1 in 100 babies have a heart defect

Congenital heart defects are the most common birth defect.

Pulse oximeters can catch both heart defects and respiratory problems

by measuring the amount of oxygen in the blood.

Pulse oximetry screening is quick, non-invasive and inexpensive.

Signs and symptoms of heart defects in infants are:

- Pale or bluish skin color
- Tires easily during feeding or has trouble breathing and nursing at the same time
- Poor weight gain
- Excessive sweating, especially during feeding
- Labored breathing while resting
- Puffy face, hands and/or feet
- Rapid or irregular heart rate
- Constant lung infections

A missed or delayed diagnosis can be life threatening.

Help us mandate this life saving test. Visit our facebook page Pulse Ox Oregon (Kaleb's Law) for more information on how to get involved.

Kaleb's Story

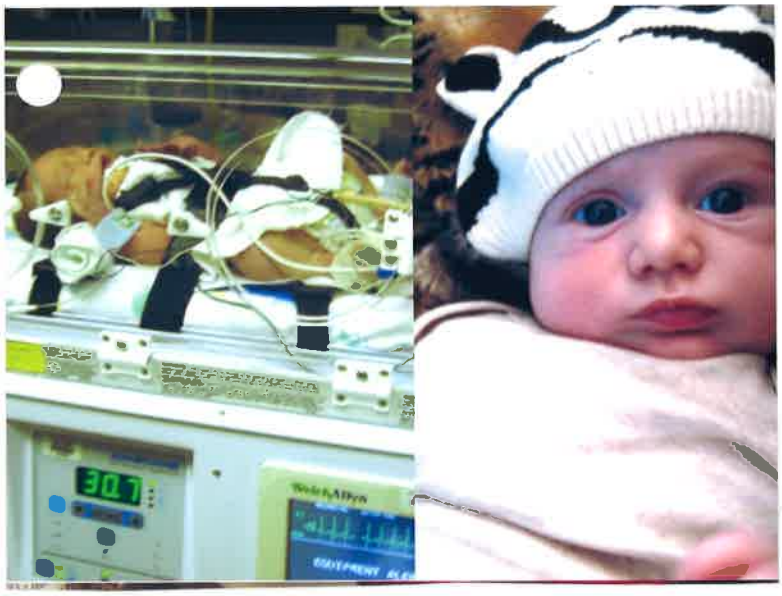
In 2010 my beautiful son Kaleb was born. It wasn't until 14 hours later that a pulse ox test was done only to discover he had an undiagnosed critical congenital heart defect.

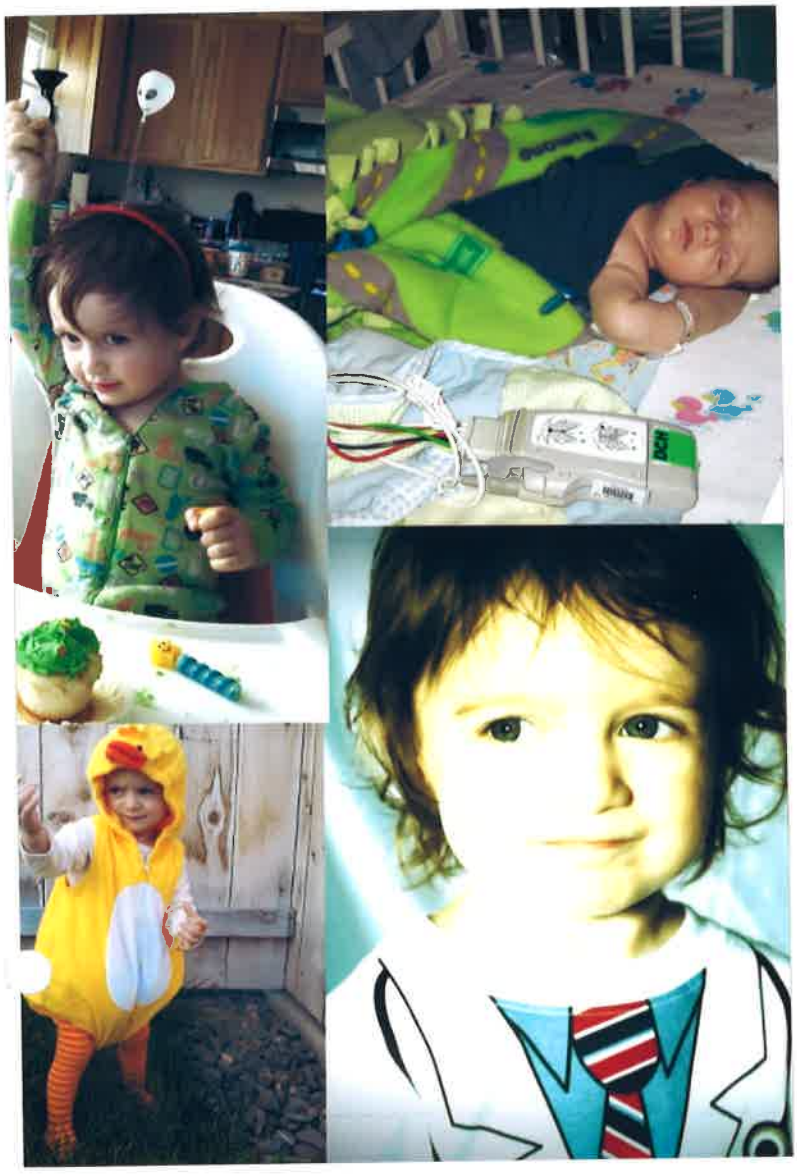
Kaleb had Aortic Stenosis and Endocardiofibroelastosis and his heart was only working at 10%. He was not expected to live.

