

MINUTES OF THE SENATE PUBLIC HEALTH & WELFARE COMMITTEE.

The meeting was called to order by Chairperson Senator Susan Wagle at 1:30 p.m. on January 23, 2003 in Room 231-N of the Capitol.

All members were present except:

Committee staff present: Ms. Emalene Correll, Kansas Legislative Research Department
Mr. Norm Furse, Revisor of Statutes
Ms. Margaret Cianciarulo, Administrative Assistant

Conferees appearing before the committee: Dr. Sue-Men Lai, Professor of Preventive Medicine
University of Kansas Medical Center

Others attending: See attached guest list

Overview - Kansas Cancer Registry

Upon calling the meeting, Chairperson Wagle welcomed and called upon Dr. Sue-Men Lai, Professor of Preventive Medicine from the University of Kansas Medical Center, who was introduced to the Committee.

Dr. Lai offered an overview of the Kansas Cancer Registry (KCR) sharing information on: the functions of the KRC; its history including the restructuring and law enacting; the use of the registry data and its policy making, K.A.R.28-70-1 to 28-70-3 and what it entails; and, the who, what, when and how to report. She touched on the completeness and timeliness of reporting and the quality data (external review). Lastly Dr. Lai offered statistics of the registry including number of records processed, reporting facilities and data utilization at the State and Regional level; data security; cancer data requests; and, the funding level. A copy of her handout and testimony is (Attachment 1) attached hereto and incorporated into the Minutes by reference

A discussion followed between Chairperson Wagle and Dr. Lai. Subject discussed included: Recurrences (are they logged into the registry as new or recurrence); is there a follow-up program in place, and Iowa and Minnesota's registries.

Adjournment

As it was going on 2:30 p.m., the meeting was adjourned.

The next meeting is scheduled for January 28, 2003.

SENATE PUBLIC HEALTH AND WELFARE COMMITTEE

GUEST LIST

15

DATE: January 23, 2003

NAME	REPRESENTING
Michael Moser	KDFE

attendance sheet did not get passed on thru the crowd

Kansas Cancer Registry

*Principal Investigator and Director
Sue Min Lai, Ph.D., MS, MBA
University of Kansas Medical Center*

Functions of KCR

- Kansas Cancer Registry collects the data from health care providers in Kansas, maintains, analyzes, and interprets these data on Kansans with cancer.

Use of registry data

- The data can be used to monitor type of cancer occurrence in Kansas over time or among sub-populations.
- The data can be useful in identifying unusual clusters of cancer cases.
- The data can be used for epidemiologic studies to identify causes of cancer.

Use of registry data

- The data can be used to assess the effects of different types of treatment over time and to evaluate the effects of early detection programs.
- The data can also be helpful in assessing the need for new hospital construction, new equipment, and to pinpoint locations of facilities for patient care.

History

- *Existence since 1968*
- *1982, regulations in place*
- *1993, registry near the end of its life due to limited funding*
- *1993, sought funding opportunities*
- *1994, KCR was funded with federal \$\$\$ via grant mechanism*

History

- *1995, testified in Topeka*
- *1996, testified in Topeka*
- *1996, the first KCR annual report*
- *1997, K.S.A. 65-1, 168 - 174*
- *1998, K.A.R. 28-70-1 to 28-70-3*

*Seniors Public Health & Welfare Committee
Date: January 23, 2003
Attachment 1-1*

K.A.R. 28-70-1 to 28-70-3

- Took effect on Feb 27, 1998
- Who, when, how, and what information each type of health care provider should report to the KCR

Who should report

- Health care providers
 - Hospital
 - Outpatient surgery center
 - Pathology laboratory
 - Radiation oncology center
 - Individual providers (a person licensed to practice medicine, surgery, or dentistry)

What to report

- Demographics (name, SSN, DOB, addresses)
- Personal history (e.g, smoking hx)
- Characteristics of tumor (dx date, cancer site, histology, staging, size)
- Treatment (e.g., surgery, radiation)
- Vital status and recurrence

When and How to report

- Cancer cases should be reported to KCR within 6 months of diagnosis
- Reporting mechanisms can be electronic and paper formats.

