

## FAQs About Congenital Heart Defects

### What is a congenital heart defect?

Congenital means inborn or existing at birth. Among the terms you may hear are congenital heart defect, congenital heart disease and congenital cardiovascular disease. The word "defect" is more accurate than "disease". A congenital cardiovascular defect occurs when the heart or blood vessels near the heart do not develop normally before birth.

### What causes congenital cardiovascular defects?

Congenital cardiovascular defects are present in about 1% of live births. They are the most common congenital malformations in newborns. In most cases, scientists do not know why they occur. Sometimes a viral infection causes serious problems. German measles (rubella) is an example. If a woman contracts German measles while pregnant, it can interfere with how her baby's heart develops or produce other malformations. Other viral diseases also may cause congenital defects.

### Is all heart disease in children congenital?

No, but most is. These defects are usually but not always diagnosed early in life. Rarely, heart disease is not congenital but may occur during childhood such as heart damage due to infection. This type of heart disease is called acquired; examples include Kawasaki disease and rheumatic fever. Children also can be born with or develop heart rate problems such as slow, fast, or irregular heartbeats, known as "arrhythmia."

### Who is at risk to have a child with a congenital heart defect?

Anyone can have a child with a congenital heart defect. Out of 1000 births, eight babies will have some form of congenital heart disorder, most of which are mild. If you or other family members have already had a baby with a heart defect, your risk of having a baby with heart disease may be higher.

### How many people in the United States have a congenital heart defect?

Estimates suggest that about 1,000,000 Americans have a congenital heart defect. Approximately 35,000 babies are born with a defect each year.

### How can I tell if my baby or child has a congenital heart defect?

Severe heart disease generally becomes evident during the first few months after birth. Some babies are blue or have very low blood pressure shortly after birth. Other defects cause breathing difficulties, feeding problems, or poor weight gain. Minor defects are most often diagnosed on a routine medical checkup. Minor defects rarely cause symptoms. While most heart murmurs in children are normal, some may be due to defects.

### How serious is the problem?

Congenital heart defects are the most common birth defect and are the number one cause of death from birth defects during the first year of life. Nearly twice as many children die from congenital heart disease in the United States each year as die from all forms of childhood cancers combined. Over 91,000

life years are lost each year in the U.S. due to congenital heart disease. Charges for care exceed 2.2 billion dollars, for inpatient surgery alone.

### **Are things improving?**

Definitely. Overall mortality has significantly declined over the past few decades. For example, in the 1960s and 1970s, the risk of dying following congenital heart surgery was about 30% and today it is around 5%.

### **How well can people with congenital heart defects function?**

Virtually all children with simple defects survive into adulthood. Although exercise capacity may be limited, most people lead normal or nearly normal lives. For more complex lesions, limitations are common. Some children with congenital heart disease have developmental delay or other learning difficulties.

### **What is the social/financial impact of congenital heart defects?**

Successful treatment requires highly specialized care. Severe congenital heart disease requires extensive financial resources both in and out of the hospital. Children with developmental delay also require community and school-based resources to achieve optimum functioning.

### **What is the impact of congenital heart disease on families?**

The presence of a serious congenital heart defect often results in an enormous emotional and financial strain on young families at a very vulnerable time. Patient/family education is an important part of successful coping.

### **What are the types of congenital defects?**

Most heart defects either obstruct blood flow in the heart or vessels near it, or cause blood to flow through the heart in an abnormal pattern. Rarely defects occur in which only one ventricle (single ventricle) is present, or both the pulmonary artery and aorta arise from the same ventricle (double outlet ventricle). A third rare defect occurs when the right or left side of the heart is incompletely formed - hypoplastic heart. Other rare defects and syndromes affect the heart. Some of these include Heterotaxy Syndrome and Vascular Rings.

*(Source: American Heart Association)*