



UNIVERSITY OF HAWAII SYSTEM

Legislative Testimony

Written Testimony Presented Before the House Committee on Health and House Committee on Higher Education

March 18, 2008 at 2:15 p.m.

by

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and

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University of Hawai'i at Mānoa

SB 2040 SD1– RELATING TO CANCER SURVEILLANCE

Chair Representative Josh Green, Vice Chair Representative John Mizuno, Members of the House Committee on Health;

Chair Representative Jerry L. Chang, Vice Chair Representative Joe Bertram, Members of the House Committee on Higher Education:

The University of Hawaii strongly supports S.B. No. 2040, SD1 Relating to Cancer Surveillance, which would help us to achieve the goals of Hawaii Comprehensive Cancer Control Consortium (HCCCC), namely to save lives and improve the quality of life for individuals affected by cancer. First, the revised statute would give Hawaii citizens the right to choose whether or not they wish to participate in cancer research studies. Presently, physician permission is required in Hawaii before individual contact can be made. The requirement for physician permission preempts our citizen's ability to make personal decisions about their healthcare and limits their accrual to beneficial cancer research.

The second obstacle to achieving the goals of the HCCCC Plan is the ambiguous meaning of 'data or relevant material' that is part of the statute. The Hawaii Tumor Registry currently collects tissue and other biological specimens from cancer patients as part of its activities. It is important that the statute be clarified in this regard, providing the Tumor Registry with the authority to collect and house biological specimens that might be used in de-identified/anonymized research.

Finally, although information on pre-cancerous lesions has been collected by the HTR in the past (e.g., cervical dysplasia), specific statutory authority to do so is unclear. Collection of information on individuals with pre-cancerous disease is an important means to monitor cancer screening activities (e.g., prostate cancer screening) or to monitor the efficacy of cancer vaccines, such as the newly introduced vaccine against the human papillomavirus.

We therefore advocate these minor revisions to H.R.S. § 324-21 and 321-29 to 1) increase community participation in research studies; 2) increase the research utility of the Hawaii Tumor

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Registry; 3) allow comprehensive monitoring of the efficacy of cancer screening and cancer vaccination activities; 4) enhance the quality of life of cancer survivors; and 5) stimulate community awareness of the Cancer Information Service and local community cancer prevention efforts. We urge the Committee to pass S.B. No. 2040, SD1. Thank you for this opportunity to testify.

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Testimony of
Phyllis Dendle
Director of Government Affairs

Before:
House Committee on Health
The Honorable Josh Green M.D., Chair
The Honorable John Mizuno, Vice Chair

House Committee on Higher Education
The Honorable Jerry L. Chang, Chair
The Honorable Joe Bertram, III, Vice Chair

March 18, 2008
2:15 PM
Conference Room 309

SB 2040 SD1 RELATING TO CANCER SURVEILLANCE

Chairs Green and Chang and committee members, thank you for this opportunity to provide testimony on SB 2040 SD1 which amends the law regarding the Hawaii Tumor Registry

Kaiser Permanente Hawaii opposes the bill in its current form but supports it with amendments.

We appreciate the intent of the bill which is to reduce impediments to appropriate research on cancer. We are however, concerned about the way this is being done in the SD1 version of the bill. Since the last hearing, the parties interested in this bill met and redrafted it to make it useful for all concerned. Attached is a list of amendments which we all agreed to.

We urge this committee pass this bill with amendments. Thank you for your consideration.

Proposed amendments to SB 2040 SD1

1. Page 1 line 3 insert after the word goals “ of the Hawaii Comprehensive Cancer Control Coalition “
2. Page 2 lines 5-7 delete the following phrase “, including clinical trials they may be eligible to participate in, to assist in the fight against cancer.”
Add period after the word research on line 5.
3. Page 3 line 12 after the period add the following sentence “All data collected by the cooperating agency may be shared with the Department of Health in a form compatible with the Department of Health specification.”
4. Page 4 line 6 insert an additional item to the list
“(5) For improving the cause of death reporting on death certificates.”
5. Page 4 line 12 insert the following phrase between the word association and the period
“and the appropriate federally authorized human subjects protection board”
6. Page 4 line 14 delete “and (b)”
7. Page 4 line 19 insert the following phrase after the word cancer “or pre-cancerous conditions”
8. Page 4 line 22 insert the following phrase between the word association and the period
“and the appropriate federally authorized human subjects protection board”
9. Page 5 lines 1-16 delete subsection (b)
10. Page 5 line 18 insert the following phrase after the word amended “by amend subsection (b) “
11. Page 5 lines 19-22 delete
12. Page 6 lines 1-4 delete
13. Page 6 line 11 insert the following phrase after the word studies “after being”
14. Page 6 line 11 insert the following phrase after the word commission “and the appropriate federally authorized human subjects protection board”
15. Page 6 lines 11 delete “; provided”
16. Page 6 lines 12-22 delete
17. Page 7 line 3 delete “on January 1, 2050.” insert “upon approval”



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March 18, 2008

To: Rep. Josh Green, M.D., Chair
Rep. John Mizuno, Vice Chair
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Rep. Jerry L. Chang, Chair
Rep. Joe Bertram III, Vice Chair
Higher Education Committee

From: Cynthia J. Goto, M.D., President
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Philip Hellreich, M.D., Legislative Co-Chair
Paula Arcena, Executive Director
Dick Botti, Government Affairs Liaison

Re: SB2040 SD1 Relating to Cancer Surveillance (Allows a cancer patient to be contacted directly without initial physician contact for purposes of cancer surveillance. Adds pre-cancer to diseases about which data are authorized for collection. Adds biological specimens to the materials that may be collected to assist cancer research.)

The Hawaii Medical Association supports SB2040 SD1.

The HMA has worked with representatives of the University of Hawaii, Department of Health and Kaiser Permanente to identify amendments to the bill. We support the amendments submitted by the University of Hawaii.

We respectfully request the committee accept these suggested amendments.

Thank you for the opportunity to testify on this matter.

PLEASE DELIVER
HLT/HED COMMITTEE

Tuesday
3/18/2008
2:15pm
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