

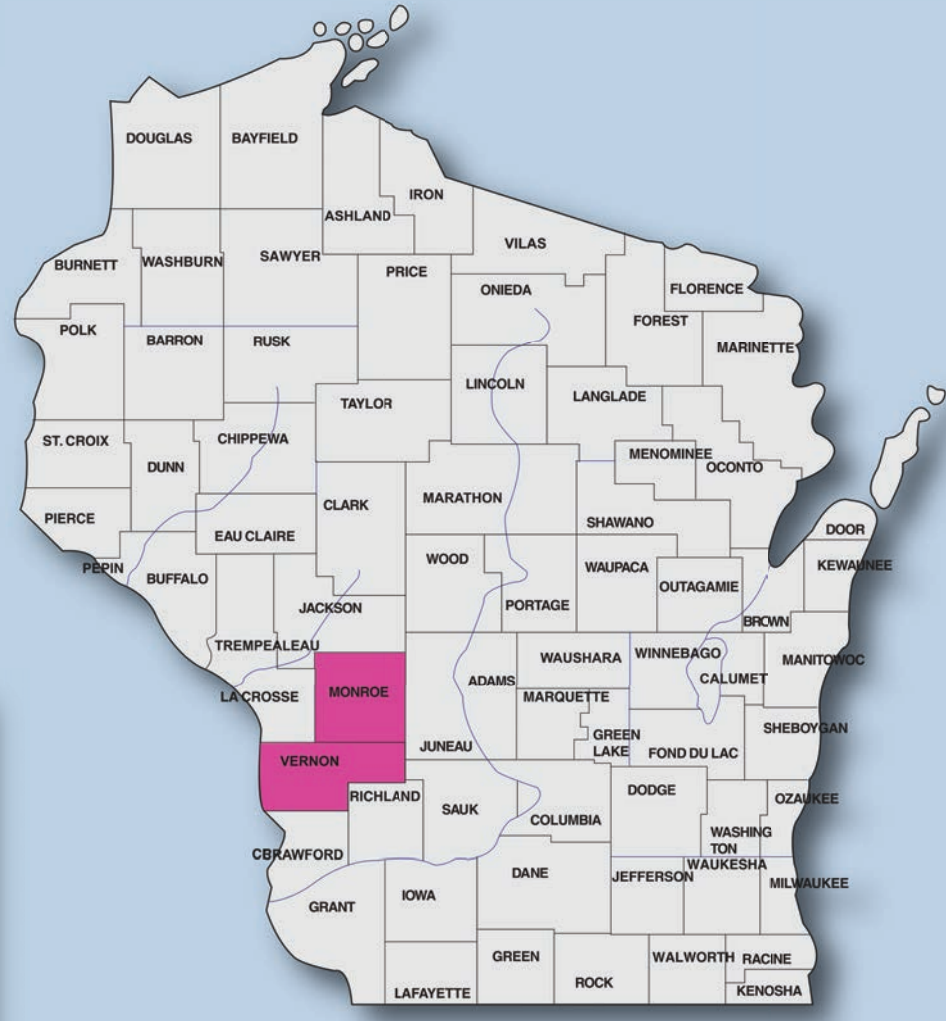
Cross-System Engagement to Improve Newborn Screening in Wisconsin Plain Communities

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Problem:

Wisconsin is the state with the 4th largest population of people living in Plain Communities Pennsylvania, Ohio and Indiana). A majority are Amish, followed by Mennonite and a few other German Anabaptist sects, with 16,000 - 18,000 individuals living in about 50 communities in the state. With 600-800 births per year, these communities make up about 1/2 of all out of hospital (OOH) births in Wisconsin annually, and an estimated 200 per year do not receive newborn screening (NBS). Public health programs and health care providers are engaging with Plain communities to increase the rate of NBS, early identification and treatment of disorders identifiable at birth. The role of the WI LEND program and UCEDD at the Waisman Center has been to add funding to provide systems integration, sustainability and training opportunities to this effort.

