

STANDING COMMITTEE REPORT NO. 15-113

RE: C.B. NO. 15-05/HESA

SUBJECT: TO FURTHER AMEND TITLE 41 OF THE CODE OF THE FEDERATED STATES OF MICRONESIA TO ESTABLISH A CANCER REGISTRY SYSTEM IN THE FEDERATED STATES OF MICRONESIA

MAY 27, 2008

The Honorable Isaac V. Figir  
Speaker, Fifteenth Congress  
Federated States of Micronesia  
Fourth Regular Session, 2008

Dear Mr. Speaker:

Your Committee on Health, Education and Social Affairs ("HESA"), to which was referred C.B. No. 15-05 entitled:

"A BILL FOR AN ACT TO FURTHER AMEND TITLE 41 OF THE CODE OF THE FEDERATED STATES OF MICRONESIA, AS AMENDED, BY ENACTING A NEW CHAPTER 11 THEREOF, TO ESTABLISH A CANCER REGISTRY SYSTEM IN THE FEDERATED STATES OF MICRONESIA FOR THE COLLECTION OF INFORMATION ON THE INCIDENCE OF CANCER AND RELATED DATA; TO PROVIDE FOR THE CONFIDENTIALITY OF IDENTIFYING INFORMATION REGARDING CANCER PATIENTS, HEALTH CARE FACILITIES AND HEALTH CARE PROVIDERS, AND FOR OTHER PURPOSES."

begs leave to report as follows:

The intent and purpose of the bill are expressed in its title.

The proposed new chapter 11 of title 41 would create a national cancer registry in the FSM. The goal of the registry is to gather information regarding the incidence of cancer and related data. All cancers diagnosed or treated in the FSM will be required to be reported to the Secretary of the Department of Health.

Your committee notes that an implementation grant for the proposed cancer registry has already been provided by the United States Centers for Disease Control and approved by the Fourteenth Congress of the FSM through C.R. No. 14-123. The total amount of funding is \$2,079,985. Your committee understands these funds are to be used over a period of five (5) years. The funds may not be accessed without the passage of the subject bill into law.

The subject bill provides for the joint adoption of rules by the Secretary of Health and Social Affairs, as well as health care providers, for the reporting of data on the incidence of cancer for the registry.

Health care facilities will be required to report each identified

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cancer case to the Secretary. All information for the registry will be confidential and protected. The Secretary and health care providers will be required to take strict measures to ensure identifying information is confidential. The subject bill provides for penalties for non-compliance with its confidentiality requirements.

The Secretary may use the information gathered to cooperate with the US National Institute and the Center for Disease Control in providing data on cancer incidence. The Secretary may also exchange confidential information with foreign health care facilities or cancer registries, if FSM residents are treated there, or residents of their countries are treated in the FSM. Further, statistical information may be provided to foreign entities for collaboration in registries or control and research studies. Before releasing confidential information, the Secretary must obtain evidence of the approval of her academic committee for the protection of human subjects.

#### **STATE HEARINGS**

Your committee held hearings in our four states from March 10 until 21, 2008 on the subject bill, among others. Your committee was accompanied by representatives of the FSM Department of Health, who ably responded to questions regarding the proposed legislation. Comments from the hearings are set out below.

#### **Kosrae**

Your committee met with the Kosrae State Executive in the morning of March 11, including the Governor and Lieutenant Governor of Kosrae, the State Attorney General and the Kosrae Director of Health.

Comments regarding the subject bill focused on how the proposed cancer registry would help FSM patients who are currently living with cancer. It was noted that the collection of information is one thing whereas the provision of health care is another. The registry was referred to as an academic exercise. It was pointed out by the Kosrae Director of Health that the FSM has no resources to provide specific cancer treatments such as chemotherapy and radiation. Neither do we have the tools to diagnose cancer; rather, a patient's biopsy is sent to the US for diagnosis.

Your committee met with members of the Kosrae State Legislature on the

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morning of March 12. Again, the question was raised as to how patients would benefit from the proposed cancer registry, as well as concern for the confidentiality of patients whose information is submitted to the registry.

A representative of the Kosrae State Cancer Coalition explained that the funding would be spread over a period of five (5) years and that capacity would be built up so that the registry, once established, can be managed after the five years. The data gathered will have many uses, including to identify the scope of cancer in the FSM and the stage of cancer in each patient. The registry, he said, will improve the FSM's health information infrastructure.

