

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 March 7, 1996 in Room 423-S of the Capitol.

All members were present except: Representative Yoh
Representative Kirk

Committee staff present: Norman Furse, Revision of Statutes
Bill Wolff, Legislative Research Department
Francie Marshall, Committee Secretary

Conferees appearing before the committee: Dr. Steven Potsic, KDHE
Dr. Sue-Min Lai, KU Medical Center
Meg Henson, Kansas Medical Society

Others attending: See Guest List. Attachment 1.

Chairperson Mayans requested the members to review the minutes of March 5, 1996 meeting for approval.

The hearing on **SB 536** was opened.

SB 536 - Cancer registry

Dr. Steven Potsic, KDHE, testified in support of **SB 536**. He stated that cancer is the second leading cause of deaths in Kansas. The proposed legislation would accomplish four objectives (see Attachment 2). He commented on the importance of cancer registry with the tracking of breast cancer.

Dr. Sue-Min Lai, KU Medical Center, testified in support of **SB 536** (see Attachment 3).

Meg Henson, Kansas Medical Society, testified in support of **SB 536**. She assured the committee that the information is confidential and will be maintained. (see Attachment 4).

Written testimony was submitted by Keith Greiner, American Cancer Society, in support of the bill (see Attachment 5).

The hearing was opened for questions to the proponents from the committee.

Questions regarding information included in the report, confidentiality of the reports, and the ownership of information were directed to proponents. On questions dealing with information included in the report, Dr. Lai responded that the report would track new and existing cancer in the state, calculate the age, gender, county, city, survival, and death rates. On questions regarding the confidentiality of the reports, Dr. Potsic answered that providers will not have access to information. A concern was raised that the data might point the finger at an industry for a cause of cancer. On questions dealing with ownership of information, Dr. Potsic stated that there is a public trust between the Cancer Registry and individuals. He further stated that general information would be given out, but that information on individuals must be done by the request of the individual and are then determined by KDHE to release the information. Discussion followed on compiling and releasing of data, the relationship between Cancer Registry and Health Care Governing Board, and reasons for the need of this statute.

The hearing on **SB 536** was closed.

Chairperson Mayans then called for action on **SB 536**.

Norman Furse, Revision of Statutes, suggested that language be added that provides confidentiality between

the patient and the health care provider. On motion of Representative Geringer, seconded by Representative O'Connor, the committee unanimously adopted to insert the language on page 3, line 10, after thereto, "any other Kansas statute which provides for privileged information between a patient and a health care provider."

Representative Landwehr offered an amendment to insert language after Line 4, (d) "assessing the cancer risk of having an abortion;" and inserting in Line 22, "and the cancer risk related to having an abortion."(see Attachment 6). The motion was seconded by Representative Merritt.

Representative Landwehr expressed her concerns that abortion is an unrecognized risk factor of cancer in the bill. More discussion followed about the many factors that cause cancer, the collection of data, and the confidentiality. Concerns were raised by Dr. Potsic about the time line between abortion and cancer, and concerned that the collection of one factor may draw erroneously conclusion. Following discussion, the committee voted to adopt the proposed amendment by Representative Landwehr.

On motion of Representative Merritt, seconded by Representative Hutchins, the committee voted to pass SB 536 as amended. Representatives Wells, Haley, and Flaharty requested to have their votes recorded as "No". Representative Landwehr will carry the legislation.

The meeting was adjourned at 3:05 p.m.

The next meeting is scheduled for March 11, 1996.

House Health & Human Services COMMITTEE GUEST LIST

DATE March 7, 1996

NAME	REPRESENTING
Melissa Wangemann	Hein Ebert & Weir
Su Yin Lai	University of Kansas Medical Center
Wen Hanson	Kansas Medical Society
Michelle Peterson	Peterson Public Affairs Group
Amy Campbell	KS State Ophthalmological Society
Burr H. H.	American Cancer Society, Kansas Division, Inc.

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attm # 1

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

Senate Bill 536

I am pleased to present testimony in support of Senate Bill 536, 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 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; and
- 4) protect the confidentiality of registry data.

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

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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:

1. Immunity for persons reporting;
2. Reporting by certain 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 trails).

Although coordination with the Health Care Data Governing Board will occur 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 Health Care 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 our registry operating funds. One of the requirements for continued receipt of federal dollars 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 grant 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 copy of each cancer tissue result. Effectiveness of hospital plus pathology laboratory reporting has been demonstrated in at least one other state (e.g., Minnesota).

Thank you for your consideration of this important legislation which will improve our ability to reduce death and disability due to cancer in Kansas (the second leading cause of death).

