



STATE OF HAWAII
DEPARTMENT OF HEALTH
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Testimony in SUPPORT of SB 337, SD 1
RELATING TO HEALTH

SENATOR JILL N. TOKUDA, CHAIR
SENATE COMMITTEE ON WAYS AND MEANS

Hearing Date: March 2, 2015 Room Number: 211

1 **Fiscal Implications:** None. The added data collection, analysis, and dissemination activities
2 will be absorbed by the current Newborn Metabolic Screening Program staff and resources.

3 **Department Testimony:** The Department of Health supports SB337, SD1 to mandate birthing
4 facilities to do newborn screening for Critical Congenital Heart Defects (CCHD) using pulse
5 oximetry or another method recommended by the American Academy of Pediatrics, and to
6 provide newborn CCHD screening data to the Department of Health for quality assurance and
7 improvement activities.

8 Data collection and information dissemination for quality improvement is needed. The
9 algorithm and methodology for CCHD screening is not evidence-based but rather the best guess
10 of a group of experts. Therefore, data need to be collected from real time screening of newborns
11 with the outcomes to support and/or refine the methodology. This quality improvement activity
12 is a required process especially in a state with a low birth rate like Hawaii and will allow Hawaii
13 to participate in the national effort to refine and improve the methodology for CCHD screening.
14 Data are also needed to help birthing facilities recognize potential problems with their CCHD
15 screening that may cause inaccurate results.

16 The national incidence of CCHD is 2/1000 births. National and local pediatric
17 cardiologists report that about 50% of the cases are detected prenatally. Some cases will have
18 symptoms at birth. Best estimates are that about 1/2000 newborns with CCHD are asymptomatic
19 and may be detected using pulse oximetry screening. With Hawaii's birth rate, screening could
20 detect approximately 10 asymptomatic newborns with CCHD per year.

21 Thank you for the opportunity to testify on this measure.

Monday – March 2, 2015; 1:00 pm
Conference Room 211

SENATE COMMITTEE ON WAYS AND MEANS

Senator Jill Tokuda, Chair
Senator Ronald Kouchi, Vice Chair

From: Charles Neal, Jr., MD, PhD
Chief, Neonatology Department

Re: SB 337, SD1 Relating to Health
Testimony In Support

My name is Dr. Charles Neal, Jr., MD, PhD and I am the chief of the Neonatology Department of Kapi`olani Medical Center for Women & Children (Kapi`olani). Kapi`olani Medical Center is the state's only maternity, newborn and pediatric specialty hospital. It is also a tertiary care, medical teaching and research facility. Specialty services for patients throughout Hawai'i and the Pacific Region include intensive care for infants and children, 24-hour emergency pediatric care, air transport, maternal-fetal medicine and high-risk perinatal care. The not-for-profit hospital offers several community programs and services, such as the Kapi`olani Child Protection Center and the Sex Abuse Treatment Center. Additionally, Kapi`olani's Women's Center is ranked among the top in the nation. Kapi`olani Medical Center is an affiliate of Hawai'i Pacific Health, the state's largest health care provider.

I am writing in support of SB 337, SD1. This measure requires that birthing facilities perform a critical congenital heart defect screening using a pulse oximetry on every newborn in its care prior to discharge. The pulse oximetry is a non-invasive test that is an effective means of detecting critical, life-threatening congenital heart defects which may otherwise go undetected by current screening methods.

Kapi`olani Medical Center for Women & Children (Kapi`olani) has long followed the Academy of Pediatrics (AAP) guidelines which recognizes the importance of screening for congenital heart defects. We have established and apply pulse oximetry screening as the standard of care for all newborns to screen for congenital heart disease.

Thank you for the opportunity to provide this testimony.

Date: February 28, 2015

March of Dimes Foundation

To: Senator Jill Tokuda, Chair
Senator Ronald Kouchi, Vice Chair

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From: Lin Joseph
Director of Program Services
March of Dimes Hawaii Chapter

marchofdimes.com/hawaii

Re: In support of
SB337 SD1
Hearing: Committee on Ways and Means
Monday, March 2, 2015
Conference Room 211, State Capitol

Chair Tokuda, Vice Chair Kouchi, Members of the Committee:

I am writing to express strong support for SB337 SD1: *Relating to Critical Congenital Heart Defects Newborn Screening*.

The March of Dimes is the leader in advocacy for newborn screening of all infants in the United States. Our mission is to *improve the health of babies by preventing birth defects, premature birth, and infant mortality*. As part of that mission, we support screening for conditions and disorders for which there is a documented medical benefit to the affected infant from early detection and treatment; there is a reliable screening test for the disorder; and early detection can be made from newborn blood spots or other specific means. In 2009, March of Dimes presented the state of Hawaii with the March of Dimes National Award for Excellence in Newborn Screening for being a leader in screening newborn infants for all 29 disorders recommended at that time by the American College of Medical Genetics.

In 2011, the Secretary of the U.S. Department of Health and Human Services added critical congenital heart disease (CCHD) to the Recommended Uniform Screening Panel. CCHD is a subgroup of congenital heart defects which are problems with the heart's structure and/or function that are present at birth. "Critical" indicates that the heart defect causes severe, life threatening symptoms that require intervention, such as medical treatment or surgery, within the first hours, days or months of life. Unlike screening for metabolic disorders which utilizes a few drops of blood from a newborn's heel, CCHD, cannot be detected through blood spots and is sometimes difficult to detect by physical exam and observation. Currently, CCHD can be detected through pulse oximetry to measure the percent of oxygen saturation of hemoglobin in the arterial blood using a sensor attached to the infant's finger or foot. This screening provides that, should a newborn screen positive for CCHD, diagnostic tests can be administered before the infant's symptoms are evident and allow for early interventions to improve outcomes.

SB337 SD1 will establish statewide newborn screening to detect CCHD to ensure that newborns in Hawaii are screened for congenital heart conditions that, if undetected, can be severe and life-threatening. Mahalo for the opportunity to testify in support of SB337 SD1.

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