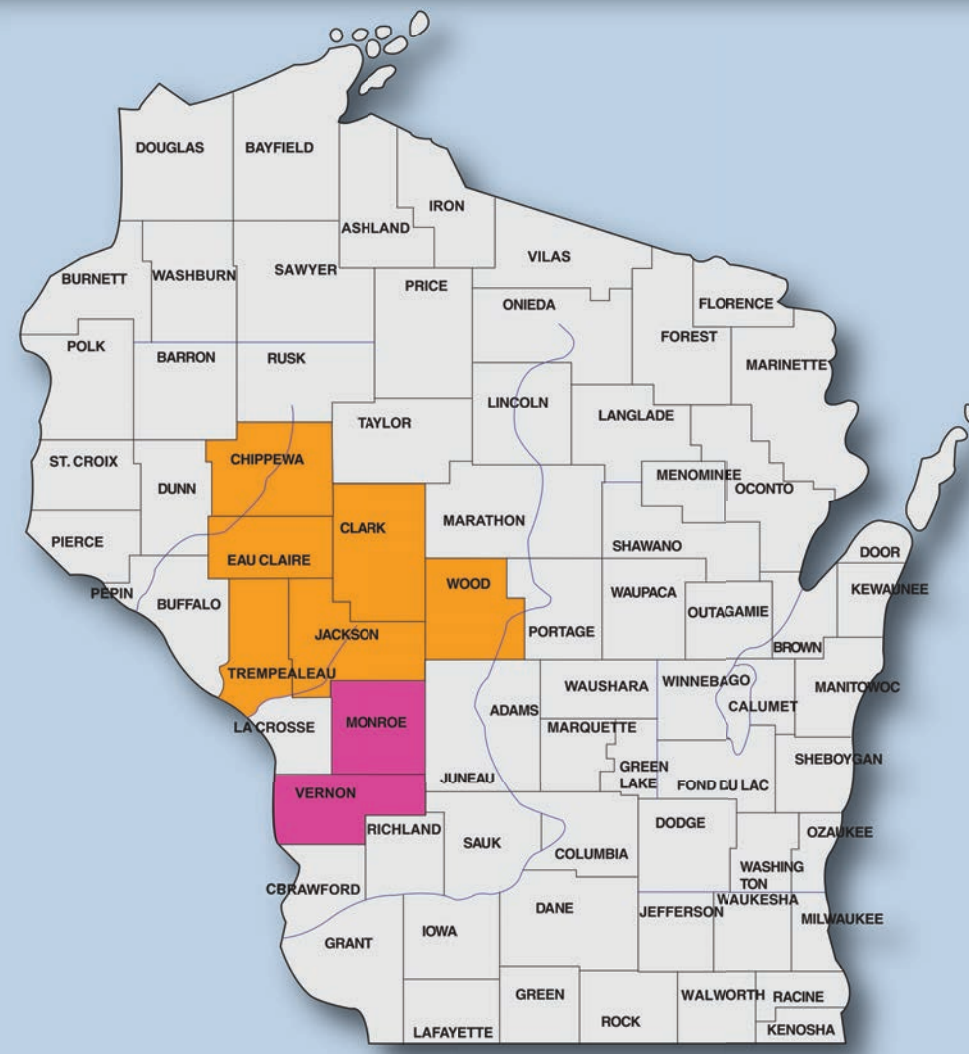


An "Impact Award" from the Genetic Alliance was funded for one year, May 2014 – April 2015. This award was designed to expand the impact of another program, called the "Amish Project." The Amish Project is funded by the Wisconsin Partnership Project, a university-community collaboration to improve the genetic screening, diagnostic and followup services available to Amish communities in Vernon and Monroe counties in western Wisconsin.

The Impact Award expands the education and outreach activities of the Amish Project into additional counties of Wisconsin with a large number of Plain communities, including Amish and Mennonite specifically.

The two objectives of the Impact Award are:
Objective 1: To conduct an education and outreach event in the Fall, 2014 in the Augusta area of Northwest Wisconsin.

Objective 2: To collect survey data from families to determine the frequency of inherited diseases in Plain communities in Northwestern Wisconsin.

