

30 years of
*Measuring Our
Nation's Progress
Against Cancer*

SEER

Surveillance,
Epidemiology,
and
End Results

30th Anniversary Program

October 16, 2003
Bethesda, Maryland

Mini-Symposium—Bethesda Marriott

*Reception and recognition of leadership and
achievements*—Cloisters, NIH campus



30th Anniversary Program

October 16, 2003

Bethesda Marriott
Cloisters/NIH Campus

EXHIBITS OPEN UNTIL 5:00 p.m.

12:00 p.m.

Registration

1:00 p.m.

Welcome

Dr. Robert T. Croyle

*Director, Division of Cancer Control and Population Sciences (DCCPS)
National Cancer Institute (NCI)*

1:15 p.m.

Greetings

Representing Dr. Andrew von Eschenbach, Director, NCI:

Dr. Alan Rabson

Deputy Director, NCI

Dr. David P. Winchester

*Medical Director, Commission on Cancer, American College of Surgeons
Executive Director, American Joint Committee on Cancer*

Dr. Michael J. Thun

Vice President of Epidemiology and Surveillance Research, American Cancer Society

Dr. Robert Smith

Director of Cancer Screening, American Cancer Society

Dr. Phyllis A. Wingo

*Chief, Cancer Surveillance Branch, Division of Cancer Prevention and Control,
Centers for Disease Control and Prevention*

2:15 p.m.

Seminar: Health Services and Outcomes Research

Dr. Martin L. Brown

Chief, Health Services and Economics Branch, Applied Research Program, DCCPS, NCI

**Using the SEER-Medicare Resource to Conduct Population-Based Studies
of Patterns of Care and Quality of Care**

Dr. Colin B. Begg

Professor of Biostatistics and Public Health, Cornell University Medical School

Health Services Research in the SEER Program:

A Crucial Resource for Improving the End Results of People with Cancer

Dr. John Z. Ayanian

Associate Professor of Medicine and Health Care Policy, Harvard Medical School

3:30 p.m.

BREAK/REFRESHMENTS

Group Photographs

4:15 p.m.

A Patient's Perspective

Ms. Ellen L. Stovall

Executive Director, National Coalition for Cancer Survivorship

4:45 p.m.

A SEER Principal Investigator's Perspective

Dr. Dee W. West

*Executive Director, Northern California Cancer Center
Chair, National Coordinating Council for Cancer Surveillance*

5:00 p.m.

Concluding Remarks

Dr. Brenda K. Edwards

Associate Director, Surveillance Research Program, DCCPS, NCI

5:45 p.m.

Board shuttle bus to campus

Reception

Cloisters/NIH Campus

6:00 p.m.

Refreshments

7:00 p.m.

Welcome and Greetings

Dr. Holly L. Howe

Executive Director, North American Association of Central Cancer Registries

Dr. Edward J. Sondik

Director, National Center for Health Statistics, CDC

Senior Advisor to the Secretary on Health Statistics, Department of Health and Human Services

Ms. Lori Swain

Executive Director, National Cancer Registrars Association

7:30 p.m.

Awards

Moderated by Dr. Robert A. Hiatt

Director of Population Sciences, UCSF Comprehensive Cancer Center and Professor of Epidemiology, UCSF School of Medicine, University of California, San Francisco

8:30 p.m.

Group Photographs

9:00 p.m.

Board shuttle bus for return to hotel

Cancer Surveillance at NCI

Cancer surveillance provides a quantitative portrait of cancer and its determinants in a defined population. The core functions of cancer surveillance are the measurement of cancer incidence, morbidity, survival, and mortality for persons with cancer. It also includes the assessment of genetic predisposition, environmental and behavioral risk factors, screening practices, and the quality of care from prevention through palliation. Cancer surveillance tells us where we are in the effort to reduce the cancer burden and also generates the observations that form the basis for cancer research and interventions for cancer prevention and control.¹

NCI's ***Surveillance Research Program*** (SRP) directs the collection and analysis of pertinent data in order to answer key questions about cancer incidence, morbidity, mortality, and cancer-related health status in diverse regions and populations in the United States. As part of the SRP mission, the Cancer Statistics Branch manages the Surveillance, Epidemiology, and End Results (SEER) Program, an integrated, comprehensive, population-based cancer registry system. SRP also provides leadership, through its Statistical Research and Applications Branch, in developing statistical methodologies appropriate for analyzing trends and for evaluating the impact of cancer control interventions as well as geographic, social, behavioral, genetic, and health care delivery factors on the cancer burden.

