

Testimony

SB 2194



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, “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 and New Mexico this 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 two 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 physicians order the test for babies insured by its organization, while other babies go unscreened), and at Hilo Medical Center where the screenings are not performed on any newborns. SB 2194, 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.

Serving Hawaii since 1948

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

Oahu:
677 Ala Moana Blvd., Ste. 600
Honolulu, HI 96813-5485
Phone: 808-538-7021
Fax: 808-538-3443

Maui County:
Phone: 808-224-7185
Fax: 808-224-7220

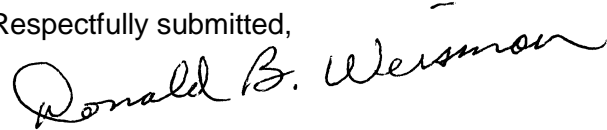
Hawaii:
Phone: 808-961-2825
Fax: 808-961-2827

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 with the attached recommended amendments.

Respectfully submitted,

A handwritten signature in black ink that reads "Donald B. Weisman". The signature is written in a cursive style with a horizontal line above the "i" in "Weisman".

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

SB 2194

PROPOSED AMENDMENTS

SECTION 1. The legislature finds that congenital heart defects are structural abnormalities of the heart that are present at birth and are the number one killer of infants with birth defects.

Congenital heart defects range in severity from simple problems, such as holes between chambers of the heart, to severe malformations, such as the complete absence of one or more chambers or valves. Some congenital heart defects can cause severe or life-threatening symptoms that require intervention within the first days of life.

Pulse oximetry is a non-invasive test that estimates the percentage of hemoglobin in blood that is saturated with oxygen. When performed on newborns in birthing facilities, pulse oximetry is effective at detecting critical, life-threatening congenital heart defects, which otherwise go undetected by current screening methods. The legislature finds that many newborn lives could potentially be saved by earlier detection and treatment of congenital heart defects if birthing facilities in the State were required to perform this simple, non-invasive newborn screening in conjunction with current congenital heart disease screening methods.

The purpose of this Act is to require birthing facilities to perform a pulse oximetry screening on every newborn in its care prior to discharge.

SECTION 2. Chapter 321, Hawaii Revised Statutes, is amended by adding a new section to be appropriately designated and to read as follows:

"§321- Newborn pulse oximetry screening. (a) ~~[The department of health shall require each]~~ A birthing facility shall perform a pulse oximetry test to screen for critical congenital heart defects from the effective date of this act until such time that an alternate medically accepted test that measures the percentage of blood oxygen saturation is approved by national medical organizations advocating on behalf of cardiovascular care or the guidelines of the American Academy of Pediatrics, [to perform a critical congenital heart defect screening using pulse oximetry] on every newborn in its care prior to discharge from the birthing facility.

~~[(b) The person in charge of each institution caring for newborn infants and the responsible physician attending the birth of a newborn, or the person assisting the birth of a child not attended by a physician, shall ensure that every infant in the person's care be tested for congenital heart defects through pulse oximetry screening; provided that this section shall not apply if the parents, guardians, or other persons having custody or control~~

~~of the child object thereto on the grounds that the tests conflict with their religious tenets and beliefs and written objection is made a part of the infant's medical record.]~~

~~[(c) The department of health shall adopt rules, pursuant to chapter 91, as necessary to effectuate the purposes of this section, including but not limited to rules regarding:~~

~~— (1) Administration of newborn critical congenital heart defect screening using pulse oximetry;~~

~~— (2) Quality and cost control of critical congenital heart defect screening using pulse oximetry;~~

~~— (4) Reporting of test results;~~

~~— (5) Guidelines for care, treatment, and follow up of infants when necessary;~~

~~— (6) Informing parents about the purposes of these tests; and~~

~~— (7) Maintaining the confidentiality of affected families.]~~

~~(d-b) For the purposes of the section, "birthing facility" means an inpatient or ambulatory health care facility licensed by the department of health that provides birthing and newborn care services."~~

SECTION 3. There is appropriated out of the general revenues of the State of Hawaii the sum of \$ _____ or so much thereof as may be necessary for fiscal year 2014-2015 for a program for newborn critical congenital heart defect screening using pulse oximetry.