Testimony presented by: Steven R. Potsic, M.D., M.P.H.
Director of Health
Division of Health
March 7, 1996

Testimony in support of Senate Bill No. 536 - Establishing a Cancer Registry in Kansas

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 \$ 341,000 for fiscal year 1995 with follow-on funding through 1999. I am a 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 1996.
- 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. The Kansas Division of the American Cancer Society has studied this bill carefully and strongly endorses it without reservation.

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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KANSAS MEDICAL SOCIETY

623 SW 10th Ave. • Topeka, Kansas 66612 • (913) 235-2383
WATS 800-332-0156 FAX 913-235-5114

March 7, 1996

To: House Health and Human Services Committee

From: Meg Henson 
Director of Government Affairs

Subject: SB 536: Establishing a Cancer Registry

The Kansas Medical Society appreciates the opportunity to appear today in support of SB 536, which formally establishes in law the authority of the Secretary to operate a cancer registry. The registry is currently operated pursuant to the authority of K.A.R. 28-1-4.

KMS believes the requirements placed on physicians under this bill are not contrary to a physician's obligation to maintain patient confidentiality. The bill specifically spells out how both confidential and non-confidential data gathered under the law may be used. In addition, it establishes important immunity provisions for health care providers when they report confidential data. KMS is also satisfied that the reporting requirements placed on physicians under this bill will not be onerous. Physicians will be required to provide cancer data only when responding to requests for information when this information is otherwise unascertainable.

KMS intends to work with KDHE to help 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. I would be happy to respond to any questions. Thank you.

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Attn # 4



KANSAS DIVISION, INC.

THERE'S NOTHING MIGHTIER THAN THE SWORD

March 4, 1996

The Honorable Carlos Mayans
Kansas State House of Representatives
Room 426-S
Topeka, KS 66612

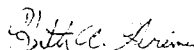
Re: Senate Bill 536

Dear Representative Mayans:

The American Cancer Society in Kansas is pleased to support Senate Bill 536. Please do your best to assure that this bill becomes law.

The cancer registry for Kansas that has operated up to now under Department of Health regulation has been a successful part of the fight against cancer. Providing for the registry by statute rather than regulation will insure both its continuation and necessary financial support for it from the U.S. Centers for Disease Control.

Sincerely,


Keith A. Greiner
Advocacy Chairperson
American Cancer Society
Kansas Division, Inc.

1 cancer;

2 (b) the design and implementation of cancer screening programs
3 which have been demonstrated to decrease cancer mortality;

4 (c) assessing the cancer risk in the Kansas population;

5 ~~(d) identifying previously unrecognized risk factors and causes of can-~~
6 ~~cer;~~

7 (e) monitoring the potential health impact of environmental expo-
8 sures;

9 (f) monitoring health care access and utilization and effectiveness of
10 services for the prevention and treatment of cancer; and

11 (g) quantifying costs associated with cancer care.

12 Sec. 4. The information contained on the cancer registry shall not be
13 subject to the provisions of the Kansas open records act. The secretary
14 shall ensure that the confidentiality of any data collected which might be
15 used to identify an individual with cancer or a health care provider is
16 maintained. Storage of cancer data shall be in a manner which will protect
17 all information which uniquely identifies individuals.

18 Sec. 5. Confidential data shall be securely locked and used only for
19 the following purposes:

20 (a) Ensuring the quality and completeness of the registry data.

21 (b) Investigating the nature and cause of abnormal clusterings of can-
22 cer

23 (c) Offering through the personal physician, to persons with cancer,
24 access to cancer *diagnostics and* treatments not available except through
25 clinical trials. *As as* long as such trials are conducted with the informed,
26 written consent of the cancer patient and are approved by existing ethics
27 board, (institutional review board (IRB)); of both the treating institution
28 and Kansas department of health and environment, *the confidential*
29 *data is approved for release by the secretary for the purpose of such*
30 *clinical trials and the clinical trials are approved by the clinical*
31 *entity.*

32 (d) Releasing data back to the institution or individual which reported
33 cases as long as such release includes only those cases previously reported
34 by the requesting institution or individual.

35 (e) As part of an exchange agreement with another state, confidential
36 data collected on a resident of another state may be released to the cancer
37 registry of that person's state of residence *if that state has confidanti-*
38 *ality requirements that provide assurance of protection of confi-*
39 *dentiality equivalent to that provided by Kansas under this act.*

40 (f) *Releasing information* upon consent, in writing, of the person
41 who is the subject of the information, or if such person is under 18 years
42 of age, by such person's parent or guardian.

43 Sec. 6. The secretary shall designate a panel, including at least one

(d) assessing the cancer risk of having an abortion;

and the cancer risk related to having an abortion.

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