

FACTS

Small Hearts – Big Challenges

Congenital Heart Defects (CHD) in Children, Youth and Adults

OVERVIEW

Often viewed as a problem of adults, cardiovascular disease also exacts a terrible toll on the young. Congenital cardiovascular defects, also known as congenital heart defects (CHD), are the most common birth defect in the U.S.¹ and the leading killer of infants with birth defects.² The incidence of CHD ranges between 4 and 10 per 1,000 live births.³ Tragically, more than 1,500 of them do not live to celebrate their first birthday.² Beyond the terrible death toll, physical and mental suffering, and lost potential and productivity that CHD causes, it also comes with a steep price tag. In 2004, hospital costs for all individuals with CHD totaled \$2.6 billion.^{4,5}

But there is still real reason for hope. Due to research, most survive to adulthood, including many who formerly would have died.⁶ However, the survivors – particularly those with more complex forms of CHD – are more likely to develop additional heart problems later in life. Young adults with CHD also face enormous barriers to effective health care, particularly when they are no longer covered by their parents' health plans. While the Affordable Care Act requires that these patients be offered coverage, few life insurance companies are willing to underwrite them or the cost is prohibitive.

CHD AND THEIR CAUSES

CHD are problems with the heart's structure that are present at birth, such as holes in the heart, narrowed or leaky valves and malformed or missing vessels and heart chambers. The risk is higher if a sibling or a parent, especially the mother, has CHD – the absolute risk increasing from 1% to 2-10%.⁷ While the causes of non-inherited CHD are still largely unknown, researchers have identified both genetic and non-inherited⁸ 3 risk factors, including:

- Genetic or chromosomal abnormalities
- Environmental factors, such as maternal exposure to certain medications or organic solvents
- Maternal infections, such as rubella or influenza
- Maternal smoking just before or during pregnancy
- Exposure to second hand smoke
- Binge drinking before or during pregnancy
- Maternal diabetes
- Maternal overweight or obesity.⁹

PREVALENCE AND MORTALITY

The prevalence of congenital cardiovascular defects in both adults and children has increased strikingly due to increased survival.

- One study shows that severe CHD rose by 85% in adults and 22% in children from 1985-2000.¹⁰

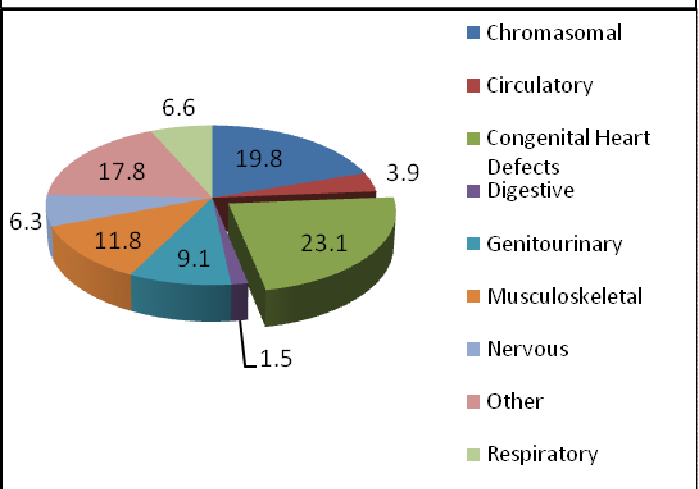
- As of 2002, it was estimated that 650,000 to 1.3 million Americans had CHD. More recent studies show these numbers could be increasing.¹¹
- CHD are about 60 times more prevalent than childhood cancers.^{12,13,14}

Although the mortality rate for CHD has sharply declined since 1994, CHD is still a major killer.¹⁵

- Nearly one in three infants who dies from a birth defect has a heart defect,^{2,16} the most common cause of infant death resulting from birth defects.⁵
- CHD directly caused or contributed to the deaths of 5,359 in 2008.³
- In 2007, 189,000 life years were lost before age 55 due to deaths from heart defects existing at birth – nearly equivalent to the life-years lost from leukemia, prostate cancer and Alzheimer's disease combined.³

INFANT DEATHS FROM BIRTH DEFECTS, BY CAUSE (%)
United States, 2008

Source: National Center for Health Statistics. Calculations by the American Heart Association 2012.



