

Congenital Heart Defects: CDC's Tracking and Research Activities

CDC works to better understand how often and why congenital heart defects (CHDs) occur, and the characteristics and health outcomes, use of services, and racial/ethnic differences of people living with CHDs. By learning more about those living with CHDs, CDC can 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 structural 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.
- More than 1 in 6 adults with CHDs have physical, educational, or occupational limitations.

Tracking Congenital Heart Defects at Birth

CDC supports state-based birth defects tracking systems to collect information about many birth defects, including CHDs. Data from these systems provide a basis for identifying the potential causes of CHDs and understanding the longer-term health needs of people living with CHDs across the lifespan.

Learning about Congenital Heart Defects Across the Lifespan

As treatment has advanced, infants with CHDs are living longer and healthier lives, many into adulthood. Since 2012, CDC has worked to estimate the number of people living with CHDs and learn more about their long-term health outcomes. This information can help identify opportunities to support the health and wellness of all people living with CHDs.

In 2019, CDC launched the Congenital Heart Defects Surveillance across Time And Regions (CHD STAR) project. CDC is funding seven sites through 2024, University of Arizona, Duke University, Emory University, University of Iowa, New York State Department of Health, South Carolina Department of Health and Environmental Control, and the University of Utah, to link and examine 10 years of data on children, adolescents, and adults with CHDs. CHD STAR will continue CDC's effort to evaluate survival, health outcomes, healthcare use, and racial/ethnic differences in outcomes among people living with CHDs.



Centers for Disease
Control and Prevention
National Center on Birth Defects
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Identifying Preventable Causes

Not all CHDs can be prevented. Although researchers have learned a lot about CHDs and their risk factors, more research is needed to understand the causes of most CHDs.

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 help to identify the possible causes of birth defects with a focus on risk factors that can be changed, such as behaviors and harmful exposures at work and in the home.

Advancing Newborn Screening for Critical Congenital Heart Defects

About 1 in 4 babies born with a heart defect will have a critical congenital heart defect (CCHD). Babies with a CCHD usually require surgery or other procedures in the first year of life. As of 2019, babies born in all 50 states and the District of Columbia have the opportunity to be screened for CCHDs at birth. CCHD newborn screening can help identify some babies with CCHDs before they go home from the birth hospital, which 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 impacts the lives of those with CCHDs.



CDC's Congenital Heart Defects Tracking and Research activities provide important insights to guide continued efforts to prevent congenital heart defects and support families affected by them.

To learn more about congenital heart defects, please visit www.cdc.gov/heartdefects.



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