

June 11, 2014

Washington State Board of Health  
PO Box 47990  
Olympia, WA 98504-7990

Dear State Board of Health Members:

The American Heart Association, in proud partnership with the March of Dimes and the American College of Cardiology, asks for your support to add critical congenital heart disease (CCHD) to Washington's newborn screening panel. We understand forming an advisory group is the first step in the rulemaking process and we respectfully ask you to establish this group to begin this important work without delay.

We understand the Board uses five criteria when considering adding a disorder to the panel; we feel there is strong rationale on all five counts to add CCHD.

- **Public Health Rationale/ Prevention Potential and Medical Rationale:** Congenital heart defects occur in nearly 1 in 100 live births and are the most common cause of infant death, accounting for 27% of infant deaths that are caused by birth defects. In many cases, outwardly healthy infants may be discharged from hospitals before signs of disease are detected. Failure to detect CCHD may lead to serious morbidity or death. These life threatening conditions often require serious medical interventions, in some cases even requiring multiple open-heart surgeries. Evidence suggests that measuring blood oxygen saturation can increase the chances for early diagnosis and detection of CCHD. In 2011, Secretary Sebelius endorsed the addition of CCHD screening to the Recommended Uniform Screening Panel for newborns.
- **Treatment Available:** Once detected, many heart defects can be surgically repaired. It is estimated that 85% of neonates who undergo surgery for CCHD will reach adulthood.
- **Available Technology:** Pulse oximetry detects oxygen levels in the blood. It is a low-cost, non-invasive and painless test - completed in as little as 45 seconds. Pulse oximetry screening for CCHD has a less than one percent chance of giving false positive results, though roughly 25% of infants with low blood oxygen without CCHD may be diagnosed with other conditions that require medical intervention. Pulse oximeters are available in most neonatal units, and hospital staff are trained in how to perform pulse oximetry screening.
- **Cost-Benefit/Effectiveness:** A 2012 cost-effectiveness analysis estimated that universal screening would cost just under \$4 per infant. Research suggests cost savings associated with early detection of a single case of CCHD could exceed the costs associated with screening 2,000 infants. Currently pulse oximetry screening is not billed for but may be included in the bundle of services that hospitals provide.

Adding CCHD to the newborn screening panel is needed to ensure every newborn in Washington is screened. While some may be content with voluntary screening, voluntary compliance today doesn't guarantee screening tomorrow. CCHD is a matter of life and death; this is not the same as the hearing screening. The consequences of missing a baby are too great. Moreover, Washington has high rates of out of hospital births and while data collection is a critical component of a quality screening program, hospital data reporting alone would not guarantee universal screening.

*"Building healthier lives,  
free of cardiovascular  
diseases and stroke."*

Please remember the American Heart Association in your will.



Puget Sound Division  
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More than 30 other states have established a statewide requirement for screening – including Oregon, Alaska and California. Washington has long been a leader in health care and we urge the Board to begin the rulemaking process to add CCHD to the newborn screening panel and ensure Washington remains a leader in children's health.

Sincerely,

A handwritten signature in cursive script, appearing to read "Lindsay Hovind".

Lindsay Hovind  
Government Relations Director