Two years and three surgeries later he's doing well but will need a life time of surgeries.

We will never know how much damage could have been avoided if he'd been tested right after birth and that has motivated me to make sure every newborn in Oregon has the oppertunity to be screened with Pulse Oximetry.

Lindsey Lahr





march of dimes

FAQ: Newborn Screening for Critical Congenital Heart Disease (CCHD)

The Secretary's Advisory Committee on Heritable Disorders in Newborns and Children (SACHDNC) is charged with advising the Secretary of the U.S. Department of Health and Human Services (DHHS) in areas relevant to heritable conditions in children, particularly newborn screening. In September 2010, SACHDNC voted to recommend adding critical congenital heart disease (CCHD) to the Recommended Uniform Screening Panel, and the Secretary adopted the addition of CCHD to the panel in September 2011.

Q. What is critical congenital heart disease (CCHD)?

Critical congenital heart disease (CCHD) is a subgroup of all of the congenital heart diseases evident at birth. Congenital heart disease is a problem with the heart's structure and/or function which is present at birth. "Critical" means that the heart defect causes severe, life threatening symptoms and requires intervention (e.g., medical treatment or surgery) within the first few hours, days or months of life. These conditions are sometimes difficult to detect by physical exam and observation in the first few days of life, but there is significant enough hypoxemia (low blood oxygen) to allow detection by a simple non-invasive test called pulse oximetry, in the newborn nursery.

The specific heart diseases that are included in the group called **CCHD** include:[1]

- **Hypoplastic left heart syndrome**
- **Pulmonary atresia, intact septum**
- **Tetralogy of Fallot**
- **Total anomalous pulmonary venous return**
- **Transposition of the great arteries [vessels]**
- **Tricuspid atresia**
- **Truncus arteriosus**

Explanatory note: Every fetus receives its oxygen supply from the mother's blood through the umbilical cord attached to the placenta rather than from its lungs. During fetal life, a blood vessel called the ductus arteriosus directs blood to flow away from the fetal lungs to the body. Once the baby is born and the umbilical cord is cut, the lungs expand, the ductus arteriosus closes and the blood normally flows into the now functioning lungs to be oxygenated before being sent to the heart and then on to the rest of the body. However, when there are structural abnormalities such as the disorders designated as CCHD, the closure of the ductus arteriosus causes progressive problems with oxygenation that can result in very serious symptoms and even death for the neonate. The low oxygen level in the baby can be detected by measuring oxygen levels in the skin using a simple test called pulse oximetry. Pulse oximetry is used in every hospital to monitor oxygen levels of patients in operating rooms, intensive care units, and emergency departments. Routine pulse oximetry screening in nurseries is currently being performed in some hospitals[2] and regional programs in the U.S. and Europe, and has been shown to successfully identify asymptomatic neonates with CCHD.[3]

Q. How common is CCHD?

Congenital heart disease (CHD) is the most common cause of infant mortality (death in the first year of life), accounting for 24% of infant deaths due to birth defects.[4] CHD affects about 7 to 9 of every 1,000 live births in the U.S. and Europe, or approximately 40,000 babies born each year in the U.S. The seven CCHDs listed above account for approximately 17-31% of all congenital heart disease.[1] The prevalence of CCHD varies according to different studies, but it is estimated that about 4,800 (or 11.6 per 10,000) babies are born each year with CCHD.[4]

Q. How will newborns be screened for CCHD?

CCHD can be identified using a non-invasive and painless method called pulse oximetry in the newborn period before the baby is discharged from the hospital/birthing center. Pulse oximetry measures the percent oxygen saturation of hemoglobin in the arterial blood through a sensor that is usually attached to the baby's finger or foot. If low levels are detected and confirmed on repeat testing, then further testing [e.g., an echocardiogram (ultrasound of the heart)] can be performed to diagnose any abnormalities in heart structure or blood flow through the heart.

Pulse oximetry is a completely separate test from newborn screening that uses blood spots. It is a non-metabolic, functional, point of care test similar to newborn hearing screening that is done in addition to blood spot screening.

Q. What is the treatment for CCHD?

All types of CCHD have medical and surgical interventions that can improve outcomes.[1] There are varying short- and long-term morbidities and success rates among the different approaches to treatment. In the seven CCHDs, the five-year survival rates after intervention ranges from 65% to 97% with five of the seven conditions having five-year survival rates above 85%.

Q. What are some challenges for states in adding CCHD to their standard newborn screening panel?

CCHD screening with pulse oximetry is different from metabolic newborn screening using blood spots. It will require adoption of standardized screening methods related to best timing for screening, probe placement, optimal threshold value of a positive test, and quality control measures. In addition, each state will have to determine how best to implement this screening program, track data, educate families about this new test, and ensure the availability of proper and timely follow-up.

Q. Why does March of Dimes support the inclusion of CCHD in the mandatory core panel for newborn screening?

Evidence from CCHD research reviewed by the SACHDNC[1] meets the March of Dimes criteria as outlined in our Newborn Screening Field Advisory to support its inclusion in the mandatory core panel for newborn screening. The three criteria are: 1) There is documented medical benefit to the affected infant from early detection and treatment; 2) There is a reliable screening test for the disorder; and 3) Early detection can be made from newborn blood spots, or other specific means.