

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

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

## Understanding Congenital Heart Defects

Congenital heart defects 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 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 1.4 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 disparities in health and survival for those who have a congenital heart defect;
- Plan for services across the lifespan; and
- 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, as well as to improve the health of people living with congenital heart defects.

## Identifying Preventable Causes

The Centers for Birth Defects Research and Prevention (CBDRP) are research centers across the nation funded by CDC to understand the causes of birth defects, including congenital heart defects. 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). The size and scope of these studies provide opportunities to look at possible causes of birth defects.

CDC's research on the causes of congenital heart defects highlights the need for birth defects prevention strategies for women of childbearing age. Recently, CBDRP collaborators reported important findings about factors during pregnancy that can increase the risk for congenital heart defects. Being obese, using tobacco, and taking certain medications, for example, could potentially be avoided by pregnant women and thus hold promise for preventing some 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 factors during pregnancy, such as fever, infection, and medications on the risk for congenital heart defects;
- Exploring approaches to decrease the number of women with uncontrolled diabetes during pregnancy, which could prevent some congenital heart defects, as well as other major birth defects; and
- Evaluating long term health outcomes, healthcare costs, and quality of life in order to identify opportunities to support the health and wellness of children and adults living with 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 a CCHD 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 nearly every state. It is a priority for public health to ensure that all babies are identified early to prevent death and disability from a CCHD.

CDC and partners have collaborated on three areas to assess the impact and health outcomes of CCHD screening: building capacity to improve the effectiveness of CCHD screening, evaluating the cost effectiveness of CCHD screening, and using electronic health records to improve reporting.

## 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.

In 2012, CDC received funding to enhance and expand public health tracking of congenital heart defects among adolescents and adults. From 2012 - 2015, CDC worked on a pilot project with Emory University in Atlanta, 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 congenital heart defects. Data analysis from this pilot project is ongoing.

As a result of increases in funding, CDC has had the opportunity to begin additional projects that will determine the public health impact of congenital heart defects across the lifespan.

- In 2015, a new four-year project was started to expand upon the three-site pilot project that tracked adolescents and adults with congenital heart defects. Five sites—University of Colorado in Denver, Duke University in Durham, North Carolina, Emory University in Atlanta, Georgia, the New York State Department of Health, and the University of Utah in Salt Lake City—will work to better understand the survival, healthcare use, and longer term health outcomes of individuals with congenital heart defects across the lifespan.
- CDC, in partnership with March of Dimes, has launched a survey of adults with congenital heart defects. This survey will assess health, social and educational status, and quality of life for survivors of congenital heart defects. CDC, along with the University of Arizona College of Medicine and the Arkansas Center for Birth Defects Research and Prevention, plan to distribute the survey in fall 2016.
- CDC is collaborating with the New York State Department of Health to evaluate barriers to care for individuals with congenital heart defects, and to assess geographic patterns of care and longer term health outcomes for children, adolescents, and adults with congenital heart defects. Data from this project will be analyzed in 2017.

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](http://www.cdc.gov/heartdefects)**

### National Center on Birth Defects and Developmental Disabilities

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