



STATE OF HAWAII
DEPARTMENT OF HEALTH
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**Testimony in SUPPORT of HB 467, HD 1
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: March 19, 2015 Room Number: 229

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 HB467, HD1 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.

Thursday – March 19, 2015; 9:00 am
Conference Room 229

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: HB 467, HD1 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 HD 467, HD1. 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.



American Heart Association testimony in strong SUPPORT of HB 467, HD1 “Relating to Health”

The American Heart Association strongly supports HB 467, HD1 “Relating to Health.”

Congenital heart defects (CHD) are the most common birth defect in the U.S. and the leading killer of infants with birth defects. In the US, about 7,200 (or 18 per 10,000) babies born each year have one of seven critical congenital heart defects (CCHDs). An estimated 300 infants with an unrecognized CCHD are discharged each year from newborn nurseries in the United States. These babies are at risk for having serious problems within the first few days or weeks of life and often require emergency care.

Pulse oximetry newborn screening can identify some infants with a CCHD before they show any signs. Once identified, babies with a CCHD can be seen by cardiologists (heart doctors) and can receive specialized care and treatment that could prevent death or disability early in life. Treatment can include medications and surgery.

One of the best ways to detect CCHD 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. It is a simple bedside test to determine the amount of oxygen in a baby's blood and the baby's pulse rate. Low levels of oxygen in the blood can be a sign of a CCHD. The test is done using a machine called a pulse oximeter, with sensors placed on the baby's skin. The test is painless and takes only a few minutes.

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.

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. At the time of this hearing, at least 36 states have passed legislation requiring pulse ox screening for all newborns. Others are expected to follow suit this year. Hawaii remains in the minority of those that currently don't require the screening.

HB 467, HD1 would help to insure that all Hawaii families are provided with the most recent standard of care-based health screenings for their newborns. The AHA urges Hawaii legislators support HB 467, HD1.

Respectfully submitted,

Donald B. Weisman

Hawaii Government Relations Director

*“Building healthier lives,
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Please remember the American Heart Association in your will.



Senate Committee on Health
Hawaii State Capitol, Room 407
415 South Beretania St.
Honolulu, HI 96813
Re: HB 467, HB 1- Testimony in Support

March 16, 2015

Aloha Chair Sen. Green, Vice Chair Sen. Wakai, and Committee Members,

I would like to submit my testimony in strong support of HB 467, HD 1.

My 3 year old daughter was born with a severe heart defect. Her defect was not detected until she was 6 days old and was struggling to live. She spent the first 8 months of her life in a children's hospital, suffering unimaginable pain and fear.

We were extremely fortunate that she survived although her life will be a challenging one. If we would have known about her condition right away, her body, specifically her lungs, would most likely be stronger and her hospital stay and subsequent care would have been less.

A pulse-ox test is simple, painless, and inexpensive. 8 months in the Neonatal Intensive Care Unit is none of these.

Thank you for letting you share my heart. I urge you to consider all the little hearts that can be saved by passing this bill.

Mahalo,

Alison E Riggs

Kapolei Homemaker
Ali_riggs@yahoo.com

To whom it may concern

I would like to submit a testimony in support of HB 467 regarding critical congenital heart disease (CCHD) screening for all newborns. I am a bachelor's of nursing student at the University of Hawaii at Hilo and am currently working as an LPN in the newborn nursery in Maui.

In working at an institution that participates in the screening for congenital heart defects, I am in support of such an affordable non-invasive screening test that is invaluable to the health of Hawaii's newborns. This simple screening tool helps to detect problems not visible to the eye, and allows for quick intervention in the event that a cardiac defect is present. Given the geographic nature of our state and the limited ability for neighbor islands to accommodate babies with these heart defects, this bill is that much more important. It is crucial to screen for these defects before it is too late to take action in resolving the problem. Our babies deserve the best start to a healthy life.

Thank you for the opportunity to provide this testimony,

Mary Emmons LPN, BSN student

Date: March 17, 2015

March of Dimes Foundation

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

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
HB467, HD1
Hearing: Thursday March 19, 2015
Conference Room 229, State Capitol

Chair Green, Chair Baker, Members of the Committees:

I am writing to express support for HB467 HD1: *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.

Adding CCHD to Hawaii's Newborn Screening Panel will bring the state in line with all current recommended screenings. Mahalo for the opportunity to testify in support of HB467 HD1 and for your support of this bill.

march  of dimes®

I am writing in support of the Keiki Heart Bill. My family and I have supported this bill from the beginning. We have been affected by congenital heart defect. Our son, Shayden, was born with a congenital heart defect. His condition was not detected until one week after his birth. He was then immediately medivaced to California, where he spent months in the hospital. He went through many procedures, surgeries, and tests. He also went into cardiac arrest. During his stay in the hospital, Shayden contracted multiple infections. In November 2011, Shayden's body could not handle any more. He passed away at four months old.

Supporting this bill not only gives us a chance to speak out about our experience, but it also gives us a chance to fight for our son and many other families. We have met families whose babies' defects were detected after being sent home. Those families are still fighting to this day. Passing this bill will help doctors treat these babies immediately. Children are our future, they deserve a fighting chance in life. If Shayden had pulse oximetry screening done, he may be alive today. Please give children the chance in life that my son didn't have.

Thank you

From: mailinglist@capitol.hawaii.gov
To: [HTHTestimony](#)
Cc: kelsey_joh@hotmail.com
Subject: Submitted testimony for HB467 on Mar 19, 2015 09:00AM
Date: Tuesday, March 17, 2015 8:36:58 PM

HB467

Submitted on: 3/17/2015

Testimony for HTH/CPN on Mar 19, 2015 09:00AM in Conference Room 229

Submitted By	Organization	Testifier Position	Present at Hearing
Kelsey Popp	Individual	Support	No

Comments: To Whom it May Concern, Did you know that 1 in every 100 babies is born with a critical congenital heart defect (CCHD)? This means that heart defects are the number one MOST COMMON birth defect in the United States. As the mother of a baby born with a critical heart defect, I fully support the efforts of HB467, HD1. My son Christian was born in in Kailua in 2009 with Total Anomalous Pulmonary Veinous Return - a life threatening heart defect. Soon after his birth, a routine pulse oximetry test detected my son's heart failure, and ultimately saved his life. Had he not received a pulse oximetry test at birth, we may have taken home a baby who appeared healthy, but could have died unexpectedly in our care. Instead, he went on to have open heart surgery as a newborn, and is a joyful healthy 5 year old boy today! We're very fortunate that his hospital already implements routine pulse oximetry testing on newborns, but it isn't currently a requirement in all Hawaii hospitals. Routine pulse oximetry tests are inexpensive (less than \$5), painless, noninvasive, and quick. All hospitals are already equipped to administer these routinely at birth and then again before discharge home. Considering this test is capable of detecting over 90% of heart defects, the American Academy of Pediatrics has clear guidelines suggesting the use of pulse oximetry as the standard of care for newborns. You'll learn more about this bill in the joint Senate Health, and Commerce and Consumer Protection committees hearing on Thursday (3/19). As a heart mom, I urge you to PLEASE support this bill to save the lives of Hawaii-born keiki like my son Christian! Thank you for your consideration, Kelsey Popp (360)649-3680 788 SW 12th Ct Oak Harbor, WA 98277

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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