Your committee later received a letter from the Kosrae State Director of Health Services, providing further comment on the bill. The Director again expressed his concern that the FSM currently lacks the resources to treat the cancers we do detect. He further pointed out that MiCare does not provide adequate coverage for a cancer patient's treatment. He suggests that treatment options be linked to screening and suggests we seek resources to provide treatment.

### **Chuuk**

Your committee met with members of the Chuuk State Legislature on March 14.

There was a question as to what disadvantages might follow if the bill were not to pass into law. Mr. Marcus Samo, of the FSM Department of Health, responded that, without the cancer registry, our ability to report the incidence of cancer in a standardized manner is hampered. In addition, our establishment of a cancer registry may also increase our chances of receiving further funding for health projects.

In response to a question as to how the funds would be distributed among the states, Mr. Samo responded that any division would be based on work plans submitted by the states. He further noted that most of the funding would go to the states and that the national government would receive funding for administrative purposes only.

### **Yap**

Your committee met with members of the local business community on March 18, to review the subject bill, among others. A very able

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presentation was offered by the Yap State Cancer Coordinator. She outlined the reasons why the FSM Cancer Coalition supports the establishment of the cancer registry. The proposed cancer registry, she said, will facilitate the monitoring and tracking of FSM cancer patients and their data for purposes of planning, research, grant funding, etc. She noted the potential benefits of reliable data on cancer: monitoring trends over time, determining patterns in various segments of the population, guiding planning of programs, setting priorities for the allocation of health resources, advancing health services research and providing information on cancer incidence.

Your committee met with members of both the Yap State Legislature and Executive on March 19. Mr. Samos explained that planning for the proposed cancer registry started in the 1990s as a concerted effort among Pacific nations to get a true reflection of cancer in our islands.

Representatives of the State of Yap had no comments at the hearing but may send written comments.

### **Pohnpei**

Your committee met with members of the Pohnpei State Executive, including the Governor and Lieutenant Governor, on March 24. The Pohnpei State Cancer Coordinator also participated in the hearing. He explained that the proposed registry would involve simple data collection. The registry would be implemented at the state level and monitored at the national level. The Governor of Pohnpei expressed his support for the registry, on the condition that no additional funding will be required.

### **Concerns regarding Confidentiality**

As discussed above, the subject bill in its current form requires that informed consent be received from each cancer patient before that patient's information may be provided to the Secretary of Health for inclusion in the registry.

Your committee has been advised by Secretary Skilling of the Department of Health and Social Affairs that patients will be identified by number only and never by name. The Secretary advised that the usual practice is for medical data to be collected without the express consent of the patient, when the patient is not to be

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identified other than by number. Secretary Skilling also advised that the requirement of informed consent from the patient may negatively affect the integrity of the registry. For this reason, Secretary Skilling advocated against the requirement of informed patient consent for participation in the registry. Your committee notes that Secretary Skilling's concerns regarding requirements for informed consent were also raised at hearings by representatives of the FSM Cancer Coalition.

After careful consideration, your committee agrees with Secretary Skilling and recommends that the subject bill be amended to remove the requirement of informed consent on the part of cancer patients for the inclusion of their anonymous medical data in the registry.

#### **Penalties**

The subject bill currently empowers the Secretary of Health and Social Affairs to issue regulations to determine penalties for the offense of disclosing confidential information. Your committee recommends this be deleted and replaced by penalties defined by Congress. Your committee is also confident that the imposition of criminal penalties for the disclosure of confidential information will be a sufficient deterrent to protect the confidentiality of our citizens living with cancer.

#### **CONCLUSION**

Your committee is in agreement with the goals of the proposed legislation, the creation of a national registry for cancer patients. Your committee takes the view that the inclusion of our patients' data in the registry will not violate their rights to confidentiality and privacy.

With the foregoing changes, your Committee on Health, Education and Social Affairs is in accord with the intent and purpose of C.B. No. 15-05 and recommends its passage on First Reading, and that it be placed on the calendar for Second and Final reading, in the form attached hereto as C.B. No. 15-05, C.D.1.

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Respectfully submitted,

/s/ Joseph J. Urusemal  
Joseph J. Urusemal, chairman

/s/ Claude H. Phillip  
Claude H. Phillip, vice chairman

/s/ Dohsis Halbert  
Dohsis Halbert, member

Tiwiter Aritos, member

Resio S. Moses, member

/s/ Setiro Paul  
Setiro Paul, member

/s/ Joe N. Suka  
Joe N. Suka, member