Completeness of reporting

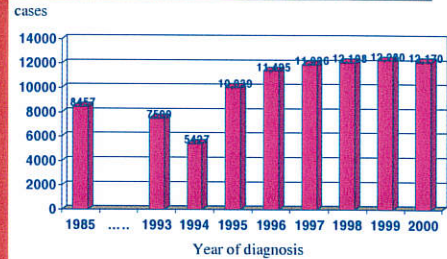
Expected number of invasive cases

- Kansas population – about 2.6 millions
- Apply IOWA SEER rates to KS population
- The expected number of cases were
 - 11,900 for years 1995 – 1997
 - 12,289 for years 1998 - 1999
 - 12,728 for years 2000 - current

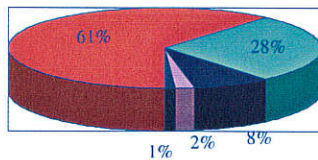
Reporting facilities

- Hospitals (131)
- Pathology labs (44)
- Surgical centers (4)
- Radiation clinics (18)
- Physicians (1000+)
- Death certificates
- Data exchange with other states (5)

Invasive Cancer Registration



Number of Facilities Involved in Reporting Cases



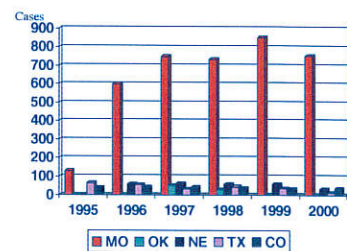
Number of records processed

- 20,766 records (2000 dx cases)
- 22,726 records (1999 dx cases)
- 22,643 records (1998 dx cases)
- 22,717 records (1997 dx cases)

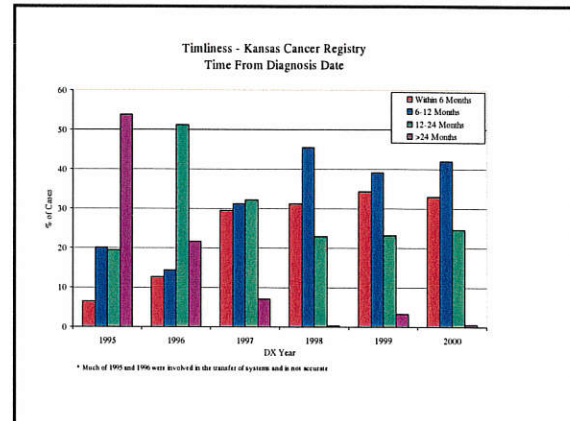
Other sources

- Death certificates
- Data exchange

New Incident Cases via Data Exchange



Timeliness of reporting



Quality data

External Review

- NAACCR certification since 1996
- NAACCR independent audit
- NPCR Call for Data
- Received gold standards in completeness, timeliness, and data quality

Use of registry data

Data Utilization

- At the national level
 - 2000, President's Cancer Panel
 - Cancer burden in rural settings
 - 2001, U.S. Senate Sub-committee
 - Procedures for conducting cancer cluster investigations
 - Is there evidence of cancer clusters?
 - 2002, U.S. Cancer Statistics
 - NPCR call for data

Data Utilization

- At the regional level
 - Heartland Triad Cancer Control
 - Cancer Statistics published by the American Cancer Society
 - Assisted other states for cancer cluster investigation efforts

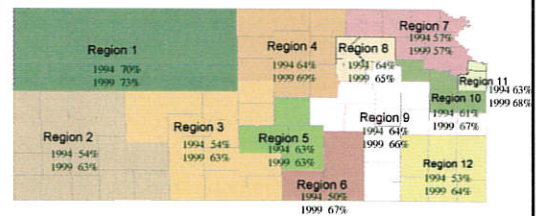
Data Utilization

- At the State level
 - Annual reports published for cases diagnosed in 1995, 1996, 1997, 1998, 1999, and 2000.
 - Identified top leading cancers for the Kansas Comprehensive Cancer Control Initiatives
 - Data linkage with Breast and Cervical Cancer Early Detection Program
 - Healthy Kansans 2000 and 2010 Objectives

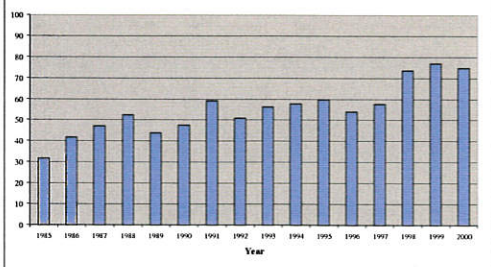
Data Utilization

- At the State level
 - Statewide cancer cluster investigations
 - Market share assessment
 - Health policy issues
 - Health care needs assessment
 - Assessment of disabilities resulting from cancers
 - Research

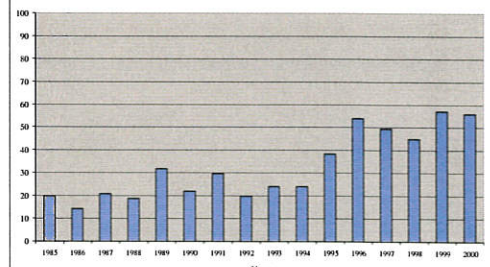
% Breast Cancer Diagnosed at Local Stage
In 1994 & 1999



