

With Strong Partners, Wisconsin Combines Newborn Screenings, Saving Time and Money

By having the right partners, Wisconsin was able to add pulse oximetry screening to an existing state data collection system and demonstrate implementing universal CCHD screening in newborns.

In September 2011, HHS Secretary Kathleen Sebelius approved adding screening for critical congenital heart disease (CCHD) to the Recommended Uniform Screening Panel of the Secretary's Advisory Committee on Heritable Disorders in Newborns and Children. With a grant from the U.S. Health Resources and Services Administration (HRSA), the Wisconsin Department of Health Services (WDHS), University of Wisconsin School of Medicine and Public Health, Medical College of Wisconsin, and Wisconsin State Laboratory of Hygiene launched a collaborative effort to implement universal CCHD screening in the state.

The Wisconsin **S**creening **H**earts in **NE**wborns (SHINE) Project was created to evaluate the costs and effectiveness of pulse oximetry (POX) screening for CCHD in newborns. The project's goal is to demonstrate implementing screening for CCHD by POX by educating healthcare providers, including licensed certified midwives, improving access to screening, and creating a statewide CCHD screening and data collection system.

Steps Taken:

- In June 2012, Wisconsin was one of six states that received a three-year grant by HRSA to study POX screening in newborns.
- To determine how they were going to collect CCHD screening data, the existing state data systems were reviewed by the principal investigators to determine if one could be used to track CCHD.
- The newborn hearing screening system, Wisconsin Early Hearing Detection and Intervention (EHDI) – Tracking Referral and Coordination (WE-TRAC), was determined to be the ideal choice to incorporate the additional screening test. WE-TRAC is relatively easy to modify and uses a similar data flow to the one needed for CCHD screening—every baby is screened soon after birth and either passes or fails.
- WDHS worked with the Wisconsin State Laboratory of Hygiene to add labels to the newborn screening bloodspot cards to document the POX screening results. The lab made the change immediately by allocating staff time to the project and modifying the newborn hearing screening data set to include CCHD. The dataset is messaged to WE-TRAC and CCHD data go into a separate staging table.
- A data committee was established with representatives from WDHS, the University of Wisconsin, the Medical College of Wisconsin, the Wisconsin State Laboratory of Hygiene, and the Wisconsin Guild of Midwives. The committee is responsible for monitoring the progress of the project; discussing and resolving any current issues; reviewing and discussing monthly summary reports that show the number of babies born at each enrolled organization, screening results, and the number missed; and making decisions on reports, analyses and evaluations required throughout the three-year cycle.

Adding a label to document pulse oximetry screening results on the bloodspot cards gave the Wisconsin SHINE project an opportunity to see that using the WE-TRAC system would work for everyone involved in the screening process before making changes to the final cards.

- SHINE began rolling out the POX training and protocol hospital by hospital. The initiative is voluntary, but many hospitals are already conducting CCHD screenings and are willing to participate in the SHINE Project.

Results:

- Newborns are screened using POX equipment at approximately 24 hours of age. Results are recorded on the newborn bloodspot card and become part of the newborn screening record in WE-TRAC Heart, the designation for the CCHD-dedicated portion of WE-TRAC.
- The university was charged with training all birthing hospitals in POX screening and ensuring that a standard protocol is followed statewide. Pulse oximeters are also provided to midwives who enroll to participate in the data collection and reporting.
- For newborns who fail the CCHD screening, a paper form is completed and sent to SHINE and all follow-up results are entered into WE-TRAC Heart. All confirmed cases of CCHD are posted in the Wisconsin Birth Defects Registry. Bloodspot card numbers are included on birth certificates in Wisconsin and will be critical in matching CCHD data to birth certificate data.
- The paper form is also used to collect information on babies who do not have a bloodspot card, have a pulse oximetry screening outside of a hospital, or have known/suspected congenital heart disease.
- After the end of the first year, there will be information available about the costs and effectiveness of universal CCHD screening, which will demonstrate if it is working and what changes will be necessary to ensure the program's sustainability.

Lessons Learned:

- To have a successful program, you need to have partners that are cooperative and willing to work together. The university, pediatric cardiologists, state lab, and WE-TRAC staff were ready and willing to make the necessary changes to ensure that CCHD screening could be implemented and tracked.
- The SHINE project partners found it helpful to have the paper form as part of education and outreach when enrolling partners.
- Changing the bloodspot card in stages, by first adding a label to existing bloodspot cards, gave the program an opportunity to see that it would work for everyone involved before making changes to the final cards.
- Adding the POX screening to an existing application and system, rather than developing a completely new application, decreased the amount of time and expense for implementation.

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