



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



Center for Special Children  
A program of Vernon Memorial 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 <b>Raymond Fox</b> Plain Community Rep.	Vice Chairman <b>Jerry McGeorge</b> Vice President of Cooperative Affairs, Organic Valley	<b>Ervin Bontrager</b> <b>James DeLine, M.D.</b> <b>Joseph Schrock</b> <b>Barbara Regnery</b> <b>Gretchen Spicer, CPM, LM</b> <b>Tammy Raeder, R.N.</b> <b>Marlin Weaver</b> <b>Christine Serogy, M.D.</b>	Plain Community Rep. La Farge Medical Clinic Plain Community Rep. English Community Rep. Guild of Midwives County Nurse - Eau Claire Plain Community Rep. University of Wisconsin
Board Treasurer <b>Nathan Nolt</b> Plain Community Rep.	Board Treasurer <b>Kyle Bakkum</b> CEO, Vernon Memorial Healthcare		

## About Our Funding

In 2018, the Program has an operating budget of \$264,000. Our goal is to raise two-thirds of this amount at our two benefit auctions, which will be held in Cashton, WI, on June 16 and Withee, WI, on July 21. 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 and cardiology. 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, BBA, at (608) 625-4039
- La Farge Medical Clinic, 206 North Mill Street, La Farge, WI 54639

Summer Newsletter 2018



## A Specialized Clinic in Our Community

By Dr. James DeLine

Clinics specializing in the rare inherited disorders in the Plain (Amish and Mennonite) communities benefit the patients and families, but also help doctors and researchers learn more about these uncommon conditions. Over time this leads to more efficient and less costly diagnosis and better informed care. For conditions which have only been seen on a few occasions, the chances of identifying them are greater when seen in one of the specialty clinics. And great efforts are being made to provide a diagnosis and care at the lowest cost.

A family was seen at the Center for Special Children because of poor vision, light sensitivity, and very poor teeth. The children were otherwise bright and healthy. Evaluation by our colleague Melanie Schmitt, a children's eye doctor from University of Wisconsin, suggested degeneration of the retina, the thin lining in the back of the eye. The teeth were browning and chalky and broke off easily. After several visits to meet the children and evaluate their vision, collaborators from the Windows of Hope from Exeter England performed exome analysis (genetic testing of all of the genes that code for proteins) on the children and parents. To our surprise, they identified Jalili syndrome, a condition which had never been identified in the Amish or indeed in the United States. It had been seen in the Middle East and a couple of families in the Kosovo region of Europe. Though it required months of study to identify initially, we now recognize the condition and have seen a second family in Wisconsin, with another family identified in Ohio. While so far there is no known treatment, diagnosis can now be easily made by a clinician suspecting the disorder by submitting a sample to the University of Wisconsin Diagnostics Laboratory. They have developed a rapid genetic test for the low cost of \$50. With each new condition identified, the identification of affected patients becomes easier – and the search for treatment or cure can begin. If families have children with vision problems, low cost diagnosis and treatment is available at one of our pediatric eye consultation clinics.

# Family Days

Family Days are a heartwarming way to help families and children with special needs. 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. These gatherings allow families to connect and share their experiences. They are also an opportunity for doctors to share the latest information on treatments or research into these rare conditions. In the past year we have hosted two family days.

Pierson Syndrome Family Day was hosted in Colby, Wisconsin. While there are less than 10 children with the condition in the state, over 100 family and community members attended to learn about the condition and how to support these children. Dr. Kevin Strauss (Clinic for Special Children, PA), the first to identify the genetic cause of the condition, was a featured speaker. He shared what is known about the condition. Local Dr. Troy Schrock shared his experience caring for the children. Dr. Christopher Galang (Eye Clinic of Wisconsin) described the results of his eye exams. The local Braille and mobility teachers described techniques used to teach the children to read and navigate through their daily activities. It was a heartwarming experience for families to see such support and interest in their community.

Troyer Syndrome Family Day was hosted in Cashton, Wisconsin. Three families visited with Drs. Emma Baple and Andrew Crosby, from Exeter England. These collaborators were the first to identify the genetic cause of this condition and they shared what is known about the condition. VMH therapists (speech, occupational and physical therapy) shared techniques to maintain the children’s communication skills and mobility. This was a wonderful day for the children and families to visit with each other.