The sum appropriated shall be expended by the department of health for the purposes of this Act.

SECTION 4. New statutory material is underscored.

SECTION 5. This Act shall take effect on July 1, 2014.

Wednesday – February, 26 2014 – 10:00am
Conference Room 211

SENATE COMMITTEE ON HEALTH

Senator Josh Green, Chair
Senator Rosalyn H. Baker, Vice Chair

SENATE COMMITTEE ON COMMERCE AND CONSUMER PROTECTION

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

SENATE COMMITTEE ON WAYS AND MEANS

Senator David Y. Ige, Chair
Senator Michelle N. Kidani, Vice Chair

From: Martha Smith
Chief Executive Officer

Re: SB 2194
Testimony Supporting the Intent but with Comments/Revisions

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 the intent of SB 2194, but offers comments on this measure.

SB 2194 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 measure also requires that the person in charge of each institution caring for newborn infants and the responsible physician attending the birth or the person assisting the birth of a child not attended by a physician ensure that every infant

in the person's care be tested for congenital heart defects using pulse oximetry. Additionally, the measure requires the Department of Health to adopt rules regarding the administration of newborn critical congenital heart defect screening using pulse oximetry, quality and cost control of the screening, reporting of test results, the creation of guidelines for care, treatment, and follow up of infants when necessary, and informing parents about the purposes of the tests.

Kapi'olani Medical Center for Women & Children (Kapi'olani) has long followed Academy of Pediatrics (AAP) guidelines which recognizes the importance of screening for congenital heart defects and has established pulse oximetry screening as a standard of care for all newborns to screen for CCHD. However to ensure that the hospitals have the flexibility to utilize more advanced technology as the science in this field evolves, we suggest that the bill reference the use of pulse oximetry screening **as well as other procedures as specified in the AAP guidelines.**

Additionally, specifying the personnel who would be responsible for ensuring that every infant is tested for congenital heart defects using pulse oximetry creates a cumbersome practice. Staffing responsibilities and care models differ at each birthing center making a statutory definition of accountability practically difficult. **Thus, we suggest that subsection (b) on page 2 of the measure be deleted.**

Similarly we also question the necessity of adopting administrative rules to govern implementation of pulse oximetry screening. The hospitals have developed internal procedures which deal with the reporting and implementation requirements that the bill seeks to address through the creation of administrative rules. **Thus, we also suggest that subsection (c) on page 3 be deleted.**

We respectfully suggest that this measure be simplified such that the Department of Health would require birthing facilities to perform a critical congenital heart defect screening using pulse oximetry on newborns or to follow and adopt the guidelines of the AAP within one year of adoption by the AAP. This would allow birthing facilities to remain compliant with statutes as best practices for CCHD screening may evolve.

An amended bill with proposed language is attached to our testimony for your consideration (Attached Below)

We ask that you pass the bill as amended. Thank you.

SB 2194

PROPOSED AMENDMENTS

SECTION 1. The legislature finds that congenital heart defects are structural abnormalities of the heart that are present at birth and are the number one killer of infants with birth defects. Congenital heart defects range in severity from simple problems, such as holes between chambers of the heart, to severe malformations, such as the complete absence of one or more chambers or valves. Some congenital heart defects can cause severe or life-threatening symptoms that require intervention within the first days of life.

Pulse oximetry is a non-invasive test that estimates the percentage of hemoglobin in blood that is saturated with oxygen. When performed on newborns in birthing facilities, pulse oximetry is effective at detecting critical, life-threatening congenital heart defects, which otherwise go undetected by current screening methods. The legislature finds that many newborn lives could potentially be saved by earlier detection and treatment of congenital heart defects if birthing facilities in the State were required to perform this simple, non-invasive newborn screening in conjunction with current congenital heart disease screening methods.

