



STATE OF HAWAII
DEPARTMENT OF HEALTH
P. O. Box 3378
Honolulu, HI 96801-3378
doh.testimony@doh.hawaii.gov

**Testimony COMMENTING on S.B. 337
RELATING TO HEALTH**

SENATOR JOSH GREEN, CHAIR
SENATE COMMITTEE ON HEALTH
SENATOR ROSALYN H. BAKER, CHAIR
SENATE COMMITTEE ON COMMERCE AND CONSUMER PROTECTION
Hearing Date: February 6, 2015 Room Number: 414

Fiscal Implications: None. If data collection, analysis, and dissemination activities are added to the Newborn Metabolic Screening Program activities, the efforts would be absorbed by the current staff and resources.

Department Testimony: The Department of Health supports the intent of this bill with a recommendation to add an amendment to include provision of newborn Critical Congenital Heart Defect (CCHD) screening data from the birthing facilities to the Department of Health for quality assurance and improvement activities. The inability for health departments to collect data to help assure the quality of screening has been the most cited problem with currently enacted legislation in other states and many are moving to revise their mandate to include this important provision.

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

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

6 **Offered Amendments:** The Department recommends that language be added to the bill to
7 require the birthing facilities to report a minimum data set to the DOH for quality improvement
8 activities. The minimum data set should include:

- 9 • newborns screened and not screened;
- 10 • timing of screening after birth;
- 11 • pulse oximetry results;
- 12 • outcomes of the newborns that fail the pulse oximetry screening; and
- 13 • infants that are detected with a CCHD that passed pulse oximetry screening.

14 Thank you for the opportunity to testify.

Date: February 5, 2015

To: Senator Josh Green, Chair
Senator Rosalyn Baker, Chair

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

Re: In support of
SB337
Hearing: Wednesday, February 6, 2015
Conference Room 414, State Capitol

March of Dimes Foundation

Hawaii Chapter
1580 Makaloa Street, Suite 1200
Honolulu, HI 96814
Telephone (808) 973-2155
Inter-island 1-800-272-5240
Fax (808) 973-2160

marchofdimes.com/hawaii

Chair Green, Chair Baker, Members of the Committees:

I am writing to express support for SB337: *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 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.



Friday – February, 6, 2015; 1:15 pm
Conference Room 414

SENATE COMMITTEE ON HEALTH

Senator Josh Green, Chair
Senator Glenn Wakai, Vice Chair

SENATE COMMITTEE ON COMMERCE AND CONSUMER PROTECTION

Senator Roselyn H. Baker, Chair
Senator Brian T. Taniguchi, Vice Chair

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

Re: SB 337 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. 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.

From: mailinglist@capitol.hawaii.gov
To: [HTHTestimony](#)
Cc: rdimaui@gmail.com
Subject: Submitted testimony for SB337 on Feb 6, 2015 13:15PM
Date: Wednesday, February 04, 2015 9:19:35 PM

SB337

Submitted on: 2/4/2015

Testimony for HTH/CPN on Feb 6, 2015 13:15PM in Conference Room 414

Submitted By	Organization	Testifier Position	Present at Hearing
Lauren Wilson	Individual	Support	No

Comments: In full support of this sensible legislation. According to The March of Dimes, the leading cause of birth defect related neonatal deaths are congenital heart defects. While not all heart defects are treatable or compatible with life- the sooner one is discovered the sooner families can make plans to either receive treatment or mindfully plan the days with their child. Lauren Wilson Maui

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