start in a very humble and amazing way, Dr. Morton has gotten to be known worldwide, and has helped many, many people to answers they might never have gotten.

The Center for Special Children has continued this work. From the first meeting in 2012 with Dr. Morton, to establishing the program in 2015, to the over 215 families we now help. We help communities with the conditions we now know so much more about. We continue to learn more about treatment options that improve the health and daily life of our patients and their families. We continue to discover new conditions, providing answers for families.



As Dr. Morton's work continues, our work continues, and it becomes clear that the need continues. It is up to the present generation to keep it going in a humble and caring way. It takes commitment in many ways; recognizing the need to ask others, educating ourselves, working together, willingly sharing of the knowledge we have gained and realizing the need for financial support.

So, at the end of the day, we can feel we have done our all; and say we have only done our duty.

How Can You Help the Center for Special Children?

You are invited to join us for our 2019 Benefit Auctions

The benefit auction proceeds are 2/3 of the program's annual operating budget, which allows CSC to continue to provide primary care with advanced genetic testing to improve the lives of special children and their families.

- June 15th at Growers Produce Auction, 2347 Dell Road, Cashton
- July 20th at Central WI Produce Auction, N14676 County Highway 0, Withee

"What is this donation auction for? Dr. Morton from PA came to WI for a meeting, and before the meeting he said to somebody, 'You need a clinic here.' I was at a meeting on April 10, 2018 where a lot of information was given, what these doctors do. They will see a patient for a minimal fee. If you have a baby that isn't healthy, you can take it to Dr. DeLine at the La Farge Clinic and he will evaluate it, and if he isn't sure what is wrong they will do testing to see what is the problem. In some cases it will take some medication, other cases it will need to go to the hospital, or depending what it is, he will say you can take it home to love and care for it, as they have nothing to help the child. There is much more that could be written, but let's think about what these doctors are doing to test these diseases and finding the medication to help them. This takes a lot of money and that is what these auctions are about. So why don't we help support them?" – Anonymous

For more information, or to make a donation, please contact

Cashton Auction: Contact Sheri Hammond at 608-625-4039

Withee Auction: Contact Curvin Brubacher at 715-644-5195.

All donations are tax deductible.





Parent's Note

It took some acceptance to arrive at the Center for Special Children and knowing why we were there. Being told your baby has signs of a genetic defect is, at its best, distressing. But it has been a journey which has enriched our lives. First of all we met doctors, nurses, and other staff whom we now consider our friends. Their goal is to provide care for children with difficulties. And provide the parents with understanding of the conditions, and how this affects the child's life.

We have learned how amazing our genes are. They make up our body size, our facial features, our hair and eye color, the shape of our body... The list could go on. They impact our character by supplying us with talents and difficulties.

It has broadened our understanding of the differences in our children. We see a character trait in some of the children that needs strengthening or correction. And we recognize the trait as one we ourselves had to struggle with and feel humbled that they inherited that gene from us. But beings we dealt with it ourselves we can now offer understanding and make their struggle easier. In other areas we see a very positive character trait and realize we also gave them those genes. In that way God can boost our morale. (Every person can use one now and then).

In many ways this journey has blessed our lives. Dr. DeLine deserves a blue ribbon on the compassionate care he has offered us. His whole staff follows his example. They have helped us through all the medical check-ups...scheduling appointments, reducing our costs, etc. They have linked us with Drs. Emma Baple and Andrew Crosby from whom we hope to receive answers about our child's condition. And hopefully by studying this condition and working with it there will be help for families the future.

By giving us a child with a special condition God has given us a condition with special blessings.

We are thankful,
Sam and Ruby Miller



Family Days

Family Days gives family members and their children a chance to connect and share their experiences. Since many of the conditions we see are very rare, families may not see other children similar to their own or be able to find answers to basic questions about caring for their children. They are also an opportunity for doctors and others to share the latest information on treatments or research into these rare conditions.

Beginning with the Family Days hosted in 2017, we continue to create opportunities for families to share and learn from one another. In August 2018, we hosted a SNIP1 (symptomatic epilepsy with skull dysplasia) Family Day in Mauston. This was an opportunity for Dr. Zineb Ammous (The Community Health Clinic) and Dr. DeLine to meet with families to learn more about this condition as research continues regarding the possibility of specific seizure medications that may be beneficial for treating this disorder.

In collaboration with UW-Madison Genetics team, we hosted a MSUD (maple syrup urine disease) Family Day in September 2018 with over 40 family members visiting, playing games and gathering around the potluck buffet. This was so well attended and enjoyed, we will continue hosting this family day annually. And because of this success, UW-Madison and CSC will be hosting a PA (propionic acidemia) Family Day and a PKU (phenylketonuria) Family Day in 2019.

