Improved Healthcare Delivery to Wisconsin Amish Infants

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Amount Spent: $147,245

Grant Program: PERC Opportunity Grant

The Challenge: Wisconsin has one of the best newborn screening programs in the country, screening for 44 treatable disorders; and, all newborns in the state are required to undergo newborn screening (NBS) to identify genetic and metabolic diseases that result in severe developmental delay or death if early recognition and treatment does not occur.

Wisconsin Plain infants (Amish or Old Order Mennonites) have lower rates of NBS in the state with likely several hundred Plain infants not being tested annually. Many of these children are at high-risk for long-term disability and fatal outcomes after costly hospitalizations. Access to NBS and affordable healthcare would likely prevent disability and infant and child mortality in this population.

Project Goal: The project aims were focused on: 1) Community survey for NBS perspectives and unmet healthcare needs; 2) Community outreach activities for educational and healthcare purposes; and 3) Implementation of genetic testing to define the genetic disorders in the Wisconsin Plain community and inform development of low-cost genetic testing. By determining the barriers to newborn screening and establishing access to appropriate care for the Wisconsin Plain populations, this project aimed to gain the knowledge necessary to achieve early diagnosis and treatment for genetic disorders. The long-term goal of the project is to improve access to culturally-appropriate, high-quality affordable healthcare for all Wisconsin Plain children.

Results: The published survey data from 474 households showed decreased rates of newborn screening compared to the total Wisconsin NBS rate. Longitudinal NBS tracking show a trend toward increasing NBS in Plain infants since the inception of the project’s community educational and outreach meetings. Beginning in 2015, through partnership with the LaFarge Medical Clinic Center for Special Children, UW Pediatric subspecialty faculty (genetics, cardiology, ophthalmology, immunology) have staffed 27 outreach clinics seeing 173 patients with 81 diagnosed genetic disorders. Overall, the work has resulted in improved NBS rates and increased our knowledge of genetic disorders within the Wisconsin Plain population. This work identified 40 distinct genetic disorders in the Wisconsin population. Of these disorders, over 50 percent were previously unrecognized conditions in Wisconsin and several of these disorders are not commonly seen in Plain communities in other states. As a result, 23 low cost genetic tests are now clinically available with many more being validated.

This project enabled establishment of strong community-academic partnerships, enhanced trust in relationships with Plain communities, improved access to evidence-based healthcare, and enriched knowledge of the genetic disorders present in Wisconsin Plain people. This project was recognized by University of Wisconsin-Madison Chancellor Rebecca Blank through a Community-University Partnership Award in 2017. Genetic diseases in Plain populations are similar to, not different from, the genetic diseases in the general population, and the project team’s ongoing collaborations and newly awarded projects have implications for all Wisconsin children and families.