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~~[(b) The person in charge of each institution caring for newborn infants and the responsible physician attending the birth of a newborn, or the person assisting the birth of a child not attended by a physician, shall ensure that~~

~~every infant in the person's care be tested for congenital heart defects through pulse oximetry screening; provided that this section shall not apply if the parents, guardians, or other persons having custody or control of the child object thereto on the grounds that the tests conflict with their religious tenets and beliefs and written objection is made a part of the infant's medical record.]~~

~~[(c) The department of health shall adopt rules, pursuant to chapter 91, as necessary to effectuate the purposes of this section, including but not limited to rules regarding:~~

- ~~— (1) Administration of newborn critical congenital heart defect screening using pulse oximetry;~~
- ~~— (2) Quality and cost control of critical congenital heart defect screening using pulse oximetry;~~
- ~~— (4) Reporting of test results;~~
- ~~— (5) Guidelines for care, treatment, and follow up of infants when necessary;~~
- ~~— (6) Informing parents about the purposes of these tests; and~~
- ~~— (7) Maintaining the confidentiality of affected families.]~~

(d-b) For the purposes of the section, "birthing facility" means an inpatient or ambulatory health care facility licensed by the department of health that provides birthing and newborn care services."

SECTION 3. There is appropriated out of the general revenues of the State of Hawaii the sum of \$ or so much thereof as may be necessary for fiscal year 2014-2015 for a program for newborn critical congenital heart defect screening using pulse oximetry.

The sum appropriated shall be expended by the department of health for the purposes of this Act.

SECTION 4. New statutory material is underscored.

SECTION 5. This Act shall take effect on July 1, 2014.

Testimony of Phyllis Dendle

Before:

Senate Committee on Health
The Honorable Josh Green, Chair
The Honorable Rosalyn H. Baker, Vice Chair

Senate Committee on Commerce and Consumer Protection
The Honorable Rosalyn H. Baker, Chair
The Honorable Brian T. Taniguchi, Vice Chair

Senate Committee on Ways and Means
The Honorable David Y. Ige, Chair
The Honorable Michelle N. Kidani, Vice Chair

February 26, 2014
10:00 am
Conference Room 211

SB 2194 RELATING TO HEALTH

Chair Green, Chair Baker, Chair Ige and committee members, thank you for this opportunity to provide testimony on SB 2194 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 and document it 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 are also concerned that creating another documentation requirement simply creates another issue for compliance. Right now the results of this pulse oximetry screening are in our electronic medical record, reviewed and action taken as appropriate--no forms. This bill seems to create a new liability for heads of institutions, attending physicians and persons assisting at the birth.

We don't think we need rules about how to handle the screening and follow up on this test. It's clear both how to do it and that treatment and follow up are essential for children whose tests indicate a heart defect. Without the need for rules it also removes the need for funding the department to create the rules and any program associated with this test.

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 or other appropriate body.

We support the draft that has been created in cooperation with the American Heart Association –Hawaii Chapter. It is simple and direct. It requires the use of this test and ties future screening to recommendations made by organizations of medical professionals.

Thank you for your consideration.

**American Congress of Obstetricians and Gynecologists
District VIII, Hawaii (Guam & American Samoa) Section**

Lori Kamemoto, MD, MPH, FACOG, Chair
94-235 Hanawai Circle, #1B
Waipahu, Hawaii 96797



February 26, 2014-Wednesday

10:00 AM

Conference Room 211

State Capitol

**To: Senator Josh Green, Chair
Senator Rosalyn H. Baker, Vice Chair
Senate Committee on Health**

**From: Lori Kamemoto, MD, MPH, Chair
Greigh Hirata, MD, Vice Chair
American Congress of Obstetricians and Gynecologists, Hawaii Section**

Re: SB2194, Relating to Pulse Oximetry Screening

Position: Support

Dear Chair Green, Vice Chair Baker, and Health Committee Members:

The American Congress of Obstetricians and Gynecologists (ACOG), Hawaii Section, strongly supports SB2184, requiring birthing facilities to screen for congenital heart disease by performing a pulse oximeter screening test on all newborns prior to discharge.

