



STATE OF HAWAII
DEPARTMENT OF HEALTH
P.O. Box 3378
HONOLULU, HAWAII 96801-3378

In reply, please refer to:
File:

House Committee on Health

SB2194 S.D. 1, RELATING TO HEALTH

**Testimony of Linda Rosen, M.D., M.P.H.
Director of Health**

March 19, 2014

1 **Department's Position:** The Department of Health (DOH) supports this bill provided that our concerns
2 about the bill language are addressed. The DOH recommends amendments to clarify the language
3 mandating screening and require birthing facilities to report a minimum data set to the DOH for quality
4 improvement purposes.

5 **Fiscal Implications:** The DOH will use existing resources to collect critical congenital heart defects
6 (CCHD) screening and follow-up data from birthing facilities and disseminate information for quality
7 improvement purposes, therefore the appropriation to the department will not be needed.

8 **Purpose and Justification:** This bill mandates newborn screening for CCHD in birthing facilities. It
9 also requests a state general fund appropriation for the DOH to expend for the purposes of this bill.

10 CCHD is one of the disorders on the federally Recommended Uniform Screening Panel (RUSP).
11 Due to serious nature of the disorders that can be detected, CCHD screening requires screening the baby
12 in the hospital before discharge and doing all additional screening and diagnostic tests before the baby
13 goes home. If needed, the baby is transferred to a facility that can do the tests. A baby with a CCHD
14 cannot be allowed to go home without monitoring, treatment and intervention or the baby risks dying

1 suddenly when the heart stops working. Currently only two birthing facilities in Hawaii are not doing
2 universal newborn CCHD screening.

3 The Department has two concerns about this bill that need to be addressed, so that Hawaii can
4 have effective and universal newborn screening for CCHD.

5 1) Language mandating screening (page 2, lines 10-14) should be clarified. The concern is that
6 the bill requires birthing facilities to screen not only for CCHD, but perhaps do all other procedures
7 specified by the American Academy of Pediatrics (AAP) guidelines. To clarify that the procedures are
8 only for CCHD screening and not for diagnostic purposes, we recommend the following language: “A
9 birthing facility shall perform critical congenital heart defect screening using pulse oximetry, or other
10 standard of care method as recommended by the American Academy of Pediatrics, on every newborn in
11 its care prior to discharge from the birthing facility.” and

12 2) Data collection and information dissemination for quality improvement is needed. The
13 algorithm and methodology for CCHD screening is not evidence-based but rather the best guess of a
14 group of experts. Therefore, data needs to be collected from real time screening of newborns with the
15 outcomes to support and/or refine the methodology. This quality improvement activity is a required
16 process especially in a state with a low birth rate like Hawaii and allows us to participate in the national
17 effort to refine and improve the methodology for CCHD screening. The DOH recommends that
18 language be added to the bill to require the birthing facilities to report a minimum data set to the DOH
19 for quality improvement activities. The minimum data set should include:

- 20 a) newborns screened and not screened;
- 21 b) timing of screening after birth;
- 22 c) pulse oximetry results;
- 23 d) outcomes of the newborns that fail the pulse oximetry screening; and
- 24 e) infants that are detected with a CCHD that passed pulse oximetry screening.

1 In turn, the DOH will be able to compile, analyze and disseminate the aggregate information
2 back to the birthing facilities for their quality improvement activities.

3 Thank you for the opportunity to testify.



THE QUEEN'S HEALTH SYSTEMS

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S.B. 2194, S.D. 1
RELATING TO HEALTH
House Committee on Health
March 19, 2014 8:30a.m.

The Queen's Health System supports SB2194, SD1.

Pulse oximetry screening is an effective, noninvasive, inexpensive tool that drastically helps increase detection rates for critical congenital heart defects. QMC follows the Academy of Pediatrics (AAP) guidelines and has already established pulse oximetry screening as a standard of care for all newborns.

Thank you for the opportunity to provide testimony in support of this measure.