REDUCING RISK FACTORS FOR CHD & EARLY DETECTION

The American Heart Association makes the following recommendations to help prospective mothers lower the risk of CHD in their babies:⁸

- Take a daily multivitamin with folic acid.
- Obtain preconception and prenatal care, with specific attention to detection and effective management of diabetes.
- Get rubella vaccine and avoid contact with people with fever-related illnesses.
- Discuss prescription and over-the-counter medication use with a doctor.
- Avoid exposure to organic solvents.

The AHA also advocates for effective screening for CHD in newborns before they are discharged from a hospital/birthing center.

In September 2011, the U.S. Secretary of Health and Human Services recommended that Pulse Oximetry screening be added to the Recommended Uniform Screening Panel for newborns, a series of tests conducted on babies before they are discharged from the hospital after birth.

Pulse oximetry screening is a non-invasive test that estimates the percentage of hemoglobin in the blood that is saturated with oxygen. The level of oxygen saturation is indicative of how well the heart is functioning. When conducted on newborns at the time of delivery, and in conjunction with current CHD screening methods, pulse oximetry screening greatly improves the effectiveness and likelihood of detecting critical or possibly life-threatening heart defects that might otherwise go undetected.

ACCESS TO HEALTH CARE

Prior to the implementation of the Affordable Care Act (ACA), children who suffered from CHD often found it difficult to obtain health insurance in childhood (if their parents have individual or small-group coverage) and adulthood because of restrictions relating to “preexisting conditions.” Between 10% and 22% of adults with CHD were uninsured, and 67% reported difficulty obtaining health insurance or changing jobs to guarantee coverage.¹⁷ Others found themselves in so-called “job lock” because they could not afford to switch to another company where they may have lost their insurance.

Under the ACA, however, no person can be denied coverage because of a preexisting condition, and young people, including those with CHD, can remain on their parents’ policy until the age of 26. The AHA is committed to ensuring that access to care continues for all patients with CHD.

Underinsurance, resulting in high out-of-pocket medical bills, remains a significant concern for those with CHD. Common barriers include:

- Losing dependent insurance coverage due to marriage or reaching adulthood.
- Although illegal, some employers will not hire a person with a history of CHD for fear of their health insurance premiums rising.
- Managed insurance plans with “gatekeepers” or inadequate networks of providers may make it more difficult for patients to gain access to a cardiologist skilled in CHD, resulting in possibly suboptimal care.¹⁸
- Qualifying for life insurance may be impossible or require high premiums that the patient cannot afford.

THE ASSOCIATION ADVOCATES

The AHA is committed to advancing public policies that will allow children and adults with heart defects to live longer and fuller lives. These policies include:

- More public resources devoted to researching the causes and treatment of CHD throughout the lifespan, along with specialized programs of care needed for children and adults with CHD.

- Support for CDC’s Birth Defects Centers to advance our knowledge of the preventable causes of CHD.
- Support for activities across the lifespan including research in transition of care; increasing awareness among parents, families, and healthcare providers about CHD; and improving understanding of healthcare utilization, costs, and needs for the growing adult population.¹⁸
- Improved access to preconception and prenatal care for women of reproductive age to reduce modifiable risk factors for CHD.
- Monitoring implementation of health reform to assure access to health insurance coverage and care for those with CHD by prohibiting health insurance plans from denying or dropping coverage due to a pre-existing medical condition, preventing health plans from charging patients more for their coverage because of their health status, allowing young adults to stay on their parents’ policy until age 26, and ensuring that health plan networks include adequate numbers and types of providers.
- Advocating for effective screening, including pulse oximetry, for congenital heart defects in newborns before they are discharged from a hospital/birthing center.

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