Congenital heart lesions constitutes a major portion of the anomalies in the newborn (approximately 0.8-1 % of all live births) and is a leading cause of neonatal mortality and morbidity. Although targeted prenatal ultrasound examination has been helpful in detecting these lesions prior to birth, many women lack access to these high level examinations and as a consequence, babies are born with undiagnosed heart lesions. Any delay in the diagnosis will lead to preventable neonatal death and morbidity.

Hawaii ACOG supports SB2194, that will allow for early detection and treatment for our newborn keiki.

Thank you for the opportunity to submit this testimony.

Date: February 24, 2014

To: Honorable Josh Green
Honorable Rosalyn Baker
Honorable David Ige

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

Re: In support of
SB2194

Hearing: February 26, 2013 10:00am
Conference Room 211, 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, Chair Ige, 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.

February 24, 2014

Honorable Josh Green
Honorable Rosalyn Baker
Honorable David Ige
Page 2

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 undetected, can be severe and life-threatening.

Mahalo for the opportunity to testify in support of SB2194.



Hawaii Chapter

AAP - Hawaii Chapter
5414 Kirkwood Place
Honolulu, HI 96821

Hawaii Chapter Board

President

R. Michael Hamilton, MD, MS, FAAP
Department of Pediatrics,
Hawaii Permanente Medical Group
2828 Paa Street
Mapunapuna Clinic, 2nd Floor
Honolulu, HI 96819
Phone : 808/432-5604
Fax : 808/432-5601
Email: Michael.R.Hamilton@kp.org

Vice President

Mae S. I. Kyono, MD, FAAP
1319 Punahou Street, 7th Floor
Honolulu, HI 96826
Phone: 808/780-5286
Fax: 808/983-6109
Email: mkyono@hawaii.edu

Secretary

Josephine Quensell, MD, FAAP
1319 Punahou Street, Suite 1050
Honolulu, HI 96826
Phone: 808/942-8144
Fax: 808/955-3827
Email: quensell@hawaii.edu

Treasurer

Milette Oliveros, MD, FAAP
1319 Punahou Street
Honolulu, HI 96826
Email:
Milette.Oliveros@kapiolani.org

Chapter Executive Director

Kathryn Sthay
5414 Kirkwood Place
Honolulu, HI 96821
Phone: 808/377-5738
Fax: 808/377-3683
E-mail: ksthay@aap.net

Immediate Past President

Kenneth T. Nakamura, MD, FAAP
1319 Punahou Street, Room 743
Honolulu, HI 96826
Phone: 808/983-8020
Fax: 808/983-6343
E-mail: kennethn@kapiolani.org

Chapter Web site

www.hawaii.aap.org

AAP Headquarters

141 Northwest Point Blvd
Elk Grove Village, IL 60007-1098
Phone: 847/434-4000
Fax: 847/434-8000
E-mail: kidsdocs@aap.org
www.aap.org

Wednesday – February, 26 2014 – 10:00am
Conference Room 211

SENATE COMMITTEE ON HEALTH

Senator Josh Green, Chair
Senator Rosalyn H. Baker, Vice Chair

SENATE COMMITTEE ON COMMERCE AND CONSUMER PROTECTION

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

SENATE COMMITTEE ON WAYS AND MEANS

Senator David Y. Ige, Chair
Senator Michelle N. Kidani, Vice Chair

Re: SB 2194 Testimony Supporting the Intent with Suggested Revisions

I am writing in support of the intent of SB 2194, but suggest revisions.

SB 2194 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 measure also requires that the person in charge of each institution caring for newborn infants and the responsible physician attending the birth or the person assisting the birth of a child not attended by a physician ensure that every infant in the person's care be tested for congenital heart defects using pulse oximetry. Additionally, the measure requires the Department of Health to adopt rules regarding the administration of newborn critical congenital heart defect screening using pulse oximetry, quality and cost control of the screening, reporting of test results, the creation of guidelines for care, treatment, and follow up of infants when necessary, and informing parents about the purposes of the tests.

