

SB 2010

WRITTEN ONLY

LINDA LINGLE
GOVERNOR OF HAWAII



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In reply, please refer to:
File:

Senate Committee on Health

S.B. 2010, RELATING TO NEWBORN SCREENING

Testimony of Chiyome Leinaala Fukino, M.D.
Director of Health

January 29, 2010, 2:45 p.m.

1 **Department's Position:** The Department of Health (DOH) strongly opposes S.B. 2010. The current
2 newborn screening (NBS) statute (HRS 321-291) allows the DOH, in consultation with the Hawai'i
3 Newborn Screening Advisory Committee, to modify the NBS panel based on national recommendations,
4 evidence based findings, and changing technology. In addition, five of the eight disorders listed are not
5 recommended by the American College of Medical Genetics/March of Dimes consortium or National
6 NBS Advisory Committee to be on state newborn metabolic screening panels. The remaining three
7 disorders are already included in the Hawai'i screening panel.

8 **Fiscal Implications:** If the five additional disorders are added to the newborn metabolic screening,
9 there will be additional cost to the Newborn Metabolic Screening Program (NBMSPP), central laboratory
10 that does the testing, hospitals that pay for these newborn screens, and to the health insurance that covers
11 the cost of hospital newborn care. There would also be additional follow-up costs to figure out what to
12 do with the newborns since there is no clear evidence that any type of treatment is beneficial in the
13 newborn period.

14 **Purpose and Justification:** S.B. 2010 specifies the addition of eight disorders to the Hawai'i NBS
15 Panel.

1 The Hawai'i legislature revised the NBS statute (HRS 321-291) in 1995 to allow the DOH to
2 determine what disorders should be on the NBS panel due to the evolving national recommendations,
3 new technology, needs of the state. This forward thinking change allows the state to consult with
4 experts, families, health care providers, and the community to determine which disorders should be on
5 the Hawai'i NBS panel. Currently, Hawai'i screens for 32 disorders (including hearing) and exceeds the
6 recommended American College of Medical Genetics/March Of Dimes (ACMG/MOD) recommended
7 panel.

8 S.B. 2010 bill lists eight specific disorders. Three of the eight disorders are identified by the
9 current newborn metabolic screening panel (defects of biopterin cofactor biosynthesis; defects of
10 biopterin cofactor regeneration; tyrosinemia type III).

11 The remaining five disorders listed are not in the current panel (dienoyl-CoA reductase;
12 galactose epimerase; galactokinase; medium/short chain L-3-hydroxy acyl-CoA dehydrogenase;
13 medium-chain ketoacyl-CoA thiolase). These disorders have not been recommended by ACMG/MOD
14 or the National NBS Advisory Committee for inclusion in state NBS panels. Also, there is no clear
15 evidence that some type of treatment in the newborn period is beneficial to the newborn.

16 Thank you for the opportunity to testify.

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Friday, January 29, 2010 – 2:45pm
Conference Room 016

The Senate Committee on Health

To: Senator David Ige, Chair
Senator Josh Green, Vice Chair

From: Laurie Seaver, MD
Medical Director
Hawai'i Community Genetics/Kapi'olani Medical Specialists

Re: **Testimony in Opposition to SB 2010 Relating to Newborn Screening**

I am Laurie Seaver, MD, Medical Director of Hawai'i Community Genetics and Kapi'olani Medical Specialists.

I am writing in strong opposition to SB 2010 Relating to Newborn Screening which would require the Department of Health to screen for certain newborn diseases, disorders & deficiencies.

The current newborn screening statute (HRS 321-291) allows the Department of Health, in consultation with the Hawai'i Newborn Screening Advisory Committee, to modify the newborn screening panel based on national recommendations, evidence based findings and changing technology. I am one of the members of the Hawai'i Newborn Screening Advisory committee.

Five of the 8 disorders listed are not recommended by the American College of Medical Genetics/March of Dimes consortium or National NBS Advisory Committee to be on state newborn metabolic screening panels. The remaining 3 disorders are already included in the Hawai'i screening panel.

Thank you very much for hearing this testimony in opposition to SB 2010 Related to Newborn Screening.

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