



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

In reply, please refer to:
File:

House Committee on Health

H.B. 905, RELATING TO NEWBORN SCREENING

Testimony of Loretta J. Fuddy, A.C.S.W., M.P.H.
Director of Health

February 6, 2013

1 **Department's Position:** This is an administrative bill. The Department of Health (DOH) strongly
2 supports the establishment of a statute to authorize the DOH to implement Point of Care (PoC) newborn
3 screening. This will strengthen DOH efforts to help Hawai'i families have healthy babies.

4 **Fiscal Implications:** The cost to the DOH for oversight, education, and quality assurance for the
5 administration these new tests will be covered by the newborn metabolic screening program user fees
6 charged to birthing facilities. The user fee and cost for newborn screening activities are recovered by
7 the birthing facilities and providers through reimbursement by third party payers.

8 **Purpose and Justification:** This bill authorizes the DOH to implement PoC newborn screening, and
9 allows the newborn metabolic screening fund to be used for PoC screening services.

10 Babies born in our state now are screened for 32 disorders. Traditionally, newborn screening is
11 done by collecting a tiny amount of blood from the baby's heel before discharge from hospital. After
12 the baby leaves the hospital, if the screening result is positive, the family is contacted and more follow-
13 up is done to determine if the baby has a disorder that needs treatment.

1 Critical Congenital Heart Defects (CCHD) is a new disorder to be added to the Hawai‘i newborn
2 screening panel, in order to meet the guidelines established by the federal Recommended Uniform
3 Screening Panel (RUSP). CCHD requires the new PoC newborn screening where the baby is screened
4 and all additional screening and diagnostic tests are done before the baby goes home due to serious
5 nature of the disorders that can be detected. If needed, the baby is transferred to a facility that can do the
6 tests. A baby with a CCHD cannot be allowed to go home without monitoring, treatment, and
7 intervention.

8 This bill clarifies the responsibilities of the state, birthing facilities, and providers for PoC
9 newborn screening for CCHD and other future disorders that may be added to the RUSP. We want to
10 provide leadership by allowing the state to establish administrative rules to ensure that the newborns in
11 the state receive quality PoC newborn screening services. Parents will expect the state to provide as
12 much guidance and oversight for the PoC newborn screening as we do for metabolic disorders and
13 hearing loss, especially since the Affordable Care Act requires that all third party payers cover the cost
14 of newborn screening for all disorders on the RUSP.

15 Thank you for the opportunity to testify.



HILOPA'A

Family to Family Health Information Center

Date: February 2, 2013

To: COMMITTEE ON HEALTH
Representative Della Au Bellatti, Chair
Representative Dee Morikawa, Vice Chair

Fr: Leolinda Parlin, State Coordinator for Family Voices of Hawai'i

Re: **SUPPORT** – HB 905 – RELATING TO NEWBORN SCREENING

On behalf of Family Voices of Hawai'i, I offer testimony in support of HB 905, which seeks provide the department of health the flexibility to implement point of care newborn screening protocols through the administrative rules. As an organization, Family Voices is national grass roots organization of family of friends of child with special health care needs. In Hawai'i, we operate the federally funded Hilopa'a Family to Family Health Information Center.

Hawaii's newborn screening program is a hallmark of our health care system. As such, any administrative remedy available to support the program as well as its expansion should be lauded.

Thank you for your time and consideration in passing HB 905.



EXECUTIVE OFFICE ON EARLY LEARNING
HONOLULU

TERRY LOCK
DIRECTOR

Testimony in **Support** of
H.B. 905, Relating to Newborn Screening
By Terry Lock, Director

House Committee on Health
February 6, 2013
10:30 a.m., Room 329

Chair Au Belatti, Vice-Chair Morikawa, and Members of the Committee:

Aloha, I am Terry Lock, Director of the Executive Office on Early Learning (EOEL). EOEL is in support of House Bill 905.

EOEL is charged with coordinating efforts on behalf of young children by creating partnerships and alignment of policies and programs to achieve improved outcomes in health, safety, and school readiness and success. Over the past year, EOEL has engaged partners across the state to define the desired outcomes for children and families, as well as the critical strategies to achieve those outcomes, which should be prioritized over the next three to five years. This work – the Hawaii Early Childhood Action Strategy – is described in *Taking Action for Hawaii's Children*, which can be found at earlylearning.hawaii.gov.

One of these priority strategies is to improve birth outcomes for our keiki. H.B. 905 aligns with this strategy as it establishes point of care newborn screenings, and extends support for the screenings through the Newborn Metabolic Screening Special Fund, to prevent newborn mortality and morbidity in the state.

Thank you for the opportunity to testify.

Date: February 5, 2013

To: Honorable Della Au Belatti
Honorable Dee Morikawa

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

Re: In support of
HB905

Hearing: February 6, 2013 10:30am
Conference Room 329, 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 Belatti, Vice Chair Morikawa, Members of the Committee:

I am writing to express strong support for HB905: *Relating to 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. CCHD can be detected through a point of care screening called 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 point of care screening provides that, should a newborn screen positive for CCHD, diagnostic tests can be administered before the infant is discharged to go home. This can allow for early medical and surgical interventions to improve outcomes.

march  of dimes®

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HB905 will establish point of care screening for detecting CCHD and other disorders. March of Dimes supports HB905 in order to ensure that newborns in Hawaii are screened for conditions that can be detected through point of care screening.