

Congenital Heart Defects

Frequently Asked Questions

What is a congenital heart defect?

- Congenital heart defects (CHDs) are problems with the heart's structure that are present at birth.
- Common examples include holes in the inside walls of the heart and narrowed or leaky valves. In more severe forms of CHDs, blood vessels or heart chambers may be missing, poorly formed, and/or in the wrong place.

How common are congenital heart defects?

- CHDs are the most common birth defects. CHDs occur in almost 1% of births.
- Nearly 40,000 infants in the U.S. are born each year with CHDs.
- CHDs are about 30 times more common than cystic fibrosis and 50 times more common than childhood cancer.
- In 2010, approximately 2.4 million individuals were estimated to be living with CHD in the United States, 1.4 million of whom were adults. Because there is no U.S. system to track CHDs beyond early childhood, precise counts are not available.

What is the lifelong impact of congenital heart defects?

- CHDs are the most common cause of infant death due to birth defects.
- Approximately 25% of children born with a CHD will need heart surgery or other interventions to survive.
- Over 85% of babies born with a CHD now live to at least age 18. However, children born with more severe forms of CHDs are less likely to reach adulthood.
- Surgery is often not a cure for CHDs. Many individuals with CHDs require additional operation(s) and/or medications throughout their lifetime.
- People with CHDs face a life-long risk of health problems such as issues with growth and eating, developmental delays, difficulty with exercise, heart rhythm problems, heart failure, sudden cardiac arrest, stroke, breathing problems, kidney failure, seizures, mental health challenges, and increased risk of cancer.
- People with CHDs are now living long enough to develop illnesses like the rest of the population, such as obesity, high blood pressure, high cholesterol, coronary artery disease, and other acquired heart disease.
- CHDs can have important lifelong neurodevelopmental and neurocognitive effects, leading to challenges in education, employment, and social relationships.
- CHDs are now the most common heart problem in pregnant women.

What causes congenital heart defects?

- Most causes of CHDs are unknown. Only 15-20% of all CHDs are related to known genetic conditions.
- Most CHDs are thought to be caused by a combination of genes and other risk factors, such as environmental exposures and maternal conditions. Because the heart is formed in early in pregnancy, the damage may occur before most women know they are pregnant.
- Environmental exposures that may be related to risk of having a CHD include the mother's diet and certain chemicals and medications. Maternal diabetes is a recognized cause of CHDs. Maternal obesity, smoking, and some infections also may raise the risk of having a baby with a CHD. Addressing these factors before and during pregnancy may lower, but not eliminate, the risk of a fetus developing CHD.
- A baby's risk of having a CHD is increased by 3 times if the mother, father, or sibling has a CHD.

What are the health care access and cost challenges related to congenital heart defects?

- In 2013, hospital costs for all individuals with CHD exceeded \$6.1 billion; this represents 27% of all birth defect-associated hospitalization costs.
- Adults with CHD may face challenges in obtaining health insurance coverage with appropriate access and benefits.
- Compared to the general population, adults with CHD have 3 – 4 times higher rates of Emergency Room visits, hospitalizations, and Intensive Care Unit stays.
- Loss to follow-up is common among those with CHD. About a quarter of patients do not see a CHD provider after age 6 and about half after age 13.
- Less than 10% of adults with CHDs in the U.S. who need care from specialty adult CHD centers are receiving the recommended care.