Support Newborn Screening for Critical Congenital Heart Disease in Wisconsin

March of Dimes supports AB111 and SB104 legislation which ensure that all newborns in Wisconsin will be screened for critical congenital heart disease.

Critical Congenital Heart Disease Must Be Diagnosed Early
- Congenital heart disease is a problem with the heart’s structure and/or function which is present at birth.
- Critical congenital heart disease (CCHD) means that the heart defect causes severe, life threatening symptoms and requires intervention, such as surgery, within the first few hours, days or months of life.
- Infants with CCHD are at significant risk for death or disability if their condition is not diagnosed soon after birth.
- Some infants born with CCHD can appear healthy at first and can be sent home with their families before their heart defect is detected.

CCHD Screening Will Save Lives
- Congenital heart disease occurs in approximately 8 of every 1,000 live births and 25 percent of these babies will have CCHD.
- All types of CCHD have medical and surgical interventions that can improve outcomes.
- Early detection via newborn screening will allow affected infants to receive life-saving interventions promptly.

Screening For CCHD Is Simple, Fast And Inexpensive
- CCHD can be identified using pulse oximetry, a non-invasive and painless test that measures oxygen saturation of hemoglobin in arterial blood.
- Cost estimates are $4 per infant screened.

March of Dimes Recommends Passage of AB111 and SB104
- March of Dimes has been instrumental in expanding newborn screening in Wisconsin.
- In adding conditions to the State’s newborn screening panel, it is important that SB104 and AB111 allow for flexibility in use of future screening methods.
- March of Dimes recommends passage of AB111 and SB104 to ensure that all newborns are screened for critical congenital heart disease.

Key Points
- Screening newborns for CCHD saves lives.
- CCHD means that the heart defect requires medical intervention within the first few hours, days or months of life.
- It has been estimated that at least 280 infants with unrecognized CCHD are discharged each year from newborn nurseries in the United States.
- CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the infant is discharged from the hospital or birthing center and before the baby shows signs of the condition.
- Cost of screening is estimated at $4 per infant.
- The Secretary of the U.S. Department of Health and Human Services added screening for CCHD to the Recommended Uniform Screening Panel (RUSP) in September 2011.
- Wisconsin currently screens for all recommended conditions except CCHD.

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The March of Dimes is a national voluntary health agency whose volunteers and staff work to improve the health of infants and children by preventing birth defects, premature birth and infant mortality. Founded in 1938, the March of Dimes funds programs of research, community services, education and advocacy. For the latest resources and information, visit marchofdimes.com or nacersano.org.
**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. and the leading killer of infants with birth defects. The incidence of CHD ranges between 4 and 10 per 1,000 live births. Tragically, more than 1,500 of them do not live to celebrate their first birthday. 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.

But there is still real reason for hope. Due to research, most survive to adulthood, including many who formerly would have died. 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. Few health and 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%. While the causes of non-inherited CHD are still largely unknown, researchers have identified both genetic and non-inherited risk factors:

- 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 during pregnancy
- Maternal diabetes
- Maternal overweight or obesity. Women who are overweight or obese are 18% to 30% more likely to give birth to babies with CHD.

**PREVALENCE AND MORTALITY**

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

- 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.

- CHD are about 60 times more prevalent than childhood cancers.

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

- Nearly one in three infants who dies from a birth defect has a heart defect.
- CHD directly caused or contributed to the deaths of 5,359 in 2008.
- 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.

**REDUCING RISK FACTORS & EARLY DETECTION**

The American Heart Association guidelines to help prospective mothers lower the risk of CHD in their babies urges them to:

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

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**INFANT DEATHS FROM BIRTH DEFECTS, BY CAUSE**

United States, 2008

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

- Chromosomal: 3.9%
- Circulatory: 17.8%
- Congenital Heart Defects: 19.8%
- Digestive: 6.6%
- Genitourinary: 11.8%
- Musculoskeletal: 9.1%
- Nervous: 23.1%
- Other: 1.5%
- Respiratory: 6.3%
The AHA also advocates for effective screening for CHD in newborns before they are discharged from a hospital/birthing center.

Recently, 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.” Under the ACA, 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.

Between 10% and 22% of adults with CHD are uninsured, and 67% have reported difficulty obtaining health insurance or changing jobs to guarantee coverage. Others find themselves in so-called “job lock” because they cannot afford to switch to another company where they might lose their insurance. Underinsurance, resulting in high out-of-pocket medical bills, is also 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 managed networks of providers may make it more difficult for patients to gain access to a cardiologist skilled in CHD, resulting in possibly suboptimal care.
- Qualifying for both health and life insurance may be impossible or require high premiums that the patient cannot afford.

THE AHA 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.
- Improving access to preconception and prenatal care for women of reproductive age to reduce modifiable risk factors for CHD.
- Monitor 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.
- Advocate for effective screening for congenital heart defects in newborns before they are discharged from a hospital/birthing center.
- Advocate for pulse oximetry screening for congenital heart defects in newborns before they are discharged from a hospital/birthing center.

References