

# SB2040

**Measure Title:**

RELATING TO CANCER SURVEILLANCE.

**Report Title:**

Cancer Surveillance and Research; Data Collection

**Description:**

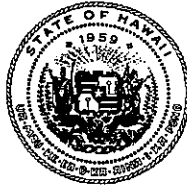
Allows a cancer patient to be contacted directly without initial physician contact for purposes of cancer surveillance. Adds pre-cancer to diseases about which data are authorized for collection. Adds biological specimens to the materials that may be collected to assist cancer research.

**Introducer(s):**

BAKER, Ige

**Current Referral:**

HTH



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

In reply, please refer to:  
File:

**SENATE COMMITTEE ON HEALTH**  
**SB2040, RELATING TO CANCER SURVEILLANCE**

**Testimony of Chiyo Leinaala Fukino, M.D.**  
**Director of Health**

**February 25, 2008, 1:15PM**

1 **Department's Position:** The Department supports the intent of SB2040 to make minor revisions to  
2 Hawaii Revised Statutes §324-22 regarding patient contact and amending §321-43 and §324-21  
3 regarding data collection. The DOH will work with partners within the cancer research and medical  
4 community to resolve concerns about specific language in the bill.

5 **Fiscal Implications:** None.

6 **Purpose and Justification:** The Department recognizes the importance of quality of life for individuals  
7 affected by cancer. The minor revisions of existing statutes will help in increasing community  
8 participation in clinical trials, increase the research utility of the Hawaii Tumor Registry, allow  
9 comprehensive monitoring of the efficacy of cancer screening and cancer vaccination activities, enhance  
10 the quality of life of cancer survivors, and stimulate awareness of cancer information services and local  
11 community cancer prevention efforts.

12 Thank you for the opportunity to testify.

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# UNIVERSITY OF HAWAII SYSTEM

## Legislative Testimony

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### Testimony Presented Before the Senate Committee on Health

February 25, 2008 at 1:15 p.m.  
State Capitol, Conference Room 016

by  
Virginia S. Hinshaw, Chancellor  
Presented by  
Carl-Wilhelm Vogel, MD, PhD  
Director, Cancer Research Center of Hawai'i  
University of Hawai'i at Mānoa

### **SB 2040 – RELATING TO CANCER SURVEILLANCE**

Chair Senator David Y. Ige, Vice Chair Senator Carol Fukunaga, Members of the Senate Committee on Health:

The University of Hawai'i strongly supports S.B. No. 2040, Relating to Cancer Surveillance, which would help us to achieve the goals of the 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 Hawai'i citizens the right to choose whether or not they wish to participate in cancer research studies. Presently, physician permission is required in Hawai'i before individual contact can be made. The requirement for physician permission preempts our citizens' ability to make personal decisions about their healthcare and limits their accrual to beneficial cancer research, such as clinical trials.

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 clinical trials and other research studies; 2) increase the research utility of the Hawaii Tumor 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. Thank you for this opportunity to testify.



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February 25, 2008

To: Sen. David Ige, Chair  
Sen. Carol Fukunaga, Vice Chair  
Senate Health Committee

From: Cynthia J. Goto, M.D., President  
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Dick Botti, Government Affairs Liaison

PLEASE DELIVER  
SEN CPH COMMITTEE

Monday  
2/25/08  
1:15pm  
Room 016

Re: SB2040 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 the intent of SB2040.

We request the committee defer decision-making on the measure to allow time for all interested parties to discuss concerns about the bill and suggest appropriate amendments.

Thank you for the opportunity to testify on this matter.

