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DEPARTMENT OF HEALTH AND ENVIRONMENT

Testimony for SB 366 Cancer Registry Reporting Requirements

To

House Health and Human Services Committee

By Paula F. Marmet
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Kansas Department of Health and Environment

March 10, 2004

Representative Morrison and members of the House Health and Human Services Committee, my name is Paula Marmet and I am the Director of Health Promotion in the Division of Health at the Kansas Department of Health and Environment. Thank you for the opportunity to appear before you today regarding 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 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.



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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.