

CDC's National Center on Birth Defects and Developmental Disabilities: Newborn Screening Activities

Soon after birth, all babies born in the United States are checked for certain medical conditions. This is called newborn screening. Finding these conditions soon after birth can help prevent some serious problems, such as brain damage, organ damage, and even death. CDC's National Center on Birth Defects and Developmental Disabilities (NCBDDD) supports many newborn screening activities.



Critical Congenital Heart Defects

As newborn screening for critical congenital heart defects (CCHDs) is carried out across the U.S., NCBDDD is helping states track babies with a CCHD identified through this screening and evaluate the effectiveness of the screening. NCBDDD is also looking at cost and health benefits. Assessing how well CCHD newborn screening works will help states and health care providers better understand the possible impact. This information is important for states making decisions about adding this condition to their existing newborn screening programs.

Hearing Loss

The Early Hearing Detection and Intervention (EHDI) Program at NCBDDD works with states and territories to ensure that infants are screened for hearing loss no later than one month of age, infants who do not pass the screening for hearing loss get a full hearing evaluation no later than 3 months of age, and infants with a hearing loss receive intervention services no later than 6 months of age.

Sickle Cell Disease

NCBDDD, along with the National Heart, Lung, and Blood Institute/NIH, funded 7 states to develop a population-based surveillance system for hemoglobinopathies (sickle cell disease and thalassemia). The system combined data from newborn screening, vital statistics, and administrative databases to gain a better understanding of the incidence and prevalence of these conditions, along with information about health care utilization and mortality.

Tracking

Some of NCBDDD's state-based birth defects tracking programs are able to track certain conditions identified through newborn screening. These birth defects tracking programs refer children for services they need and monitor health outcomes.

Long-Term Follow-Up

NCBDDD funded pilot projects in 4 states to collect data on long-term follow-up of children with confirmed newborn screening conditions. Follow-up of these children makes sure that they receive the full benefits of early identification through newborn screening. Tracking health outcomes for these children is also important for public health to understand ways to help children with newborn screening conditions lead healthier lives and prevent complications.

Second Testing

Routine second testing of newborns for the conditions detected through the newborn screening blood test occurs in 12 states. Opinions differ as to whether routine second testing is the most appropriate public health approach to detect cases that might otherwise be missed by a single newborn screening test. So, NCBDDD is working with the Association of Public Health Laboratories (APHL) to study differences in detection rates in certain newborn screening conditions.

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