# 2018 Translational Medicine Conference

The Center for Special Children provides care to special needs children through our rich collaboration with the Waisman Center and other University of Wisconsin medical doctors and specialists. Our work is built on the innovative work of Dr. Holmes Morton and others who have provided diagnosis and care to children with genetic and metabolic conditions.

For the past 5 years, the clinics that care for Plain communities have hosted a conference where doctors meet to share their growing knowledge. We share stories of new diagnosis, research and treatments, along with confounding cases and unknown conditions. It is a truly unique time when all of the clinics that work with genetics and the Plain communities gather to learn from each other.

This year, the meeting will be hosted at the Waisman Center in Madison, Wisconsin. The Translational Medicine in Plain Populations Conference will be July 30-31. This meeting is open to the public. If you are interested in learning more about the conference, or would like to attend, please contact Sheri Hammond or visit the website: <https://www.waisman.wisc.edu/event/plain-conference-2018/>

# A New Face at the Center for Special Children

By Claire Sandrock

Over the past 2 years, I have had the pleasure of working with many caring families, board members, medical doctors and midwives in my role as the Program Manager at the Center for Special Children. I have been honored to play a small part in promoting the amazing work of the clinic, coordinating care to families and collaborating with people from many different communities and institutions. Among the gifts I have been given in my time here is the embracing of a compassionate approach and the power of cooperation. I have decided to leave my position at the CSC to embark on a longtime dream to pursue midwife training.

We are excited to welcome a new Program Manager, Sheri Hammond. Sheri has extensive experience in program development in her work with La Crosse Family and Children’s Center. In addition, she worked at Center Point, a cooperative of mental health practitioners. Sheri is now familiar with our board and collaborators. She looks forward to supporting the mission of the Center for Special Children.

# Story From a Wisconsin Midwife

By Chris Roberts

I am a midwife who lives and serves a large Amish community in Wisconsin. We have several families with a variety of metabolic and genetic disorders. Believe me, when I started this work, I had no understanding or interest in these disorders. As time went on, the need for getting care and answers for these couples grew.

A network of research was growing, new discoveries were being made in the fields of metabolic and genetics specific to Amish culture. Dr DeLine had started the Center for Special Children (CSC) in La Farge. He and his team are dedicated to these families and serve them. They are a God send to families with special children. These families often would have nowhere to turn for answers or treatment.

Providers often didn’t know what these children were presenting with; parents would be told to take their children home to pass. No diagnosis, no treatment, no answers, no help and especially no understanding of Amish culture. Parents would feel alone, abandoned and guilty. Now, with the work being done at La Farge, parents can have hope for answers, treatments and support for their “special” children.

I know several couples who have worked with the CSC in La Farge. One couple in particular comes to mind. Their beautiful daughter was born by C-section. When she was a few months old she started “acting funny.” Eventually she started having seizures. She was rushed to the hospital, given medication and sent home, but continued to have seizures. The parents, discouraged, started home remedies, chiropractic and diet changes. Still, the little girl suffered. The family spent thousands of dollars on her care. Months passed and now their daughter was falling behind in walking, language and behavioral skills.

They started coming for prenatal care, baby number two was on its way. Their adorable little girl would often come with them for appointments. It was easy to tell she was “special”, but how? One day her Mom mentioned that it was suggested that her daughter suffered from birth trauma, and now mom’s parenting skills were being questioned. Her daughter was harder to control. The mom had no appetite, she wasn’t gaining weight. Mom wasn’t sleeping, as her daughter was often having seizures at night. Dad was missing work to give his wife a break. Grandma and aunts were helping too.

I mentioned there was a genetic seizure disorder and maybe an appointment with Dr. DeLine would be a good idea. The parents were hesitant at first, they had been let down several times already. So reluctantly they went. Yes! They did get answers! Their daughter has a genetic seizure disorder which comes with behavioral challenges similar to autism.

Their second daughter was born. Testing was done and to the relief of everyone, she does not have the disorder.

Frist daughter is being treated, medically and non-medically. She is in the Birth to 3 Program, where her parents are learning ways to help her learn even more. There are still challenges, but she is doing well. The whole family, parents and grandparents are beginning to heal. Mom is getting her confidence and smiles back.

Thank you so much for the correct diagnosis, treatment and support. Words cannot express how much I appreciate these dedicated providers at the Center for Special Children in La Farge.

*I am me, and you are you.  
Somehow our paths have crossed  
And I am blessed.*