Wednesday, March 19, 2014 – 8:30 am
Conference Room 329

The House Committee on Health

To: Representative Della Au Belatti, Chair
Representative Dee Morikawa, Vice Chair

From: Martha Smith
Chief Executive Officer

Re: SB 2194 SD1 Relating to Health
Testimony In Support with Suggested Amendment

My name is Martha Smith, and I am the Chief Executive Officer 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 with 207 beds. 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 2194, 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.

To give birthing facilities the flexibility to use other screening methodologies as those are developed in the future, we suggest the following minor amendment on page 2:

"§321- Newborn pulse oximetry screening. (a) A birthing facility shall perform a pulse oximetry test for critical congenital heart defects, ~~[as well as]~~ **or** other medically accepted test that measures the percentage of blood oxygen saturation [procedures] as [specified] approved by the guidelines of the American Academy of Pediatrics or national medical organizations advocating on behalf of cardiovascular care, on every newborn in its care prior to discharge from the birthing facility.

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.



American Heart Association | American Stroke Association

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Testimony on SB 2194, “Relating To Health”

The American Heart Association strongly supports SB 2194, SD1 “Relating to Health,” but recommends the attached amendments to the bill.

Congenital heart defects (CHD) are the most common birth defect in the U.S. and the leading killer of infants with birth defects. About 8 children are affected by CHD per every 1,000 live births. Tragically, more than 1,500, or one in three, do not live to celebrate their first birthday. The most recent Hawaii data suggests that the risk for congenital heart defects is slightly higher than the national average in Hawai‘i, with 18 out of 1000 babies born with some type of heart or circulatory defect.

Despite these grim statistics, there is still real reason for hope. Due to research, most children with CHD survive to adulthood, including many who formerly would have died, if the medical issues are identified early and prior to discharge from the birthing center.

Pulse Oximetry Screening

One of the best ways to detect CHD is through a simple, noninvasive, inexpensive test, called pulse oximetry, or pulse ox. The pulse ox test consists of sensors placed on a baby's hand and/or foot to check blood oxygen levels.

If the baby's levels are too low, additional tests may be conducted. New research suggests wider use of pulse ox screening would help identify more than 90 percent of heart defects, with costs of the testing estimated at below \$4 per baby (Kapiolani Medical Center estimates its cost per baby to implement the screening using re-useable equipment is approximately \$1).

In September 2011, U.S. Secretary of Health and Human Services Kathleen Sebelius suggested that critical congenital heart defects screening be added to the “Recommended Uniform Screening Panel” for newborns before they are released from a hospital or birthing facility. To achieve this goal efforts are underway across the country to enact pulse ox screening policies that will allow babies with heart defects to live longer and fuller lives. As a result of these efforts over 35 states have already passed laws requiring newborns to have pulse ox screenings prior to being discharged from the hospital (including Florida, New Mexico and Massachusetts last month). In New Jersey, one of the first states to establish law mandating the screening, and just hours after the state's law took effect, a newborn's life was saved.

A recent survey of Hawaii birthing centers indicated that all but three neighbor island hospitals already apply pulse oximetry screening on all newborns. However, disparities exist on screenings at Maui Memorial Medical Center based on the infant's health insurance provider (Kaiser Clinic physicians on Maui order the test for babies insured by its organization, while other babies go unscreened), at North Hawaii Community Hospital where screenings are done randomly, and at Hilo Medical Center where the screenings are not performed on any newborns. SB 2194, SD1 with the recommended amendments, would help to insure that all Hawaii families are provided with the most recent standard of care-based health screenings for their newborns.

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For information on the AHA's educational or research programs, contact your nearest AHA office, or visit our web site at www.americanheart.org or e-mail us at hawaii@heart.org

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Kauai:
(Served by Oahu office)
Phone: 866-205-3256
Fax: 808-538-3443

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

The AHA urges Hawaii legislators to give keiki born with congenital heart defects in our state the same chance of surviving and thriving. Please support SB 2194, SD1.

