

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

CDC is working with partners to identify the causes of congenital heart defects (CHDs) and learn more about how to prevent them. We want to learn more about individuals living with CHDs and identify strategies to improve their health.



Understanding Congenital Heart Defects

CHDs are conditions present at birth that 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 CHD each year.
- CHDs are a leading cause of birth defect-related infant death during the first year of life.
- In 2013, hospital costs to care for children with CHDs exceeded \$6 billion.
- About 1.4 million adults and 1.0 million children in the United States are living with CHDs.

Tracking Congenital Heart Defects

CDC supports state-based birth defects tracking systems to collect information about many birth defects, including CHDs. Information on children with CHDs obtained from these systems is used to:

- Understand their characteristics.
- Identify disparities in health and survival.
- Plan for services across the lifespan.
- Help to ensure they receive necessary medical care and services.
- This information provides a basis for research studies designed to identify potential causes of CHDs and find ways to prevent them.

Identifying Preventable Causes

The Centers for Birth Defects Research and Prevention (CBDRP) are CDC-funded research centers examining the causes of birth defects, including CHDs.

- The CBDRP collaborate on two large studies: the National Birth Defects Prevention Study (NBDPS) and the Birth Defects Study To Evaluate Pregnancy exposures (BD-STEPS). These studies can help to identify the possible causes of birth defects with a focus on risk factors that can be changed.
- For example, CBDRP researchers have learned that women who are obese, use tobacco and/or take certain medications have an increased risk of having a baby with a CHD. Changing these risk factors may hold promise for preventing some CHDs.

Although researchers are learning more about CHDs and their risk factors, the causes of most CHDs are unknown and more research is needed.



Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities

Newborn Screening for Critical Congenital Heart Defects

Of the 40,000 babies born each year with a CHD in the United States, about 7,200 have a critical CHD (CCHD), which are some of the most serious types of CHDs. Babies with a CCHD usually require surgery or catheter procedure in the first year of life. CCHD newborn screening has been implemented in nearly every state.

- States that require CCHD screening have 33% fewer infant deaths from CCHD compared to states without screening requirements.
- CCHD screening is projected to save at least 120 babies each year in the United States.
- CDC is working with partners to better understand how newborn screening is impacting the lives of those with CCHD.



Congenital Heart Defects across the Lifespan

As medical care and treatment have advanced, babies with CHDs are living longer and healthier lives, many into adulthood. Although this is remarkable progress, it presents new challenges to meet the special needs of these individuals. CDC is working to learn the number of people living with CHDs and to collect information about their long-term health outcomes, healthcare costs, and quality of life. This information can help identify opportunities to support the health and wellness of all persons living with CHDs.

- In 2012, CDC received funding to track adolescents and adults with CHDs. From 2012--2015, CDC worked on a pilot project with Emory University in Georgia, the New York State Department of Health, and the Massachusetts Department of Public Health to develop population-based tracking of adolescents and adults with CHD.
- In 2015, CDC started a four-year project to expand upon the pilot project. Five sites—University of Colorado, Duke University in North Carolina, Emory University in Georgia, the New York State Department of Health, and the University of Utah—are working to better understand the survival, healthcare use, and longer term health outcomes of individuals of all ages with CHDs.
- Since 2015, CDC has collaborated with the New York State Department of Health to evaluate geographic barriers to care and healthcare costs for adolescents with CHDs.
- In 2016, CDC, in partnership with March of Dimes, the University of Arizona College of Medicine, and the Arkansas Center for Birth Defects Research and Prevention launched the Congenital Heart Survey To Recognize Outcomes, Needs, and well-beinG (CH STRONG), a survey among adults with CHDs to assess their health, social and educational status, and quality of life.

These activities can provide important insights to guide our continued efforts to prevent CHDs and support families affected by them. To learn more about CHDs, please visit www.cdc.gov/heartdefects.