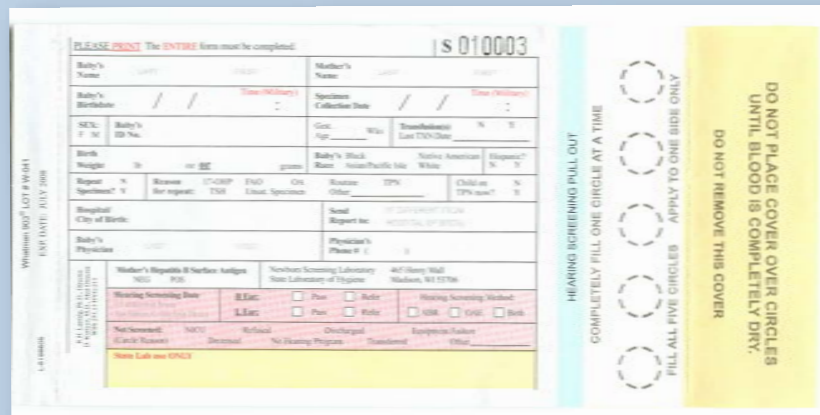


Program strategies for cross-system engagement:

- Community Advisory group** – (includes members of all groups) physician leaders, Plain community leaders, state Department of Health Services, local public health departments (formed after successful community meeting with expert Holmes Morton from Pennsylvania in 2012)
- Public health** – state Department of Health (DOH) administrators, DOH epidemiologists, DOH state lab, and local health departments
- Private and not-for-profit hospitals and health professionals** – family medicine/primary care, nurses, local midwives and plain birth attendants, local hospital and specialty clinics at tertiary care centers
- Academic partners** – physicians, LEND director and LEND trainees in genetic counseling, UCEDD contract with state Title V program for Genetics Systems Integration Hub

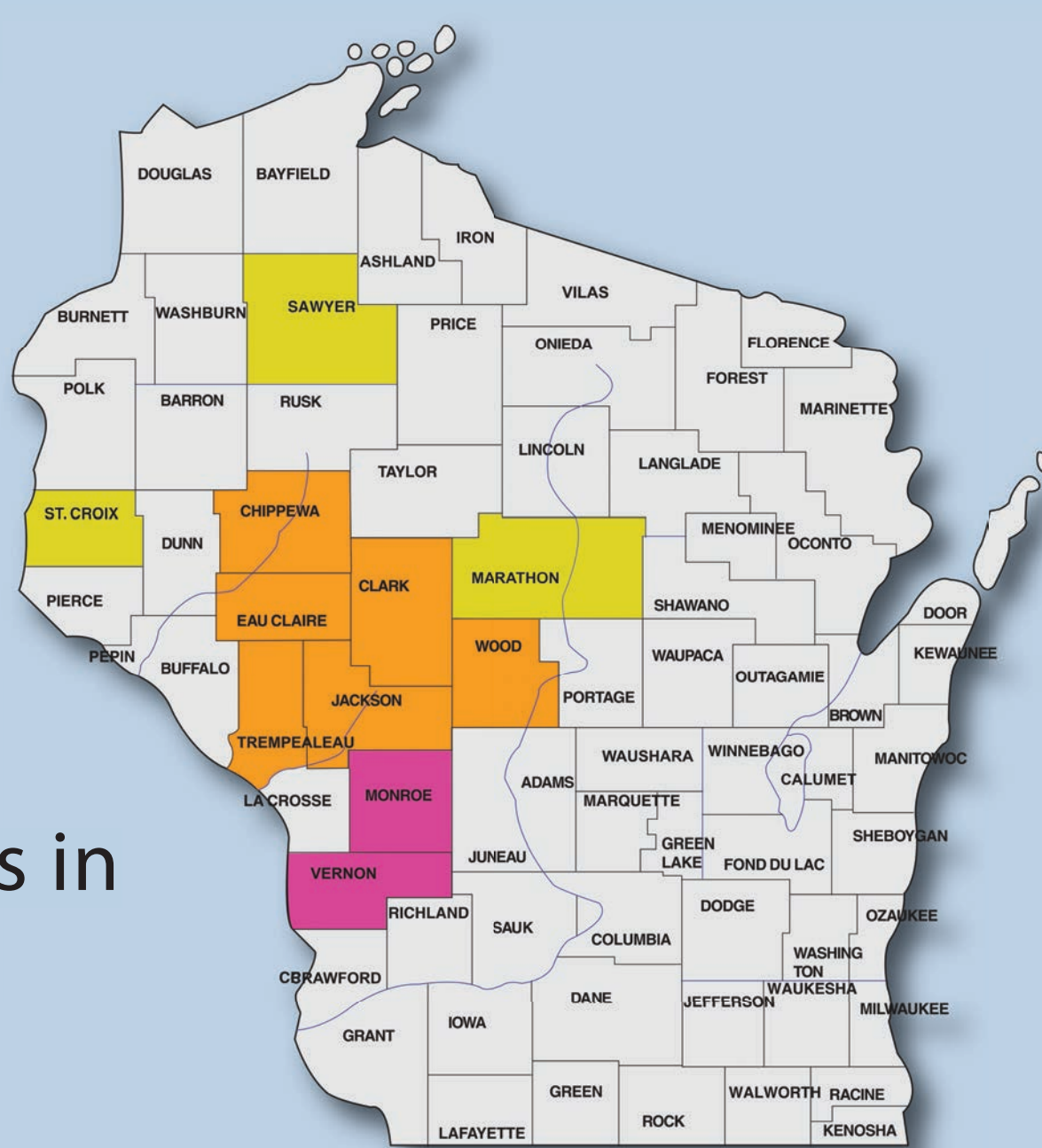
Newborn Screening Program in Wisconsin:

Wisconsin has one of the best newborn screening programs in the country, screening for 44 treatable disorders using tandem mass spectrometry, chemical, and genetic testing, screening for newborn hearing loss, and use of pulse oximetry to identify critical congenital heart defects. All newborns in Wisconsin are required by Statute and Administrative Rule to undergo newborn screening to identify congenital diseases that result in severe developmental delay or death.



Outcomes and Sustainability:

After the funding for the Impact Award is ended, staff from the Genetics Systems Integration Hub will continue data collection and data entry in conjunction with personnel from the Amish Project. Rates of newborn screening will be monitored in Plain populations and anticipated to increase, resulting in fewer OOH births in Wisconsin who do not have newborn screening completed.



Activities and Results to Date:

- Oct 21, 2014 – Community Meeting in Augusta, WI
- Attended by over 170 Plain community members, project personnel, LEND trainees
 - Surveys introduced, distributed and requests for 470 additional copies of the survey received from community leaders
 - Meeting evaluations (n=22) – 100% of respondents felt it was useful

"More awareness of Amish/Mennonite views. Having Healthcare providers in attendance to talk about the importance of newborn screenings/healthcare & immunizations"

"Very interesting"
"I especially appreciated the discussion about bridging the gap between English care providers and plain families."

- Oct 22, 2014 – Midwives Education on Newborn Screening In August, WI
- Attended by 50 Plain community midwives, 5 other local midwives serving the Plain communities, 5 local health providers and project staff
 - Meeting evaluations (n=21) – 100% of respondents felt it was useful

"Lots of great Information"

"Learning from each other"

"It was so great"

- Database in RedCap built, survey data being entered (30 surveys have been returned so far)
- Provides basis for Masters degree project for 2 LEND trainees in Genetic Counseling students

Next Steps:

- Additional midwife training requested for end of November
- Community meetings to continue to engage face-to-face with communities
- Collection of surveys, data entry and analysis



Recommendations:

- Build on successful strategies utilized in other states with high numbers of Plain communities (Pennsylvania, Ohio, Indiana) (e.g. basis for survey development and implementation, engagement with "thought leader" – Dr. Holmes Morton, respected and influential physician with relationships with Plain communities)
- Cross-system engagement starting with a Community Advisory group which provides input and oversees activities across all projects
- Obtain funding for core staff to maintain/support the Community Advisory group, build and sustain relationships across sectors, developing relationships with community leaders, build bridges across state and regional systems of care,
- Provide training opportunities with a plan for sustaining those efforts after trainees have completed their learning/work
- Leverage the unique role that the UCEDD and LEND programs can provide, working in partnership with others.

Funded by:

- Wisconsin Leadership Education in Neurodevelopmental Disabilities (LEND) – Maternal and Child Health Bureau, grant # MCJT73MC000044
- Impact Award from the Genetic Alliance, National Genetics Education and Consumer Network (NCEGN), part of the National Coordinating Center for the Regional Genetic and Newborn Screening Services Collaboratives funded by the Maternal and Child Health Bureau
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