On May 9th, we invite those affected or interested to our Jalili Syndrome and Other Low Vision Conditions Family Day. The day will include; New research on retinal replacement therapy, Braille presentation, Insights for care on amelogenesis imperfecta, and Low vision aids. We extended an invitation to all Plain Community Health Consortium patients, just as they have invited us when they host a family day. We thank the consortium clinics for allowing us to join the GM3 Synthase Family Day to be held in Mt. Eaton, OH in May and the SNIP1 Family Day held in Nappanee, IN last November.

Welcome Julie Everson



My name is Julie Everson and I joined the Center for Special Children (CSC) program as an Advanced Practice Nurse Practitioner (APRN) in August 2018. I first heard of the program from one of my friends and was instantly intrigued. I couldn't believe we had a local program that not only cares for plain patients with genetic and metabolic disorders but also participates in research with the University of Wisconsin-Madison and with Windows of Hope in Exeter, England. I have been a nurse for almost 17 years and spent most of my career in either the Neonatal Intensive Care Units (NICU) at Gundersen Health and Mayo Health Systems or the Pediatric Intensive Care Unit (PICU). I have had the pleasure to care for many premature and ill babies.

What has stood out to me from my time in the units, is how many family and friends would always come to visit the plain community patients and their families. The love, care and support given to the patients and their families by the community was remarkable to me. I come from a very close-knit family that comes together when one of us is sick or struggling and for happy times too. I knew the CSC program was where I was meant to be.

In 2009, my husband and I were blessed with a beautiful baby girl, Lydia. However, she was very ill from birth and we spent a month in Rochester before she passed away. She was found to have a very rare genetic condition that no one had heard of before. Since that time, I became very interested in genetics and I can empathize with parents who have children with rare genetic conditions, some of which are lethal. As parents, we have endless love for our children and will do anything to help make them happy, healthy, and pain free. My love for nursing and taking care of sick babies is what led me to getting an advanced degree in nursing. My love for Lydia has led me to learn more about genetics and the conditions thereof. My love for my family has led me to want to care for these precious special children and their families as they go through daily struggles. And my love for my community has led me to want to work here, close to home. Through CSC we can learn from each other so that hopefully someday no parent will have to suffer the loss of their child. I am enjoying my time here so much and I have grown as a person, parent, and a provider. I am excited to see what our future holds.



Genetics and Birthing Program: How They Complement One Another

by Dr. James DeLine, Medical Director, Center for Special Children

The Center for Special Children was established in 2015 at the La Farge Medical Clinic after several years of planning. During our planning stage, we learned much from others who had begun this work, in particular Drs. Holmes Morton at the Clinic for Special Children in Lancaster, PA and Heng Wang at Das Deutsch Clinic in Middlefield, OH. The important work at these clinics and other newer clinics in Indiana, Ohio, Pennsylvania, and now Dover, DE remain an inspiration to our work. Some 20 years earlier, I had established a birthing center to support couples in the plain community when additional assistance was needed or desired to assure safety of mother or baby during birth. From the beginning, we had a close working relationship with the home birth midwives. This active collaboration has resulted in greater support and improved outcomes for women in the plain community. In the first 1000 deliveries, the C-section rate was 4%, compared to nearly 35% in hospitals across the country.

The two projects have complemented each other in ways that were not initially anticipated. Clarification of genetic risks for couples is now commonly being done. Carrier testing is frequently performed, in order to anticipate the possibility of an affected infant. For couples with a child previously affected by an inherited disorder, cord blood sampling and early low-cost diagnosis is provided. Assistance in obtaining and processing cord blood samples has also been provided frequently to home birth midwives as well, for couples who live a distance from the birthing center or who prefer a home birth. In addition, women who have inherited conditions which are well treated go on to marry and have families. This excellent health in spite of inherited conditions is of course a primary goal of the clinic. Knowledge about how to manage pregnancies in women with genetic conditions is sometimes limited. This can make accessing care for management of pregnancy, labor, and delivery challenging. Midwives may be concerned about delivering these women at home. Small community hospitals may be similarly reluctant. Delivery at large hospitals in the city can be expensive, many miles away, and medical interventions provided can feel overwhelming to a couple. This has created a significant problem for women with inherited disorders seeking care. In our birthing center, we have been working to clarify the best approaches for management of inherited conditions.

Propionic acidemia (PA) is an inherited metabolic disease which may result in injuries to the brain or heart which can complicate pregnancy. In addition, complications during labor may occur because of the stress of labor itself. We have been working for several years with experts from the University of Wisconsin-Madison to develop an approach to management during labor and delivery which will minimize the risk of complications to the mother. We published the first case describing management of a mother with propionic acidemia during labor and delivery, to give guidance to other doctors as they work to assist women with PA. We have now delivered five women with PA. We hope to gather enough experience to describe an ideal approach which will allow women with PA in the plain community to have easier access to care across the country.

