

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES.

The meeting was called to order by Chairperson Carlos Mayans, at 1:30 p.m. on February 13, 1997 in Room 423-S-of the State Capitol.

All members were present except: Representative David Haley
Representative Tony Powell

Committee staff present: Emalene Correll, Legislative Research Department
Norman Furse, Revisor of Statutes
Lois Hedrick, Committee Secretary

Conferees appearing before the committee:

James O'Connell, Secretary, Kansas Department of Health and Environment (KDHE)
Frederick Holmes, M.D., American Cancer Society
Meg Henson, Director of Government Affairs, Kansas Medical Society
Steven Potsic, M.D., KDHE Director of Health
Greg Reser, Director, KDHE Hospital and Medical Programs, Bureau of Adult and Child Care

Others attending: See Guest List (Exhibit 1)

Chairperson Mayans opened the hearing on **HB 2181 - Establishing a cancer registry**. He reminded members that this bill was passed out of this committee last year, and that it is important that it be done again this year.

Secretary James O'Connell, testifying in support of the bill, explained the purposes and importance of the bill to ensure access to cancer data, require reporting by all health care providers, protect the confidentiality of patients and health care providers, allow access to the registry information for disease investigation and treatment, and most of all insure the state's continuing eligibility for federal funds (see testimony, Exhibit 2).

Representative Wells asked what occurs after an individual is diagnosed with cancer and then reported to the registry. He also asked if a patient has the right to not have his tissue sent to a pathology lab. Secretary O'Connell answered that, typically, when diagnosed a biopsy is ordered and the lab would forward the tissue report to the registry. Representative Wells said it is this information that has him concerned. Secretary O'Connell said the registry will provide (1) the rate and types of cancer; (2) notice of increasing rates of cancers by region; (3) allow study of treatment modalities, and (4) authorize contacting physicians to advise of registry findings.

Frederick Holmes, M.D., Professor of Medicine, KUMC, testified in strong support of the bill by the American Cancer Society and of himself for **HB 2181** (see Exhibit 3).

Meg Henson, Director of Government Affairs, Kansas Medical Society, testified in support of **HB 2181**, saying it is an incredibly important bill and should be enacted (see Exhibit 4). Representative Hutchins asked what information is sent to the pathology laboratory and how many times will additional information be required. Representative Haley questioned if there was assurance that cancer information will be handled confidentially, and the size of the federal grant request. Dr. Steven Potsic answered the information will include date of surgery, pathological diagnosis and patient ID but only the medical professionals will be in charge of the records. With respect to the grant request, Dr. Potsic stated the the Kansas grant request is relatively small in comparison to other states. The current request is approximately \$340,000.

Chairperson Mayans called attention to the written testimonies of Sue-Min Lai, Director, Kansas Cancer Registry, KUMC (see Exhibit 5) and of Terri Roberts, Kansas State Nurses Association (see Exhibit 6).

There being no other present to testify on **HB 2181**, the hearing was closed. Chairperson Mayans then called for action on the bill.

On motion of Representative Geringer, seconded by Representative Henry, the committee voted that **HB 2181** be passed. Representative Jonathan Wells asked that his "no" vote be made of record.

Chairperson Mayans then opened the hearing on **HB 2180 - Repeal of statutes concerning facilities for post-acute head-injured persons**.

CONTINUATION PAGE

MINUTES OF THE HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES, Room 423-S of the State Capitol, at 1:30 p.m. on February 13, 1997.

Greg Reser, KDHE's Hospital and Medical Programs Director, testified in support of **HB 2180**, which officially removes provisions of K.S.A. 65-461 et seq., that expired July 1, 1987 (see Exhibit 7).

Emalene Correll said the statute was originally enacted in response to an individual in the western part of the state who wanted to start a facility of this type in an old school. The project never got "off the ground" because it couldn't meet required standards.

There being no others present to testify on **HB 2180**, the hearing was closed. Chairperson Mayans then called for action on the bill.

On motion of Representative Geringer, seconded by Representative Wells, the committee voted that **HB 2180** be passed and placed on the consent calendar.

Chairperson Mayans noted that **HB 2268 - Creation of a department of health and a department of environment** - was withdrawn from the House Appropriations Committee and referred separately to the House Appropriations Committee and this committee on February 12, 1997.

The meeting was adjourned at 2:15 p.m.

The next meeting is scheduled for February 17, 1997.

