



## Center for Special Children

A program of Vernon Memorial Healthcare

# About Center for Special Children

### Who are we?

We care for special children. The focus of our work is the diagnosis and management of genetic disorders primarily in the Plain community (Amish, Mennonite, Hutterite). These conditions are often rare and have remained largely undiagnosed, causing untold suffering and expense with extensive and unsuccessful testing efforts. 115 new patients enrolled in 2023 for a total of 639 patients being served by the program as of December 31, 2023.

### What are we?

The Center for Special Children employs a full-time pediatric geneticist, a full-time program manager, a full-time nurse, one part-time administrative support and a family practice doctor who manages adult patients. We are a collaboration of many to include; UW-Madison specialties (genetics, heart, eye, nervous system, and a farming wellness research study); a team of research scientists assisting in identifying unknown conditions based in Exeter, England; newborn screening and targeted disease testing at the Wisconsin State Lab of Hygiene; and one of seven clinics collaborating on research studies, unknown cases, testing, family education and facilitating an annual conference through the Plain Community Health Consortium. There were 771 patient contacts through the program in 2023. 240 of those patient visits were through a UW-Madison Outreach Specialty Clinic.

### When and where was the program created?

The Center for Special Children program is located within a busy full spectrum family medicine practice at the La Farge Medical Clinic, a rural health clinic of Vernon Memorial Healthcare. The La Farge Clinic was started in 1983 by Dr. James DeLine. Dr. DeLine worked with the community for years, providing routine care, house calls and emergency care to families in this low-income area. The practice became known for cost-effective care for this largely underserved and uninsured community. Some members of the Plain community came to the clinic with diagnosis of genetic conditions and asked for a clinic to support their families. Driven by the vision and support of the community and Dr. DeLine, the Center for Special Children was created. The practice continues to be known for compassionate care.

### Why is the program important?

Wisconsin has the fourth largest population of Amish & Mennonite families. Early identification and treatment of these conditions may lead to complete prevention of the consequences of the disorder, with healthy children as a result. In other cases, the child's health can be improved, and disability lessened by knowledge and appropriate treatment. Some children are found to have lethal disorders, for which there is no cure and early death is certain. In this difficult situation, children and families can be spared painful and expensive diagnostic evaluation and hospital stays. Knowledge of the diagnosis can allow the child to be lovingly cared for in the comfort of their home and community. The program currently manages 157 known variants. We are working to provide answers for 136 patients with (yet) unknown diagnosis. Each year, with the help of our collaborators, we are able to identify new disease-causing genetic variants and provide answers for families.

The kind of care, which the program offers, is the future of medicine. It is often called precision medicine. We continue to learn more about how to use genetic testing to help doctors choose the best course of treatment for all patients. Plans of care are developed for expectant women with genetic disorders. Cord blood testing in at-risk families is now easily incorporated into care plans. Regular education conferences with birth attendants and community midwives give opportunity for improved care at the community level.

### How is the program funded?

A 12-member group of local community members provide guidance on financial and strategic decisions related to the Center for Special Children. As representatives of the local Amish and Mennonite communities, local businesses and citizens, they provide valuable guidance and support to the program. Three benefit auctions are held annually to support the program. The auctions are held in Platteville (2nd Saturday of June), Cashton (3rd Saturday of June), Elma, IA (1st Saturday of July) and Withee (3rd Saturday in July). These auctions provide over 2/3 of the annual operating budget of the program, which is also supported by Vernon Memorial Healthcare, Organic Valley, and many individual donations. All auction items are donated by the Amish, Mennonite and English communities of Wisconsin, Iowa and Minnesota.

For more information, please contact:

**Center for Special Children**  
**La Farge Medical Clinic**  
**206 North Mill Street**  
**La Farge, WI 54639**  
**Phone: (608) 625-4039**

### Donations & Gifts

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 conditions to supporting innovative research into rare conditions, donations make a difference. Financial gifts make 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.

Please make checks payable to  
**Center for Special Children**  
and return to  
**La Farge Medical Clinic**  
**206 North Mill Street**  
**La Farge, WI 54639**

### CENTER FOR SPECIAL CHILDREN BENEFIT AUCTIONS

If you would like to support the auctions, please see contact information below:

#### **Platteville Area Auction**

Platteville Produce Auction  
8521 County D, Platteville

**June 8, 2024**

contact Norman Snyder at  
608-943-6843

#### **Iowa Area Auction**

Cedar Valley Produce Auction  
18072 Addison Avenue, Elma, IA

**July 6, 2024**

contact Vernon Zimmerman  
at 641-393-2545

#### **Cashton Area Auction**

Growers Produce Auction  
S347 Dell Road, Cashton

**June 15, 2024**

contact Sheri Hammond at  
608-632-1235

#### **Withee Area Auction**

Central WI Produce Auction  
N14676 County Hwy O, Withee

**July 20, 2024**

contact Carl Oberholtzer  
at 715-223-0961