Respectfully submitted,


Donald B. Weisman
Hawaii Government Relations/Mission:Lifeline Director

Testimony of Phyllis Dendle

Before:
House Committee on Health
The Honorable Della Au Belatti, Chair
The Honorable Dee Morikawa, Vice Chair

March 19, 2014
8:30 am
Conference Room 329

SB 2194 SD1 RELATING TO HEALTH

Chair Belatti, and committee members, thank you for this opportunity to provide testimony on SB 2194 SD1 which requires birthing facilities to perform congenital heart defect screening on newborns.

Kaiser Permanente Hawaii supports the intent of this measure but recommends it be amended.

Kaiser Permanente Hawaii has been doing pulse oximetry as recommended by the American Academy of Pediatrics for the past year. It is usually performed on newborns by our mother/baby RNs. Even so, I have some concerns about this proposed legislation:

Kaiser Permanente Hawaii is reluctant to put a specific kind of screening or treatment into law because medicine is always improving and after we put a test in place there may be a better test developed but we will still be required by law to do what is in the law whether it is useful or not. In addition it is important to allow medical providers latitude to determine what procedures are appropriate for their patient.

We appreciate the intent of this bill and clearly KPHI has no objection to performing this screening on all the newborns at our facility but we are concerned about the effect of this law as written.

We suggest that if there is a compelling state interest in having a law mandating this screening that it require birthing facilities to follow the guidelines of American Academy of

Pediatrics on this particular test. However, as written it would also require other procedures that have no relationship to what is being considered by this bill. We suggest it should instead say:

"§321- Newborn pulse oximetry screening. (a) A birthing facility shall perform a pulse oximetry test for critical congenital heart defects, as well as other procedures as specified by the guidelines of the American Academy of Pediatrics, on every newborn in its care prior to discharge from the birthing facility.

Thank you for your consideration.

Date: March 18, 2014

March of Dimes Foundation

To: Honorable Della Au Belatti
Honorable Dee Morikawa

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

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

marchofdimes.com/hawaii

Re: In support of
SB2194
Hearing: March 19, 2014, 8:30am
Conference Room 329, State Capitol

Chair Belatti, Vice Chair Morikawa, Members of the Committees:

I am writing to express strong support for SB2194: *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 are 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 symptoms are evident. This can allow for early medical and surgical interventions to improve outcomes.

SB2194 will establish newborn screening to detect CCHD. March of Dimes supports SB2194 in order to ensure that newborns in Hawaii are screened for congenital heart conditions that, if

 march of dimes®

March 19, 2014

Honorable Della Au Belatti

Honorable Dee Morikawa

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undetected, can be severe and life-threatening. Mahalo for the opportunity to testify in support of SB2194.

morikawa2-Joanna

From: mailinglist@capitol.hawaii.gov
Sent: Tuesday, March 18, 2014 8:35 PM
To: HLTtestimony
Cc: wojo.cari@gmail.com
Subject: Submitted testimony for SB2194 on Mar 19, 2014 08:30AM

SB2194

Submitted on: 3/18/2014

Testimony for HLT on Mar 19, 2014 08:30AM in Conference Room 329

Submitted By	Organization	Testifier Position	Present at Hearing
Cari Ann Csigi	Individual	Comments Only	No

Comments: Our son, Shayden, was born with a Congenital Heart Defect in July 2011. We were sent from Oahu to San Diego, then San Diego to Palo Alto so that we could get care for him. Shayden had numerous procedures, tests and surgeries during his 4 months of life. One week after he was born, and Echo cardiogram was done on Shayden. We were told by our Neonatologist and Cardiologist that he had a heart defect, and we would need to fly to the mainland within 1-3 days so that he could receive more care. We met a lot of families who were in the same position as us. The difference between us and them was that, they took their babies home and found out by having to take their babies to the E.R. Some of these families also had to deal with the passing of their child. We strongly support this bill and believe that it could help a lot of families. Early detection is the key!! Our children are the future!!

Please note that testimony submitted less than 24 hours prior to the hearing, improperly identified, or directed to the incorrect office, may not be posted online or distributed to the committee prior to the convening of the public hearing.

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