HOUSE COMMITTEE ON HEALTH
AND HUMAN SERVICES GUEST LIST
FEBRUARY 13, 1997

NAME	REPRESENTING
GREG PESER	KDHE
Kevin Haggood and	KST Academy of Family Physicians
Mary Hanson	KMS
Susan Brown Baker	Hein & Wein
Amy Campbell	R. Rice Law Office
Bria Kraunwetter	American Cancer Society
Frederic Holms, M.D.	American Cancer Society
Ra "Jiggs" Nelson	AAP Pediatrics
Steve Posen	KDHE
Pue Yin Lai, Ph.D.	KUMC
KATH R LANDIS	CHRISTIAN SCIENCE COMMITTEE on PUBLICATION FOR KANSAS
Michelle Peterson	Peterson Public Affairs
99 Cornell	KDHE
Rich Gritter	Health Midwest
Frank Kuhn	HSGship Prog
Janet Wetla	KDHE
Steve Blanke	Hubbell + Assoc.

State of Kansas

Bill Graves



Governor

Department of Health and Environment
James J. O'Connell, Secretary

Testimony presented to

House Health and Human Services Committee

by

The Kansas Department of Health and Environment

House Bill 2181

I am pleased to present testimony in support of House Bill 2181, which establishes statutory authority for a cancer registry in the State of Kansas. The proposed legislation would:

- 1) authorize the Secretary of KDHE to require the collection of data related to cancer from hospitals, health care providers, and pathology laboratories;
- 2) authorize the establishment of regulations designating reporting requirements (including which providers would report);
- 3) grant immunity from liability for those reporting;
- 4) protect the confidentiality of registry data; and
- 5) authorize use of confidential data for limited purposes.

The purpose of the state cancer registry is to provide health data related to cancers which occur among Kansas residents. Collection of basic clinical information about each occurrence of cancer in the state provides the data needed for a) investigation of abnormal clusterings of cancer; b) decreasing cancer mortality through preventive screening; c) reducing known cancer risk factors; d) identifying previously unrecognized risk factors/causes of cancer; e) monitoring the potential health impact of environmental exposures; f) monitoring health care access and utilization of services for the prevention and treatment of cancer; g) estimating costs associated with cancer care. Use of the registry for these purposes depends upon complete and unduplicated information for each occurrence of cancer. Certainty of identity, geographic location, treatment, and survival requires the collection of confidential data (e.g., in the course of cluster investigation, reports received from concerned citizens which identify persons they know who have cancer must be matched to the registry; reports received by the registry from different providers must be matched by identity to ensure non-duplication).

The cancer registry is currently collecting data under KAR 28-1-4. Although the Secretary operates under broad authority to collect cancer data; this authority does not ensure the following:

HOUSE HEALTH/HUMAN SERVICES

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1. Immunity for persons reporting;
2. Reporting by many health care providers;
3. Use of confidential data for disease investigation and treatment (e.g., offering patients access to cancer treatments not available except through clinical trials).

Although cooperation with the Data Governing Board is necessary to ensure appropriate access to non-confidential registry data, the specific measures needed to protect the confidentiality of patients and protect health care providers from liability when they report is outside the authority of the Data Governing Board.

The need for high quality cancer registries in all 50 states has been recognized by Congress. Public Law 102-515 authorized funding for the improvement of state registries. Currently federal dollars made available as a result of this law account for approximately 75% of registry operating funds. One of the requirements for continued receipt of federal dollars for the registry is the existence (or establishment) of state enabling legislation for a cancer registry. This legislation will ensure Kansas' continuing eligibility for registry funds.

Anticipated Outcomes Resulting from the Passage of Proposed Legislation

The legislation would improve the quality and completeness of the data contained in the cancer registry. Quality of data would meet state needs for investigation of cancer occurrence in Kansas. The bill would also bring Kansas into compliance with the federal law that authorizes the national cancer registry program. Reporting requirements for hospitals would not change from current practice and regulations would exempt clinical practitioners from routine reporting. (Practitioners would be asked to provide information only on those persons with cancer previously identified and for whom hospital cancer data was not available). Pathology laboratories would be required to submit to the registry a copy of each cancer tissue result. Effectiveness of hospital plus pathology laboratory reporting has been demonstrated in other state (e.g., Minnesota).

Thank you for your consideration of this important legislation which will improve both our ability to effectively use the registry to reduce death and disability due to cancer in Kansas, as well as protect both patients and health care providers.

Testimony presented by: James O'Connell
Secretary
Kansas Department of Health and Environment
February 13, 1997



HEARTLAND DIVISION, INC.

