



UNIVERSITY OF HAWAII SYSTEM

Legislative Testimony

Testimony Presented Before the Senate Committee on Health

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by
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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.