

MINUTES OF THE SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

The meeting was called to order by Chairperson Susan Wagle at 1:30 p.m. on February 5, 2004 in Room 231-N of the Capitol.

All members were present except:

Senator Chris Steineger- excused
Senator James Barnett- excused
Senator Nick Jordan- excused
Ms. Emalene Correll, Legislative Research - excused
Mr. Norm Furse, Revisor of Statutes - excused

Committee staff present:

Mrs. Diana Lee, Revisor of Statutes
Ms. Margaret Cianciarulo, Committee Secretary

Conferees appearing before the committee:

Ms. Paula Marmet, Director, Office of Health Promotion, KDHE

Others attending:

Please See Attached List.

Hearing on SB 366 - an act concerning the cancer registry

The Chair opened the meeting by announcing to the Committee there would be a hearing on **SB 366**, an act concerning the cancer registry, relating to the definition of health care provider and parties required to report to the registry.

She then called upon the only proponent conferee to testify, Ms. Paula Marmet, Director, Office of Health Promotion, KDHE, who said that they support the bill, which will remove the exemption for physicians (persons licensed to practice medicine and surgery) to report cancer cases to the state cancer registry. She stated that hospital reports indicate that the number of reported cases have decreased due to physicians moving out of the hospital-based setting into private practices, thus diminishes the ability of the state to conduct cancer cluster investigations with a high degree of reliability. Also, the registry operation is dependent upon federal grant funding, which specifies that 90% or more of all expected cancer cases be reported within 1 year of diagnosis and 95% be reported with 2 years of diagnosis.

Ms. Marmet said that routinely, the registry staff contacts physicians to obtain missing information of cases that are reported by an institution and that, of those that did not respond, the most common reason stated for not reporting pro-actively to the registry was due to fear of potential lawsuits because of the specific exemption contained in state statute. And lastly she said with cancer being the second leading cause of death in Kansas, accounting for 22% of deaths in 2001, having a reliable population-based data on cancer incidence is imperative in order for science to continue to improve the knowledge about cancer and for the state to respond effectively in its efforts in prevention and improvement of early detection and treatment. A copy of her testimony is (Attachment1) attached hereto and incorporated into the Minutes as referenced.

As there were no opponents, neutral conferees, or written testimony, Chairperson Wagle asked for questions or comments from the Committee. Questions came from Senators Salmans, Wagle, and Brungardt ranging from dealing with fear of lawsuits (ex. Giving to much information), is there any quick application to obtain the data, margin of error, can this information be taken from birth/death certificates, are you tracking reoccurrences, are you obtaining treatment information, are there restrictions on data for follow-up data, does this information go into a national database and where is/are they located, clarification on methodology, will you still take information from labs, to return on investment.

Adjournment

The meeting was adjourned at 2 p.m. with the next meeting scheduled for Monday, February 9, 2004.



K A N S A S

RODERICK L. BREMBY, SECRETARY

DEPARTMENT OF HEALTH AND ENVIRONMENT

KATHLEEN SEBELIUS, GOVERNOR

Testimony for SB 366
Cancer Registry Reporting Requirements

To

Senate Public Health and Welfare Committee

By Paula F. Marmet
Director, Office of Health Promotion

Kansas Department of Health and Environment

February 5, 2004

Senator Wagle and members of the Senate Public Health and Welfare Committee, I am pleased to appear before you today to discuss SB366. The Kansas Department of Health and Environment supports the bill, which will remove the exemption for physicians (persons licensed to practice medicine and surgery) to report cancer cases to the state cancer registry.

Current law authorizes the Secretary of Health and Environment to collect data pertaining to all cancers occurring in Kansas into a registry and to adopt rules and regulations that specify who shall report, the data elements to be reported, timeliness of reporting and the format for collecting and transmitting data to the registry. However, KSA 65-1,169 specifically exempts persons licensed to practice medicine and surgery from reporting.

Under current rules and regulations, the cancer registry receives reports from hospitals, ambulatory surgical centers, radiology oncology centers, and pathology laboratories. These entities submit reports on about

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*Senate Public Health & Welfare Committee
Attachment 1
Date: February 5, 2004*

12,000 cancer cases to the registry each year. In recent years we have observed that the number of cancer cases being reported to the registry is dropping. Analysis of vital statistics mortality data indicate 600-700 cancer deaths occur each year in which the cancer case has not been reported to the registry. Similarly, when comparing cancer cases in Kansas to the Surveillance Epidemiology End Results (SEER) registry standard, a state of our demographics would be expected to report over 13,000 cases of cancer each year.

Hospital reports indicate that the number of reported cases have decreased due to physicians moving out of the hospital-based setting into private practices. As they move out of the hospital setting, more cases of cancer fail to be reported. As the number of unreported cancer cases increases, the ability of the state to conduct cancer cluster investigations with a high degree of reliability diminishes. Furthermore, the loss in completeness of reported cancer cases is beginning to impact quality control indicators upon which our funding is based. The registry operation is dependent upon federal grant funding, which specifies that 90% or more of all expected cancer cases be reported within 1 year of diagnosis and 95% be reported within 2 years of diagnosis. Several other states, including Florida, Minnesota and Colorado have added a requirement to include physician reporting which has resulted in obtaining more complete cancer data. The surrounding states of Colorado, Missouri and Oklahoma have already implemented state laws requiring active physician reporting.

The cancer registry staff routinely contact physicians to obtain missing cancer information on cases that are reported by an institution. Of about 850 physicians in Kansas contacted in 2003 to ascertain missing case information on reported cases, 55% responded with information to complete the case, 9% responded that they did not have the information or saw the patient before the cancer diagnosis was made, and 35% did not respond. Of those who responded, the most common reasons stated for not reporting proactively to the registry was due to fear of potential lawsuits because of the specific exemption contained in state statute.

It is critically important to improve and sustain cancer reporting in Kansas. Cancer is the 2nd leading cause of death in Kansas, accounting for 22% of deaths in 2001, despite the preventable and often treatable nature of many types of cancer. While we know that Kansans have a 1 in 3 chance of developing cancer in their lifetime, there is much about cancer that we do not know. Having reliable population-based data on cancer incidence is imperative in order for science to continue to improve the knowledge about cancer and for the state to respond effectively in its efforts in prevention and improvement of early detection and treatment.

Thank you for your attention to improving cancer reporting in Kansas. I will be happy to answer any questions you might have.