% Local Stage Breast Cancer over Total Expected Breast Cancer in
Region 11



% Local Stage Breast Cancer over Total Expected Breast Cancer in
Region 2



Cancer Data Requests

1995	1
1996	9
1997	17
1998	16
1999	35
2000	15
2001	11
2002	28

Cancer cluster investigation: 8; Follow-up study: 3; Marketing: 3
Kansas statewide project: 1

KS Comprehensive Cancer Control

- Works with cancer programs at KDHE, other cancer stakeholders throughout the state
- Continues to provide data and research support to the comprehensive cancer planning process
- Spokesperson
- Strategic planning

Confidentiality

KCR is governed by

- KUMC IRB
- KDHE IRB
- Both IRBs review and certify annually

Data Security

- Physical Security
- Netware 5.1 with NDS 8
- Internet Access Turned Off
- Uninterruptible Power Supply

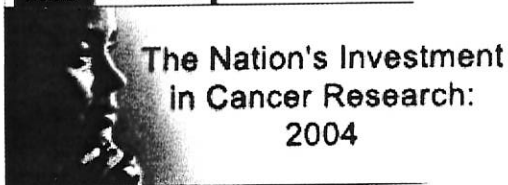
**Thank you for the opportunity to
share with you KCR operation**



- [dictionary](#)
- [site map](#)
- [search](#)

[home](#) [about NCI](#)

[cancer information](#) [clinical trials](#) [statistics](#) [research programs](#) [research funding](#)



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- [NCI Research Priorities](#)
- [Research Portfolio](#)
- [Research Sponsored by NCI](#)
- [Research Conducted at NCI](#)
- [NCI Research Resources](#)
- [Partners in Research](#)

[Research Funding](#) →

- [Funding Announcements](#)
- [Grant Application and Review](#)
- [Other Funding Organizations](#)
- [Scientific Programs and Contacts](#)
- [Training and Education Funding](#)
- [Research Policies](#)

[Cancer Information](#) →

- [Types of Cancer](#)
- [Treatment](#)
- [Prevention, Genetics, and Causes](#)
- [Screening and Testing](#)
- [Coping with Cancer](#)
- [Support and Resources](#)
- [Cancer Literature](#)
- [PDQ](#)



[Clinical Trials](#) →

- [Finding Clinical Trials](#)
- [Types of Cancer](#)
- [Conducting Clinical Trials](#)
- [Understanding Clinical Trials](#)
- [Recent Developments](#)
- [Clinical Trial Results](#)
- [Educational Resources](#)

[Statistics](#) →

- [Understanding Statistics](#)
- [Data Sources](#)
- [Statistics by Cancer Type](#)

[Advanced](#) [search](#)

[Early Reproductive Events and Breast Cancer](#)

[New Cervical Cancer Screening Guidelines Announced](#)

[Past Highlights](#)



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- [Cancer.gov Help](#)
 - [FAQs](#)
 - [Index of NCI Sites](#)

- [resources](#)
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 - [NCI Calendar of Scientific Meetings](#)
 - [Links to Other Web Sites](#)

1-7

1-1



- ▣ dictionary
- ▣ site map
- ▣ search

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clinical trials



Finding Clinical Trials →

Ways to look for specific cancer trials

→ Types of Cancer →

Information grouped by type of cancer

Conducting Clinical Trials →

Resources for new and experienced clinical investigators

How to list a trial with PDQ

Understanding Clinical Trials →

What they are; how they work
The science explained
Participant protections

Recent Developments →

New treatments
Prevention
Testing; screening
Patient care costs

Clinical Trial Results →

Summaries of newsworthy results
Ways to find outcomes of specific trials

Educational Resources →

Courses; publications
For patients and health professionals

Advanced search

New Cervical Cancer Screening Guidelines Announced

Radiation Plus Tamoxifen Lowers Recurrence Risk

Past Highlights

National Lung Screening Trial
NLST 50,000 People Needed →

CIRB INITIATIVE

featured trials

Breast Cancer and Tamoxifen (STAR)

Digital Mammography (DMIST)

Prostate Cancer Prevention (SELECT)

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- ▣ [dictionary](#)
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[cancer information](#) [clinical trials](#) [statistics](#) [research programs](#) [research funding](#)

6-1

Types of Cancer

What You Need To Know About™ Cancer Index

Information about detection, symptoms, diagnosis, and treatment of many types of cancer.