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Testimony of  
Phyllis Dendle  
Director of Government Affairs

Senate Committee on Health  
The Honorable David Y. Ige, Chair  
The Honorable Carol Fukunaga, Vice Chair

February 25, 2008  
1:15 PM  
Conference Room 016

### **SB 2040 RELATING TO CANCER SURVEILLANCE**

Chair Ige and committee members, thank you for this opportunity to provide testimony on SB 2040 which amends the law regarding the Hawaii Tumor Registry

#### **Kaiser Permanente Hawaii supports the intent of this bill.**

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. Primarily we are concerned about the requirement on page 5 lines 3 and 4 to report not only on persons diagnosed as having cancer but also those who have “pre-cancer”. There is no definition of pre-cancer and not all cancers have the same conditions that could lead to cancer. We recommend that this be a permissible activity as described in section one of the bill rather than be required. This would allow the collection of information on pre-cancer as appropriate to the research. This could be accomplished by placing pre-cancer in the amended subsection (a) (page 4) and removing subsection (b) from the bill (page 5).

It is also not clear why 324-22 (a) is being amended to permit the registry to release information to “appropriate human subject protection boards” rather than the patient’s attending physician. (page 6 lines 1-4) The referenced boards oversee research but don’t conduct it so it is not clear why information would go to them.

Subsection (b) on page 6 is also not clear. It sounds like the patient will be contacted to see if they approve contacting the patient. I suspect that the intent is to permit patients to decline upon being contacted to provide information rather than requiring the patient’s attending physician’s approval prior to contacting the patient.

We urge this committee to keep this bill alive and to make amendments to allow it to meet its stated purpose. Thank you for your consideration.

## **SUPPORT OF SB 2040, RELATING TO CANCER SURVEILLANCE**

Hearing of the Senate Committee on Health, Monday, February 25, 2008  
Chair Senator David Y. Ige, Vice-Chair Senator Carol Fukunaga

Testimony By

Marc T. Goodman, PhD, MPH  
Principal Investigator, Hawaii Tumor Registry

Following is my personal testimony in support of SB 2040, Relating to Cancer Surveillance. I am a Professor at the University of Hawaii and lead the contract from the National Cancer Institute (NCI) that supports the Hawaii Tumor Registry. Cancer registries are a valuable resource for cancer prevention and control activities. However, physician permission as a requirement for patient contact hampers our ability to improve the health of our community. The established physician-patient relationship, once assumed as an advantage of this role, no longer exists. Furthermore, patients are more knowledgeable now than when the current statute was promulgated and they have access to numerous information resources that did not previously exist.

The inability to contact patients without physician permission means that many Hawaii residents with cancer are unable to take advantage of vital clinical trials and resources that are offered to most other US citizens. For example, we would like to send all cancer patients valuable information about their disease from the NCI's Cancer Information Service, but are prohibited from doing so without physician contact. Such contact is time consuming and requiring physician permission does not guarantee careful consideration of patient eligibility nor added privacy protection. Furthermore, the physician of record available to researchers is often the surgeon listed on the pathology report, who may have no ongoing responsibility or knowledge of the patient's condition.

Recruitment strategies in Hawaii must be sensitive to research quality. Identifying and characterizing exposures to our citizens that are associated with increased risk of cancer offers great promise for understanding cancer biology. Potential benefits include the development of risk reduction strategies based on knowledge of cancer determinants and susceptibilities, innovative approaches to cancer screening and treatment, and safer and more effective use of prophylactic and therapeutic vaccines/drugs. Research is an essential component of the Hawaii's Comprehensive Cancer Control plan and is therefore necessary to achieving hoped for societal benefits. In particular, successful cancer research requires adequate accrual of an unbiased sample of the population. Investigators need direct contact with cancer patients from the outset to ensure that the research is properly described and that all potential participants are informed of the opportunity to participate.

The current statute strips the community of the right to make personal decisions regarding their health and research participation. The revised statute will provide the cancer survivor an opportunity to access and receive cancer-prevention education materials, information on patient's rights and advocacy, and potential opportunities for research participation in special studies and/or clinical trials eligibility. Although such recruitment raises potentially competing concerns about patient privacy and participant accrual, the Hawaii Tumor Registry utilizes the research ethics boards that review protocols to ensure appropriate criteria are met and that patients' privacy and the confidentiality of their health information is safeguarded. While trying to keep up with the advancement of healthcare, patients' privacy is monitored with the highest standards. I support this bill fully and trust the Committee members agree. Thank you for the opportunity to testify.

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