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

"I think about the pain and frustration we have been through, and my hope for other families is that we can find out what causes congenital heart defects so that we can prevent them."

—Mother of a child with a congenital heart defect

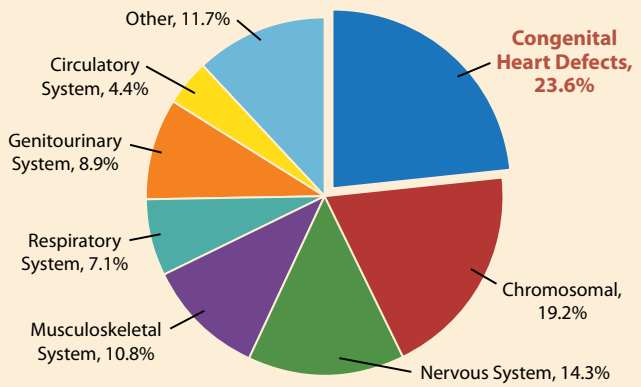
Understanding Congenital Heart Defects

- **Congenital heart defects are conditions present at birth that affect the structure and function of the heart.**
- **Nearly 40,000 infants in the U.S. 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 U.S., in 2004, the costs for hospital care of people of all ages with congenital heart defects totaled $1.4 billion.**

CDC works to identify causes and prevention opportunities for congenital heart defects by applying a public health approach—surveillance or disease tracking, research to identify causes, and prevention research and programs.

Infant Deaths from Birth Defects, By Cause

United States, 2007



Tracking Congenital Heart Defects

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

- Understand the characteristics of affected children
- 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

In addition, information from tracking systems provides a basis for research studies designed to identify potential causes and opportunities for preventing congenital heart defects and promoting the health of affected people.

Identifying Preventable Causes

CDC coordinates the largest population-based effort in the U.S. to identify the preventable causes of birth defects: the National Birth Defects Prevention Study. Population-based studies like this one evaluate the occurrence of disease across a wide group of people, which is important to make sure that study results are applicable to the US population.

National Center on Birth Defects and Developmental Disabilities
Division of Birth Defects and Developmental Disabilities

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Recently, CDC's study collaborators have reported important findings about some pregnancy exposures that increase the risk for congenital heart defects:

- **Obesity** — women who are obese before pregnancy were shown to have an increased risk of having a pregnancy affected by a congenital heart defect;
- **Diabetes** — women with diabetes diagnosed before pregnancy are more at risk of having a child with a number of birth defects, including congenital heart defects;
- **Smoking** — women who smoked anytime during the month before pregnancy through the end of the first trimester were more likely to have a pregnancy affected by a congenital heart defect.

Next Steps in Preventing Congenital Heart Defects

CDC's unique ability to study the occurrence of disease in the population holds promise for identifying risk factors for congenital heart defects that can be translated into prevention strategies. Although researchers are learning more about congenital heart defects, much work remains. For example, researchers are:

- Investigating the possible effects of other common exposures, such as maternal fever, infection, and medications.
- 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, health care costs, and quality of life to identify opportunities that will support the health and wellness of children and adults affected by congenital heart defects.

CDC's research on the causes of heart defects highlights the need for birth defects prevention strategies for women of childbearing age. Reducing obesity, providing better control of diabetes, and preventing tobacco exposure during pregnancy are all actions we can take today that hold promise for preventing congenital heart defects.

Future Opportunities for Tracking Congenital Heart Defects

As medical care and treatment have advanced, infants 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 to families and the health care system to meet the special health needs of these individuals. And yet, currently, no population-based surveillance system exists to look at this growing population of children and adults with congenital heart defects.

Improved surveillance would allow for better estimates of prevalence, types of health services needed, and costs of such services. CDC's multifaceted approach could include:

- Enhancement of existing birth defects surveillance systems to include a more diverse population of births and improved tracking for research to identify potential causes and longer term outcomes.
- Development of plans to conduct population-based surveillance of children and adults with congenital heart defects.

For more information, visit www.cdc.gov/ncbddd/heartdefects/index.html

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