▣ Common Cancers

- ▣ [Bladder Cancer](#)
- ▣ [Breast Cancer](#)
- ▣ [Colon Cancer](#)
- ▣ [Endometrial Cancer](#)
- ▣ [Head and Neck Cancer](#)
- ▣ [Leukemia](#)

- ▣ [Lung Cancer](#)
- ▣ [Lymphoma](#)
- ▣ [Melanoma](#)
- ▣ [Ovarian Cancer](#)
- ▣ [Prostate Cancer](#)
- ▣ [Rectal Cancer](#)

▣ Childhood/Pediatric Cancers

- ▣ [Childhood Cancers Home Page](#)

▣ Cancers by Body Location/System

- ▣ [AIDS-Related](#)
- ▣ [Bone](#)
- ▣ [Brain](#)
- ▣ [Breast](#)
- ▣ [Digestive/Gastrointestinal](#)
- ▣ [Endocrine](#)
- ▣ [Eye](#)
- ▣ [Genitourinary](#)
- ▣ [Germ Cell](#)
- ▣ [Gynecologic](#)
- ▣ [Head and Neck](#)

- ▣ [Hematologic/Blood](#)
- ▣ [Leukemia](#)
- ▣ [Lung](#)
- ▣ [Lymphoma](#)
- ▣ [Musculoskeletal](#)
- ▣ [Neurologic](#)
- ▣ [Pregnancy and Cancer](#)
- ▣ [Respiratory/Thoracic](#)
- ▣ [Skin](#)
- ▣ [Unknown Primary](#)

Alphabetical List of Cancers

[Advanced](#) [search](#)

[Early Reproductive Events and Breast Cancer](#)

[New Cervical Cancer Screening Guidelines Announced](#)

[Past Highlights](#)



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- ▣ [Cancer.gov Help](#)
- ▣ [FAQs](#)
- ▣ [Index of NCI Sites](#)

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- ▣ [Publications Locator](#)
- ▣ [NCI Calendar of Scientific Meetings](#)
- ▣ [Links to Other Web Sites](#)



- ▣ [dictionary](#)
- ▣ [site map](#)
- ▣ [search](#)

[home](#) [about NCI](#)

[cancer information](#) [clinical trials](#) [statistics](#) [research programs](#) [research funding](#)

Leukemia Home Page

What You Need To Know About™ Leukemia

Information about detection, symptoms, diagnosis, and treatment of leukemia. NIH Publication No. 95-3775

Acute Lymphoblastic Leukemia in Children

Acute lymphoblastic leukemia (ALL) is a cancer of the white blood cells, the cells in the body that normally fight infections.

Young People with Cancer: A Handbook for Parents

Discusses the most common types of childhood cancer, treatments and side effects, and issues that may arise when a child is diagnosed with cancer. Offers medical information and practical tips gathered from parents.

Includes a section on talking to children about cancer.

PDQ® - NCI's Comprehensive Cancer Database

Full description of the NCI PDQ database

▣ Treatment →

Information about treatment, including surgery, chemotherapy, radiation therapy, immunotherapy, and vaccine therapy

- ▣ Adult Acute Lymphoblastic Leukemia Treatment
[[patients](#)] [[health professionals](#)]
- ▣ Childhood Acute Lymphoblastic Leukemia Treatment
[[patients](#)] [[health professionals](#)]
- ▣ Adult Acute Myeloid Leukemia Treatment
[[patients](#)] [[health professionals](#)]
- ▣ More Information

▣ Prevention, Genetics, Causes

Information related to prevention, genetics, and risk factors

- ▣ Understanding Gene Testing
- ▣ Search: Cancer Genetics Services Directory
- ▣ Cancer Genetics Overview

▣ Cancer Literature

Resources available from the CANCERLIT® database

- ▣ Search CANCERLIT®
- ▣ CANCERLIT® Topic Searches: Leukemia/Lymphoma

▣ Related Information

Other information, including reports about NCI priorities for cancer research and initiatives

- ▣ Leukemia/Lymphoma/Myeloma Progress Review Group
- ▣ State of the Science: Leukemia Meetings

▣ Statistics

Information related to cancer incidence, mortality, and survival

- ▣ Leukemias: U.S. Racial/Ethnic Cancer Patterns
- ▣ Cancer Incidence and Survival among Children: US
- ▣ Data Sources

[Advanced](#) [search](#)

[Early Reproductive Events and Breast Cancer](#)

[New Cervical Cancer Screening Guidelines Announced](#)

[Past Highlights](#)



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- ▣ [FAQs](#)
- ▣ [Index of NCI Sites](#)

[resources](#)

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- ▣ [NCI Calendar of Scientific Meetings](#)
- ▣ [Links to Other Web Sites](#)

1-10