Von Willebrand's disease (VWD) is an inherited bleeding disorder which occurs in women in the plain community. It is also common in the general community. Management approaches for this condition have been complex and have required the use of very expensive medications, again typically administered in a large urban hospital. We have developed a protocol for the care of women with VWD during labor and delivery which is low cost and should be able to be administered in settings closer to home. Our first patient had an uncomplicated delivery without the excessive bleeding which had occurred with previous deliveries (before her VWD was discovered). Another patient with VWD will be delivering soon. As our experience accumulates, we hope to also be able to share this simpler lower cost approach with doctors across the country, improving access to safe and low-cost births for women from the plain community with von Willebrand's disease.

Hypertrophic cardiomyopathy (HCM) is the most common inherited heart disorder in the world, affecting people from all communities, not only the plain community. The frequency is about 1 in 500 in the general community. In some segments of the Amish community, it may be as common as 1 in 20 individuals. It may lead to sudden death during adolescence. However most people who carry the HCM mutation do not have difficulties, especially not during their youth. We are accumulating a large body of evidence demonstrating excellent tolerance of pregnancy, labor, and delivery in most Amish women with HCM. We recommend regular monitoring with an echocardiogram during each pregnancy. This knowledge should allow most women with this condition to look forward to normal pregnancies and deliveries and reassure the doctors and midwives caring for them.

Sitosterolemia is a rare disorder of plant sterol metabolism which may lead to early onset of artery disease, resulting in premature heart attacks and strokes. These episodes may occur during the teenage years or early adulthood. Blood disorders, including bleeding, are also described. We are managing a number of young people with this disorder, working hard to stop or reverse the process. There are no reports in the medical literature describing safety and management of pregnancy, labor and delivery in women with sitosterolemia. We are studying the impact of the disease on pregnancy, carefully exploring the impact on development of the placenta, growth of the unborn child, and the mechanisms of blood clotting, guiding the young mothers through pregnancy, labor, and delivery. This is being done without additional cost to the couples. So far the results have been successful, with healthy babies and no complications. The information learned should be helpful to young women with sitosterolemia throughout the world as they look forward to their own families.

As has been shown by Dr. Morton and others, care by doctors who are knowledgeable about inherited disorders in the plain community can improve the outcomes for families and save substantial costs. However, the management of these disorders during the childbearing years is an area which has not been carefully studied. We are making efforts to change that, hoping to offer every family affected by inherited disease the best hope for successful childbearing.



Mission Statement

Caring for families with rare genetic conditions.

Vision

- The Center for Special Children serves families by:
- Providing diagnosis and treatment across all stages of life
 - Respecting cultural diversity
 - Increasing awareness and education about genetic conditions
 - Collaborating to advance knowledge and research
 - Supporting all care givers, including families and healthcare providers
 - Providing and advocating for affordable healthcare

Our Organizing Board

Our program is advised by a group of twelve volunteers, who meet every other month to review our mission, activities and finances. We are honored that the following individuals have dedicated their time and talents to support this program:

Chairman
Raymond Fox
Plain Community Rep.

Vice Chairman
Jerry McGeorge
Vice President of Cooperative
Affairs, Organic Valley

Ervin Bontrager Plain Community Rep.
Joseph Schrock Plain Community Rep.
Adrian Roberg English Community Rep.
Crist Hershberger Plain Community Rep.
Korina Pubanz, RN, CPM, LM Guild of Midwives
Tammy Raeder, RN, BSN Nurse - Eau Claire County
Marlin Weaver Plain Community Rep.
Christine Seroogy, MD University of Wisconsin

Board Treasurer
Nathan Nolt
Plain Community Rep.

Board Treasurer
Kyle Bakkum
CEO, Vernon Memorial Healthcare

About Our Funding

In 2019, the Program has an operating budget of \$241,000. Our goal is to raise two-thirds of this amount at our two benefit auctions, which will be held in Cashton, WI, on June 15 and Withee, WI, on July 20. Additional support comes from three major, local sponsors.



Vernon Memorial Healthcare provides continued support for the program and serves on the organizing board. With their continued support, we are providing care for families close to home.






Organic Valley continues to generously support the program. Because of their support in 2015, we were able to begin providing care at the program's inception.



UW-Madison provides outreach clinics for metabolic disorders, cardiology, ophthalmology and neurology. Through UW-Madison's commitment, the program can offer specialty services, genetic testing, community outreach and education.

Donations to the Center for Special Children are used to provide all aspects of care. From offsetting the cost of office visits for families with genetic disorders to supporting innovative research into rare conditions, your donations make a difference. Financial gifts provide a 24 hour phone answering service, specialized medical equipment, and access to cutting edge, cost-effective genetic testing. Most importantly, you're making it possible to identify and treat rare diseases at a local level while contributing to a worldwide bank of genomic knowledge that benefits all cultures and communities.

-  Donate to The Center for Special Children on our Facebook page
-  Questions about the Program can be directed to Sheri Hammond at (608) 625-4039
-  La Farge Medical Clinic, 206 North Mill Street, La Farge, WI 54639