THERE'S NOTHING MIGHTIER THAN THE SWORD

TESTIMONY IN SUPPORT OF HOUSE BILL 2181

Establishing a Cancer Registry in Kansas

In 1968, I was asked by the Kansas Department of Health and Environment and the University of Kansas Medical Center to create a registry of cancer patients in the State of Kansas. With the assistance of the American Cancer Society and the federal government, this was accomplished over the next five years using computer technology, with special attention devoted to confidentiality of patient records. By 1985, this registry truly covered the entire State of Kansas. In 1994, funding of about \$300,000 per year was secured from the federal Center for Disease Control in Atlanta to upgrade and guarantee the future of this cancer registry. Since 1968, the data in this registry has been used hundreds of times to:

- Define the extent of cancer problems in our state;
- Identify occupational and environmental cancer risks, particularly in rural areas;
- Establish and improve the care of cancer patients by Kansas hospitals and outpatient facilities; and
- Assist in health care planning.

I support this bill for the following reasons:

- The work of nearly 30 years and the substantial support from the Center of Disease Control will be jeopardized if the bill is not enacted.
- Kansas has increasing need to define, address, and solve cancer problems and this cannot be accomplished without this cancer registry.
- Issues of accuracy of cancer patient diagnosis and quality of treatment in Kansas can only be ascertained with a statewide cancer registry.
- The American Cancer Society has studied this bill carefully and strongly endorses it without reservation.
- Kansas has been among the leading states in cancer registration over the years and it would be tragic to lose that position.
- Issues of confidentiality of patient information and security of data are more than adequately addressed in this bill.

In conclusion, I urge that this bill be enacted to benefit a large and vulnerable group of Kansas citizens - those with cancer. Scarcely a single family in Kansas is not touched by cancer over a period of time. Those who govern our state have an opportunity to continue to strengthen the well-established cancer registry program in Kansas that has been developed and is strongly endorsed by the Kansas Department of Health and Environment, the American Cancer Society, our federal government, and the University of Kansas Medical Center.

Presented by: Frederick F. Holmes, MD, Professor of Medicine
University of Kansas Medical Center
Kansas City, Kansas

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HOUSE HEALTH/HUMAN SERVICES

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KANSAS MEDICAL SOCIETY

February 13, 1997

To: House Health and Human Services Committee

From: Meg Henson *MH*
Director of Government Affairs

Subj: HB 2181 - Cancer Registry

The Kansas Medical Society appreciates the opportunity to appear today on HB 2181, regarding the formal establishment of a cancer registry. The cancer registry currently collects data pursuant to K.A.R. 28-1-4. However, statutory authority is needed so the registry can continue to receive federal funding, which the registry relies heavily on. KMS supports this legislation.

Confidentiality is always an issue when dealing with sensitive data. KMS is satisfied that confidentiality would be maintained under this legislation. The bill specifies that confidential data must be securely locked and used only for specified purposes. It also creates a panel which would review all requests for confidential data before this data is disclosed. Finally, it establishes important immunity provisions for health care providers who, in good faith, report confidential data pursuant to this bill.

KMS is also satisfied that the reporting requirements placed on physicians under this bill will not be unduly burdensome. We understand that physicians will be required to provide cancer data only when responding to requests for information when this information is otherwise unascertainable. Requests will be limited to information that is already collected by physicians. KDHE has assured us that even pathology labs, where pathologists collect and record a great deal of information, will not be required to report any data that they do not currently collect.

KMS intends to work with KDHE to educate physicians about their responsibilities to provide requested patient information under this law, which will be important to developing a complete and accurate registry database.

Thank you for your consideration. I would be happy to respond to questions.

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Testimony in support of House Bill No. 2181 - Establishing a Kansas Cancer Registry

Sue-Min Lai, Ph.D., MS, MBA
Director, Kansas Cancer Registry
Assistant Professor of Preventive Medicine
University of Kansas Medical Center
Kansas City, Kansas

In 1968 Dr. Frederick Holmes was asked by the KDHE and KUMC to create a cancer registry in the state of Kansas. By 1985 this registry truly covered the entire state of Kansas. In 1994, I became director of the Kansas Cancer Registry and have secured funding from Centers for Disease Control and Prevention in the amount of one million dollars from fiscal year 1995 through fiscal year 1997. I am a strong proponent for this bill. My support for enacting this law is based on the following:

1. Cancer is a significant public health problem.

- One in five deaths in Kansas is due to cancer. In 1995, cancer is still the second leading cause of death in Kansas.
- A rising trend in cancer occurrence has been observed since 1953. It is estimated that about 13,000 new cancer cases will be diagnosed in Kansas in 1997.
- Overall costs due to cancer in the US in 1985 totaled \$72.5 billion.

