

## About Congenital Heart Defects

Congenital Heart Defects (CHDs) are both the most common and the most lethal birth defects, accounting for 24% of all infant deaths due to birth defects and affecting more than 650 newborn infants and their families each year in Minnesota. Approximately 25% of heart defects are referred to as Critical Congenital Heart Defects (CCHD), requiring intervention in the first days, weeks or months of life. A major cause of infant mortality as a result of CCHD is that a significant number of children appear healthy at first and are not detected as having heart disease in the newborn nursery.

**Two babies are born each day in Minnesota with a heart defect.** Only one of them will be diagnosed prenatally. The other baby has a 30-40% risk of being discharged from the hospital with an undiagnosed heart defect.

Early diagnosis can reduce rates of death or disability and the costs associated with delayed diagnosis - including surgical compromise, neurological impairment, developmental delay, organ failure, and long-term feeding issues. Rural and underserved populations are particularly vulnerable to missed or delayed diagnosis - and have significantly lower rates of prenatal detection.

## About Newborn Screening for CCHD using Pulse Oximetry

Referred to by clinicians as the “5th vital sign”, pulse oximetry is a simple, non-invasive, bedside where sensors are placed on the baby’s hand and foot to determine their pulse rate and the amount of oxygen in their blood. Pulse oximetry takes just minutes, is about the cost of a diaper change, and is as simple as taking a baby’s temperature or blood pressure.

Pulse oximetry is effective at detecting critical, life-threatening CCHD when performed at approximately 24 hours of age and used along with physical examination. These heart defects would otherwise go undetected by current screening methods. Newborns with abnormal pulse oximetry results require immediate confirmatory testing, intervention, and specialized care to help prevent disability and death early in life.

## Universal Support

CCHD screening of newborns has been recently adopted by the Secretary of Health and Human Services for inclusion in the Uniform Screening Panel (RUSP), and has also been endorsed by the American Academy of Pediatrics, the American Heart Association and the American College of Cardiology.

This simple, non-blood-spot screening has now been implemented for all newborns in 3 states, required in 6 states, and an additional 12 states have legislation introduced. <http://www.cchdscreeningmap.com/>.

Pulse oximetry is simple, non-invasive, and painless, requiring no blood draw or specimen collection.



“It’s a rare day when you know a piece of legislation you signed saved a life,”

Baby Dylan’s life-threatening heart defect was detected with pulse ox screening on the very first day of implementation in New Jersey.



*“My baby went 4 and a half weeks undiagnosed despite our complaints of poor eating, and breathing strangely! He saw 4 different pediatricians, after the two he saw in the hospital and no one bothered with a pulse ox because I was a first time, very tired mother. He nearly died in our arms 3 days after his one-month check up! Inexcusable!!! What is the extra expense of babies like Gunner who then was so critical that he required a life flight and weeks of life support? Had the defect been caught initially, our entire family could have endured less trauma. Thank God we still have him and he is healthy, that is ONLY because of God’s grace. I know there are too many others who are not so lucky.”*

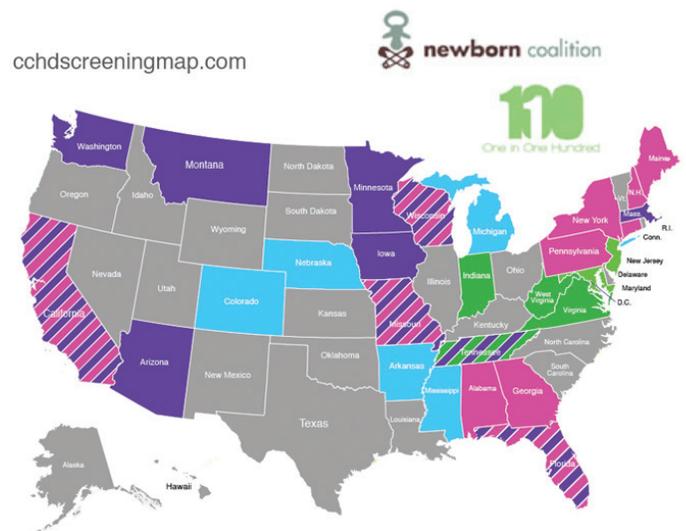
## Minnesota Model

Physicians, hospitals, and advocates clearly understand the importance of early detection of newborn diseases and disorders in saving lives and reducing healthcare cost burdens associated with late diagnosis. Minnesota can build on its successful **Newborn Heart Screening Pilot Program** by requiring each licensed hospital or birthing facility to provide that all newborns are, prior to discharge, but as much as is feasible, at 24 hours of age or later, screened for congenital heart disease as a standard of care.

Within less than two years, Minnesota’s evidence-based protocol and implementation toolkit was developed, resulting in nearly 20% of Minnesota newborns being screened for heart defects before discharge. This program has garnered national attention, and was critical to the recent federal recommendation from the U.S. Department of Health and Human Services that all newborns be screened for CCHD.

- Newborn heart screening would not require testing to be done in the health department laboratory, eliminating the need to purchase additional equipment or provide staff for this screening.
- It is assumed that the immediate follow up of patients with failed screens will occur within the provider setting, with limited resources required by the Department of Health.
- Pulse oximetry testing is currently a covered benefit when determined medically necessary by most public and private payers.

Sources: Centers for Disease Control and Prevention, U.S. Department of Health and Human Services, Newborn Coalition, 1in100



*“CCHD is the most common birth defect leading frequently to death or severe morbidity. Studies suggest that early recognition of critical congenital heart disease (CCHD) is a significant and potentially modifiable risk factor, but tragically, the diagnosis of a CCHD is often missed. Newborn screening with pulse oximetry is a promising tool to narrow the diagnostic gap. We continue to make progress in our region, implementing pulse oximetry screening one hospital at a time. This piecemeal approach leaves too many newborns and their parents vulnerable. Leadership is needed to ensure all newborns, regardless of which hospital they are born in, are screened for critical congenital heart disease.” ~ Lazaros Kochilas, MD, U of M Pediatric Cardiology, MN Newborn Heart Screening Pilot Program*

## Eve’s Story

Eve Isley Saarinen was diagnosed at two days old with critical congenital heart disease (CCHD) and associated Wolff-Parkinson-White Syndrome. Eve spent her first 5 months in 4 different hospitals and underwent two heart surgeries, 6 transfusions, and more than 120 episodes of SupraVentricular Tachycardia. Because of early intervention and excellent medical care, Eve is expected to lead a full and normal life. Although she may still have to undergo more cardiac care or surgeries, she has proven to be a very resilient and happy child. Following her surgeries, Eve’s family established the CHD community 1in100, and collaborated with Minnesota physicians, advocates, and the state Department of Health in establishing a landmark pilot program to screen newborns for heart defects using pulse oximetry. Eve’s mother, Annamarie Saarinen, went on to spearhead a federal recommendation from the Department of Health and Human Services which has resulted in the recommendation that all newborns in the United States should be screened for CCHD. That recommendation has also been formally endorsed by the American Academy of Pediatrics, the American Heart Association, and the American College of Cardiology.