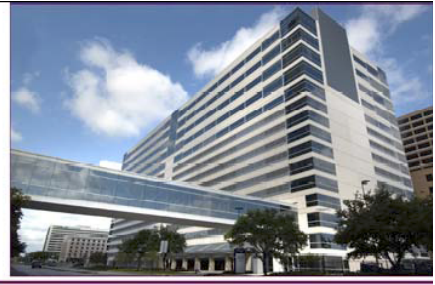


# Baylor Clinic Healthletter



## Focus on Congenital Heart Disease

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*By Wayne J. Franklin, MD, Medical Director, Texas Adult Congenital Heart Center, and Assistant Professor of Medicine and Pediatrics, Baylor College of Medicine*

Congenital heart disease, or heart defects present at birth, are the most common type of birth defect in the U.S., affecting 8 out of 1,000 babies born each year. Before the 1940s, the mortality rate of those born with congenital heart disease was extremely high. These young patients frequently died before their first birthday. Today, thanks to advances in cardiac surgery and cardiology care, more than 85 percent of children born with congenital heart disease survive into adulthood. As a result, there are now more than 1 million adult congenital heart patients living in the U.S., all with unique medical needs that grow more complex as they age.

Below, Dr. Wayne Franklin, medical director of the Texas Adult Congenital Heart Disease (TACH) Center and assistant professor of Medicine and Pediatrics at Baylor College of Medicine, talks about this disease, the need for specialized care for this burgeoning population, and the broader need for improved heart health among our nation's children.

### **Q.: What causes congenital heart defects?**

A.: Congenital heart defects can result from improper development of the heart during fetal life. While genetics and environmental factors may play a role in some cases, these defects are generally sporadic.

### **Q.: Can testing be performed during pregnancy to predict congenital heart disease?**

A.: Normal fetal ultrasounds can typically detect major heart problems in the fetus, which would require a complete evaluation of the baby's heart by a pediatric cardiologist trained in fetal echocardiography. Through early detection, we can all work together – the pediatric cardiologists, surgeons and the mother's obstetrician – to manage the baby's health and, when warranted, provide critical treatment immediately after birth, improving outcomes.

### **Q.: Are congenital heart defects always diagnosed at birth?**

A.: In some cases congenital heart disease may not be diagnosed until later in life, say as a teenager, because the defects may not cause obvious symptoms like heart murmurs, breathing problems, blueness or rhythm problems. Sometimes these are detected later through a physical exam or non-invasive imaging like an echocardiogram, which is an ultrasound exam of the heart.

### **Q.: Can congenital heart defects be cured?**

A.: Rarely. The majority of babies born with congenital heart disease face a lifetime of chronic heart problems including rhythm disturbances, chronic heart failure, and pulmonary blood flow problems leading to cyanosis or blueness. Heart problems that arise later as a result of their primary heart defect can cause other systemic problems. The heart can affect the way many other organs function, so it is important to address heart disease at any age.

### **Q.: How is congenital heart disease treated?**

A.: While treatment depends on the specific condition, most congenital heart defects are treated with medications and/or surgery, under the care of cardiologists and cardiac surgeons who are expertly trained

to diagnose and treat congenital cardiac problems. For many complex heart lesions, these should be treated at a major medical center with a team fully dedicated to these often-complicated cases.

**Q.: What happens as these congenital heart disease patients age?**

A.: Many continue to see their pediatric cardiologist well into their adult years, since they have often seen this doctor from birth. But with adulthood comes a new set of health issues and challenges which pediatric cardiologists are typically not familiar with – like pregnancy, hypertension, diabetes, high cholesterol and smoking. As a result, what we’re seeing today is an explosive demand for doctors specialized in the care of *adult* congenital heart patients, as these patients “graduate” from pediatric care.

**Q.: How is the medical community responding to that need?**

A.: Through facilities like the Texas Adult Congenital Heart (TACH) Center that specialize in transitioning congenital heart disease patients from pediatric to adult care. Currently, the demand for this type of care far exceeds the supply of qualified healthcare providers. As a result, many of these patients are turning to regular adult cardiologists for care, but these physicians often lack the training and expertise to address their unique healthcare needs.

As a medical community, we helped thousands of children survive congenital heart disease and grow into adulthood. Now we need to build on that success by ensuring the doctors, research, and high-quality care are available to address the complex medical needs these patients will face throughout their adult lives.

**Q.: How do you treat these adult congenital heart patients when they come see you?**

A.: Through a team approach – that’s imperative because of the complexity of their needs. These adult patients typically have a variety of health issues – all stemming from their congenital heart problem – that involve other organ systems, such as the lungs, kidneys, brain, or even psychological or psychiatric problems from being a chronic heart patient. Providing top-quality care requires a multidisciplinary approach, with many physicians and healthcare providers all working together to manage these health problems and take complete care of the patient, ensuring the best possible outcomes.

For example, let’s say a congenital heart patient comes in and she is pregnant. We become part of her healthcare team, working with the obstetrician to manage the mother’s care all the way through her pregnancy, planning the best type of delivery with the obstetrician, based on the mother’s heart health, and then being there in case any problems arise at delivery.

**Q.: What advice do you have for parents to improve the heart health of their children?**

A.: *All parents* – not just those of congenital heart disease patients – need to teach children from the earliest age the importance of a healthy lifestyle for a healthy heart.

We’ve experienced great success treating children with congenital heart disease. That’s the good news. The bad news is we’re treating an increasing number of young children today for *acquired* cardiovascular disease caused by obesity.

We can’t prevent congenital heart disease. We *can* prevent heart disease caused by obesity by keeping our children active, teaching them the importance of good nutrition, and setting a good example with a healthy lifestyle ourselves. It’s an area where parents can have a huge impact on their children’s future.

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*The TACH Center provides adult congenital heart disease patients a safe, smooth, uninterrupted transition of healthcare from pediatric specialists in the early stages of their lives, to a multidisciplinary medical team capable of addressing their adult healthcare needs and lifestyles, resulting in outstanding care from birth to old age.*

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