2. Cancer death and disability can be reduced by screening and early detection.

Early detection and intervention have shown to significantly reduce cancer mortality for some cancers. For example, mortality due to breast cancer can be reduced by 30% among women aged 50 and older through a screening test such as mammography. Identification of high risk individuals for prevention is crucial in the process of cancer prevention and control.

3. The Kansas Cancer Registry is the essential vehicle in identifying individuals who are at high risk for cancer and communities where a possible cancer cluster exists.

- Functions of the KCR have been clearly identified in this bill.
- Through the KCR endeavor, appropriate interventions can be delivered to those high risk individuals to prevent them from cancer and improve their chance of surviving cancer if detected.
- Communities with excess cancer risk can be identified.

4. A law requiring case reporting to Kansas Cancer Registry is the key to the success of cancer risk reduction in Kansas.

- A law which requires reporting is essential for completeness of case reporting. This effort has been proven in other states such as Iowa.
- Without complete case reporting, preventive programs can not be targeted to communities and high risk individuals where these programs would benefit the most.
- Current experience from the registry also shows wide support among hospitals and the Tumor Registrars Association of Kansas as to enacting a law requiring case reporting.

5. Enacting this bill is critical for KCR to continue and compete for CDC funding.

In conclusion, I urge this bill to be enacted so that the health of Kansans, particularly cancer and high risk individuals will benefit from it. Moreover, through a well-established cancer registry which is strongly endorsed by the KDHE, ACS, our Federal Government, and KUMC, cancer will be reduced in Kansas along with the related cost for cancer care.



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the Voice of Nursing in Kansas

Betty Smith-Campbell, M.N., R.N., AF
President

Terri Roberts, J.D., R.N.
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February 13, 1997

H.B. 2181 Establishing a Cancer Registry in Kansas

WRITTEN TESTIMONY

Chairperson Mayans and members of the House Health and Human Services Committee, the Kansas State Nurses Association is very supportive of H.B. 2181 which will establish a cancer registry for the state of Kansas for the purpose of collecting cancer health data.

We understand that the bill will provide the Secretary of the Kansas Department of Health and Environment with the authority to "require" the collection of data related to cancer from Kansas hospitals, health care providers, and pathology laboratories. We recognize that some responsibility will fall to health care providers in order to insure that 100% of the cancer is captured and reported. We value the intended purpose and use of the data collection, and therefore support the reporting obligation on healthcare providers.

This legislation insures the confidentiality of the data for disease investigation and treatment and affords healthcare personnel immunity for reporting under the statute. These statutory provisions are essential and good public policy.

From an epidemiological perspective, the more we know about the disease the greater the potential for eradicating and or diminishing its prevalence. The proposed Cancer Registry will contribute greatly to the availability of information that researchers and health scientists can use.

The Kansas State Nurses Association urges your support for the establishment of the Kansas Cancer Registry with favorable approval of H.B. 2181.

Thank you.

The mission of the Kansas State Nurses Association is to promote professional nursing, to provide a unified voice for nursing in Kansas and to advocate for the health and well-being of all people.

Constituent of The American Nurses Association

HOUSE HEALTH/HUMAN SERVICES

Attachment 6
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State of Kansas

Bill Graves



Governor

Department of Health and Environment

James J. O'Connell, Secretary

TESTIMONY PRESENTED TO
HOUSE COMMITTEE ON HEALTH AND HUMAN SERVICES
BY
THE KANSAS DEPARTMENT OF HEALTH AND ENVIRONMENT

House Bill 2180

Thank you for the opportunity to present testimony related to HB 2180. This bill proposes repeal of the provisions of K.S.A. 65-461 through K.S.A. 65-467.

K.S.A. 65-461 et seq. is the enabling legislation which provided the Kansas Department of Health and Environment with authority to develop regulations, inspect facilities, and grant certification to facilities designed specifically for the care of post-acute trauma head-injured persons. The law was to allow for a "demonstration program to determine the feasibility and effectiveness of this type of facility." Although regulations were developed, no facility applied for certification.

K.S.A. 65-467 includes a "sunset provision" with an effective date of July 1, 1987.

The provisions of K.S.A. 65-461 et seq. expired effective that date.

Since the referenced statutes have not been in effect since 1987, the passage of HB 2180 would officially remove the referenced laws from the statute books.

Presented by: Greg L. Reser, Director
Hospital and Medical Programs
Bureau of Adult and Child Care
Kansas Department of Health and Environment

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Date: February 13, 1997