

Newborn Screening for Critical Congenital Heart Disease

January 2014

In the United States, about 7,200 babies are born every year with critical congenital heart defects (CCHD). Babies with CCHD may appear healthy at birth. To prevent this life-threatening condition from going undetected in newborns, CCHD was added to the U.S. Recommended Uniform Screening Panel in 2011. Since then, CCHD screening has been implemented in many hospitals. It is a new priority for public health to ensure that all babies are identified early to prevent death and disability.

CDC and partners have collaborated on three areas to assess the impact and outcomes of CCHD screening:

- **Building capacity to improve the effectiveness of CCHD screening:**

- » Surveyed state birth defects surveillance programs about activities related to CCHD screening.
- » Conducted field investigations in Georgia and New Jersey to assess newborn screening practices and data collection in individual hospitals.
- » Convened a meeting of state birth defects surveillance and newborn screening programs to highlight effective practices and policies.
- » Collaborated with Association of Maternal & Child Health Programs to produce an issue brief on the role of birth defects surveillance in CCHD screening.
- » Conducted studies leading to improved understanding of potential impact of screening, factors associated with late detection of CCHD in newborns, impact of health insurance on the survival of infants with congenital heart defects, and hospital resource use for pediatric discharges with congenital heart defects.
- » Currently collaborating with the American Academy of Pediatrics to monitor and document trends in CCHD newborn screening legislation.
- » Currently providing ongoing CCHD newborn screening technical assistance to state public health programs.

- **Evaluating the Cost Effectiveness of CCHD screening:**

- » Conducted a cost-effectiveness analysis using a model based on state surveillance and cost data, cost databases, and other sources. The study showed that CCHD screening appears to be cost-effective.
- » Conducted an assessment of hospital costs of screening in New Jersey. The assessment found hospitals' total estimated cost per newborn screened was \$14.19 (in 2011 U.S. dollars), consisting of \$7.36 in labor costs and \$6.83 in equipment and supply costs.
- » Conducted studies on health outcomes and hospital use of infants with CCHDs to better evaluate the impact of newborn screening for CCHD.

- **Leveraging an Electronic Health Record Framework to improve reporting:**

- » Worked with the National Library of Medicine to standardize codes for clinical data elements.
- » Currently working with the National Birth Defects Prevention Network to adapt existing standards for birth defects surveillance activities.
- » Currently exploring the development of a white paper for Clinical Data Registries using congenital heart defects as a use case to provide a description of how collecting patient and disease data related to CHD for tracking and surveillance purposes could improve the quality of care provided to those patients.

Future opportunities and needs for CCHD newborn screening:

- Pulse oximetry data will be collected to evaluate the current algorithm for screening and explore alternative pulse oximetry approaches. Subsequently, an expert group will be needed to review and potentially update existing CCHD screening guidelines in light of new data.
- Continued work with states to build best practices regarding program implementation, establishing protocols, data collection, and reporting.
- Linking CCHD screening and birth defects surveillance data to evaluate current screening methods.
- Development of standardized CCHD screening protocols for neonatal intensive care units is needed.
- Research is needed on screening certain populations (e.g., those at high altitudes) and evaluating diagnostic strategies (e.g., telemedicine) for nurseries without onsite echocardiography.

For more information on congenital heart defects and CCHD screening, visit www.cdc.gov/heartdefects