Kapi'olani Medical Center for Women & Children (Kapi'olani) has long followed the American Academy of Pediatrics (AAP) guidelines which recognizes the importance of screening for congenital heart defects and has established pulse oximetry screening as a standard of care for all newborns to screen for CCHD. However to ensure that the hospitals have the flexibility to utilize more advanced technology as the science in this field evolves, we suggest that the bill reference the use of pulse oximetry screening and add "as well as other procedures as specified in the AAP guidelines".

Specifying the personnel who would be responsible for ensuring that every infant is tested for congenital heart defects using pulse oximetry creates a cumbersome practice. Staffing responsibilities and care models differ at each birthing center making a statutory definition of accountability practically difficult. We suggest that subsection (b) on page 2 of the measure be deleted.

We also question the necessity of adopting administrative rules to govern implementation of pulse oximetry screening. The hospitals have developed internal procedures which deal with the reporting and implementation requirements that the bill seeks to address through the creation of administrative rules. We suggest that subsection (c) on page 3 be deleted.

We respectfully suggest that the Department of Health require birthing facilities to perform a critical congenital heart defect screening using pulse oximetry on newborns or to follow and adopt the guidelines of the AAP within one year of adoption by the AAP. This would allow birthing facilities to remain compliant with statutes as best practices for CCHD screening may evolve. It would also ensure the best CCHD screening for Hawaii's keiki.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Michael Hamilton', with a long horizontal flourish extending to the right.

R. Michael Hamilton, MD, MS, FAAP



S.B. 2194

RELATING TO HEALTH

Senate Committee on Health

Senate Committee on Commerce and Consumer Protection

Senate Committee on Ways and Means

February 26, 2014 10:00 a.m.

The Queen's Health System supports SB2194.

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.

DATE: Wednesday, February 26, 2014
TIME: 10:00 a.m.
PLACE: Conference Room 211, State Capitol

To: Senate Committees on Health; Commerce and Consumer Protection; and Ways and Means

From: John A. Burns School of Medicine
That Nam Tran “Sony” Ton—fourth year medical student

Re: Bill SB# 2194, In Support

Chairs & Committee Members:

I, That Nam Tran “Sony” Ton support SB #2194 for the implemented screening of critical congenital heart disease by newborn pulse oximetry screening. Pulse oximetry testing is a noninvasive, painless test that measures oxygen saturation of the blood’s hemoglobin; therefore, abnormally low values are “red flags” that can indicate intrinsic problems with the body’s way of oxygenating the blood (e.g. congenital heart defects). Given that newborns can look “well”, congenital heart disease can manifest into significant illness days after birth, perhaps in the context of the newborn being at home. This test can prompt subsequent definitive testing, before newborns are sent home, to evaluate for congenital heart defects and improve more timely diagnosis.

Contextually, congenital heart disease is the most common serious birth defect (1:400 births), accounting for more deaths than any other malformation¹. Missed rates of newborns being sent home have been documented 1:3,500 to 1:25,000 births; unfortunately, more than half of patients with a missed diagnosis of critical congenital heart disease will die at home or in an emergency room before their heart disease is recognized.

The pulse oximetry screen follows a protocol that is performed at bedside, whereby the initial step in the screen requires just minutes to conduct. The rationale for use of this method is that most critical congenital heart defects have a degree of low oxygen saturation that would not necessarily produce visible cyanosis (i.e. blue appearance) and therefore might not be clinically detectable. A 2012 meta-analysis published in the Lancet showed compelling evidence for introduction of pulse oximetry as a screening method in clinical practice, functioning as a test that performs higher than present strategies based on antenatal screening and clinical examination. Strong evidence exists for health-care systems to consider introduction of pulse oximetry as a screening test for critical congenital heart defects in asymptomatic newborn². It is of no surprise that the US Department of Health and Human Services strongly recommended the addition of pulse oximetry screening for congenital heart disease to the recommended uniform screening panel

Thank you for the opportunity to submit testimony. Let’s further empower our families to confidently raise their children well

References:

- 1) R Knowles, I Griebisch, C Dezateux, J Brown, C Bull, C Wren. Newborn screening for congenital heart defects: a systematic review and cost-effectiveness analysis. *Health Technol Assess*, 9 (2005), pp. 1–152
- 2) S Thangaratinam, K Brown, J Zamorea, K Khan, A Ewer. Pulse oximetry screening for critical congenital heart defects in asymptomatic newborn babies: a systematic review and meta-analysis. *Lancet* (2012), pp. 2459-2464.

