

CDC's Tracking and Research for the Prevention of Congenital Heart Defects

CDC is working with partners to identify causes and prevention opportunities for congenital heart defects and improve the health of those living with these conditions.

Understanding Congenital Heart Defects

Congenital heart defects are conditions that are present at birth and can affect the structure of a baby's heart and the way it works. They are the most common type of birth defect.



- **Nearly 40,000 infants in the United States are born with a congenital heart defect each year.**
- **Congenital heart defects are a leading cause of infant death from birth defects during the first year of life.**
- **There are nearly 1 million adults in the United States living with a congenital heart defect.**
- **In the United States in 2004, the costs for hospital care of people of all ages with congenital heart defects totaled \$1.4 billion.**

Tracking Congenital Heart Defects

To track congenital heart defects, CDC has established state-based birth defects tracking systems. Today, many states collect information about congenital heart defects in their birth defects tracking efforts. Information obtained from these systems is used to:

- Understand the characteristics of children with a heart defect
- Identify health disparities in the occurrence of congenital heart defects and survival of those affected
- Plan for services across the life span
- Help to ensure that children with congenital heart defects receive necessary medical care and services.

Information gathered from tracking systems provides a basis for research studies. Such research studies are designed to identify potential causes and opportunities for preventing congenital heart defects and promoting the health of affected people.

Identifying Preventable Causes

The Centers for Birth Defects Research and Prevention (CDBRP) are research centers across the nation funded by CDC to understand the causes of birth defects, including heart defects. The CDBRP collaborate on two large studies: the National Birth Defects Prevention Study (NBDPS) and the Birth Defects Study to Evaluate Pregnancy exposures (BD-STEPS). The size and scope of these studies provide opportunities to look at possible causes of birth defects.

CDC's research on the causes of heart defects highlights the need for birth defects prevention strategies for women of childbearing age. Recently, CDBRP collaborators reported important findings about pregnancy exposures that increase the risk for congenital heart defects. Exposures such as obesity, tobacco and certain medications could potentially be avoided by pregnant women and hold promise for preventing congenital heart defects.

Although researchers are learning more about congenital heart defects, much work remains. For example, researchers are:

- Investigating the possible effects of other common pregnancy exposures, such as fever, infection, and medications on congenital heart defects
- Exploring approaches to decrease the number of women with uncontrolled diabetes during pregnancy to prevent congenital heart defects as well as other major birth defects
- Evaluating long term outcomes, healthcare costs, and quality of life to identify opportunities that will support the health and wellness of children and adults affected by congenital heart defects

Newborn Screening for Critical Congenital Heart Defects

In the United States, of the 40,000 babies born each year with a congenital heart defect, about 7,200 have a critical congenital heart defect (CCHD). Babies with CCHDs usually require surgery or catheter intervention in the first year of life. 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 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, evaluating the cost effectiveness of CCHD screening, and leveraging an electronic health record framework to improve reporting.

Future opportunities and needs for CCHD newborn screening:



- Collect pulse oximetry data to evaluate the current screening methods and explore alternative approaches
- Continue to work with states to build best practices regarding program implementation, establishing protocols, data collection, and reporting
- Link CCHD screening and birth defects tracking data to evaluate current screening methods
- Develop standardized CCHD screening protocols for neonatal intensive care units
- Research screening methods for certain populations (e.g., those at high altitudes) and evaluate diagnostic strategies (e.g., telemedicine) for nurseries without onsite echocardiography (specialized ultrasound equipment and expertise to examine structure of the heart)

Congenital Heart Defects across the Lifespan

As medical care and treatment have advanced, babies with congenital heart defects are living longer and healthier lives. Many are now living into adulthood. Although this is remarkable progress, it presents new challenges for families and the healthcare system to meet the special health needs of these individuals.

CDC received funding from Congress in 2012 to enhance and expand public health tracking of congenital heart defects across the lifespan. This is being done so that researchers can better understand the survival, healthcare use, and longer-term outcomes of adolescents and adults living with CHDs. With this funding,

- CDC is working with three grantees on a pilot project of population-based tracking of adolescents and adults with congenital heart defects. The grantees include the New York State Department of Health, Emory University, and the Massachusetts Department of Public Health.
- The three grantees collect and combine data from different areas and varying data sources within their states. All the data will be analyzed as a group, so any one person with a congenital heart defect cannot be identified.
- Each grantee uses the same criteria to identify individuals with congenital heart defects and collects the same types of data. This is helpful so that the data can be grouped together for analyses.
- The three grantees are in varying stages of data collection.

As a result of an increase in funding in 2014, CDC has the opportunity to plan a survey of adults with congenital heart defects. This survey will collect information on longer term outcomes, barriers to care, and out-of-pocket costs for survivors of congenital heart defects.

These activities can provide important insights to guide our continued efforts to prevent heart defects and support families affected by them.

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

National Center on Birth Defects and Developmental Disabilities

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