

## Preventing Infant Deaths from Congenital Heart Defects



*Kristine and Cora McCormick*

Kristine Brite McCormick had a healthy pregnancy and gave birth to her daughter, Cora, on November 30, 2009. Kristine and her husband soon brought baby Cora home, after getting a clean bill of health at the hospital. A few days after arriving home, Kristine was feeding Cora when the baby suddenly stopped breathing. Kristine and her husband rushed Cora to the hospital in minutes, but it was too late. Cora was gone. “We learned that she had an undetected congenital heart defect from the coroner,” said Kristine. “Neither of us had ever even heard the term.”

In the United States, every 15 minutes a baby is born with a congenital heart defect, the most common type of birth defect in this country.

After Cora’s death, her parents learned about newborn screening for critical congenital heart defects (CCHDs) using *pulse oximetry*. CCHDs are congenital heart defects that require surgery or intervention in the first year of life. Pulse oximetry is a simple bedside test to determine the amount of oxygen in a baby’s blood and the baby’s pulse rate. The test is done using a machine called a pulse oximeter, with sensors placed on the baby’s skin. The test is painless and takes only a few minutes. Low levels of oxygen in the blood can be the first sign of a CCHD. Cora’s mother Kristine wants to make sure that other parents know about newborn screening for CCHDs. In Indiana, where the McCormicks live, a new law requiring newborn screening for CCHDs is known as Cora’s Law, after Cora McCormick.

Congenital heart defects account for 24 percent of infant deaths due to birth defects. Like Cora, babies

born with a CCHD can appear healthy at first and be sent home with their families before their condition is detected. These babies are at risk for serious complications and death within the first few days or weeks of life and often require prolonged hospitalizations and emergency care.

Newborn screening for CCHDs can identify some babies with these conditions before they show signs of illness. Once identified, these babies can be seen by pediatric cardiologists and can receive specialized care and treatment. Treatment can include medications and surgery. Detecting and treating CCHDs soon after birth can help to prevent death and disability early in life and can potentially improve the long-term health of individuals with these conditions.

In September 2011, U.S. Department of Health and Human Services Secretary Kathleen Sebelius approved adding CCHDs to the recommended list of conditions that are included in newborn screening. As newborn screening for CCHDs is implemented throughout the United States, the Centers for Disease Control and Prevention (CDC) will play an important role in helping the public understand the effectiveness of such screening. The National Center on Birth Defects and Developmental Disabilities (NCBDDD) at CDC is helping assess how well screening programs are detecting CCHDs. NCBDDD also is researching the costs associated with CCHD screening. These activities will help states make decisions about adding these conditions to their existing newborn screening programs and will provide information that will be helpful for states with new or proposed CCHD screening programs.

“While we’ll never know for sure if it would have made a difference for Cora, we sure wish she’d had the simple screening. I hope for a day when no mother finds out about her child’s heart defect from the coroner,” Kristine said. “My ultimate hope is that one day no baby is born with a broken heart and that congenital heart defects are prevented in every pregnancy.”

**For more information on screening for CCHD, visit [www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html](http://www.cdc.gov/ncbddd/pediatricgenetics/CCHDscreening.html).**