**Wednesday – February, 26 2014 – 10:00am
Conference Room 211**

SENATE COMMITTEE ON HEALTH

Senator Josh Green, Chair
Senator Rosalyn H. Baker, Vice Chair

SENATE COMMITTEE ON COMMERCE AND CONSUMER PROTECTION

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SENATE COMMITTEE ON WAYS AND MEANS

Senator David Y. Ige, Chair
Senator Michelle N. Kidani, Vice Chair

From: Andras Bratincsak, MD, PhD, FACC
Pediatric and Adult Congenital Cardiology
Kapi'olani Medical Specialist

**Re: SB 2194
Testimony Supporting the Intent but with Comments/Revisions**

My name is Andras Bratincsak, and I am an assistant clinical professor of pediatric cardiology in the Department of Pediatrics at the University of Hawaii, John A. Burn School of Medicine, and an attending pediatric and adult congenital cardiologist at Kapi'olani Medical Center for Women and Children (KMCWC) and Straub Clinic and Hospital.

I am one of the 3 practicing pediatric cardiologists outside the Tripler and Kaiser medical systems in Hawai'i. As such, I have a chance to diagnose and treat the majority of infants with possible or confirmed heart defects from KMCWC and Queens Medical Center on Oahu, Wilcox Hospital in Kauai and medical centers from the Big Island.

I believe that introducing a diagnostic test to detect critical congenital heart defects as part of a newborn screening is a major step in the advancement of disease prevention in this century. Mandating such screening gives the State of Hawai'i the ability to provide a uniform and standardized screening service to the newborns validated by numerous national and international clinical trials. Therefore I am in favor of passing such a bill.

There are however, two modifications that I would like to suggest in order to provide a universal, reliable, and feasible screening program:

- 1) Pulse oximetry shall be used as a newborn screening test to detect CCHD until there will be a better screening test introduced and validated nationally and mandated by the American Academy of Pediatrics and American Heart Association.

Therefore, I suggest changing the language allowing facilities and professionals to adapt to a change dictated by the American Academy of Pediatrics and the American Heart Association.

- 2) Screening should be universal, available at home births too, unless rejected by parents.

Similar to the Newborn Metabolic Screening Program in Hawai'i, where the State mandates screening for every baby regardless under what circumstances they are born, the Critical Congenital Heart Disease screening should be offered to every baby born in Hawai'i, not only the babies, who are born in large medical facilities. In fact, the most at risk babies to have an undetected cyanotic heart defect are those, who are not monitored by medical professionals and who are born outside medical facilities. Therefore I suggest a modification to the bill by mandating the CCHD screening for all newborn babies regardless whether they are born in a medical facility or out of a hospital:

Suggested modification (Page 2, lines 9-13)

“§ 3 2 1 - **Newborn pulse oximetry screening.** (a) The department of health shall require each birthing facility, or the responsible physician attending the birth of a newborn, or the person assisting the birth of a child not attended by a physician, to perform a critical congenital heart defect screening using pulse oximetry or an alternate medically accepted test mandated by AAP/AHA on every newborn in its care prior to discharge.

Thank you for your consideration and commitment for the children of Hawai'i!

Sincerely,

Andras Bratincsak, MD, PhD, FACC

From: mailinglist@capitol.hawaii.gov
To: [HTHTestimony](#)
Cc: wojo.cari@gmail.com
Subject: Submitted testimony for SB2194 on Feb 26, 2014 10:00AM
Date: Tuesday, February 25, 2014 10:43:10 PM

SB2194

Submitted on: 2/25/2014

Testimony for HTH/CPN/WAM on Feb 26, 2014 10:00AM in Conference Room 211

Submitted By	Organization	Testifier Position	Present at Hearing
Cari Ann Csigi	Individual	Support	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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