The ***Applied Research Program*** (ARP) mission is to evaluate patterns and trends in cancer associated health behaviors, practices, genetic susceptibilities, outcomes and services. ARP carries out research and evaluation activities in three existing branches focusing on health services and economics, risk factor monitoring and methods, and outcomes research. Research within ARP is targeted to identifying, improving and developing databases and methods for cancer control related surveillance, outcomes and applied research. Research in each area informs policy decisions in cancer prevention, treatment and control.

Formerly one program, SRP and ARP continue to work together to define and give perspective to the nation's cancer burden. The frequent collaborations between these related areas of research have increased our scientific knowledge about cancer substantially.

¹ From the Futures Report, September 2001, a collaboration among the National Cancer Institute, the National Center for Health Statistics, the Centers for Disease Control and Prevention, the American Cancer Society, and the North American Association of Central Cancer Registries (National Dialogue on Cancer: Cancer Surveillance Futures Project).

The Surveillance Research Program

“For the first time, a complete picture of cancer incidence patterns across the United States has been developed using spatial ecologic regression models applied to SEER data. These results provide a basis for prediction of cancer prevalence and a quality control measure for cancer registries. Geographic information systems combined with these spatial models can be applied to examine local cancer incidence patterns, identify health disparities, and inform health services resource allocation.

“Use of SEER data in this way has stimulated development of innovative data visualization tools that communicate information about cancer statistics quickly and clearly to the public. As we move into an era of greater demand for immediate data access through the internet, the SEER Program should serve as the centerpiece for the nation’s cancer information system.”

—Linda Williams Pickle, PhD
Senior Mathematical Statistician
NCI

“As part of NCI’s continuing commitment to capitalizing on advances in bioinformatics, SEER is developing a state of the art data management system, in partnership with SEER cancer registry staff. When deployed, this system will maintain SEER’s current high data integrity and quality standards while providing more power and ease of use to registry staff. It will also facilitate dissemination of future system enhancements.”

—Marsha E. Reichman, PhD
Surveillance Research Coordinator
NCI

Office of the Associate Director (OAD)

OAD oversees a broad array of activities to facilitate NCI’s cancer surveillance efforts. These include budget management and policy development. SRP’s research related to health disparities is coordinated here, as are a number of pilot projects supporting cancer registries in Native American communities. OAD also provides central coordination for internet access to information about cancer surveillance and Web-based statistical tools.

OAD Staff:

Brenda K. Edwards, PhD, Marsha E. Reichman, PhD, Judith C. Swan, MHS, Amy L. Garson, BS, Jennifer L. Mothershead, BS, Terri L. Harshman, Millie M. Nevels, Mary E. Krause

Cancer Statistics Branch (CSB)

CSB manages the SEER Program and conducts research and developmental activities related to the surveillance of cancer patterns in the United States and monitoring progress against cancer. Staff members collaborate on epidemiologic studies to provide overall assessments of these patterns. CSB actively consults with other government, private and public organizations and prepares regular reports, geographical summaries and journal articles on cancer statistics. The entire staff collaborate on development, implementation, and promotion of data standards for cancer surveillance.

Areas of Staff Interest:

Program development:

Ben F. Hankey, ScD

Quality Control:

April G. Fritz, BA, RHIT, CTR, Carol H. Johnson, BSc,
Margaret (Peggy) B. Adamo, RHIT, CTR, Ben F. Hankey, ScD

Statistical analyses and interpretation:

Lynn A. G. Ries, MS, Milton P. Eisner, PhD, Lin X. Clegg, PhD, Barry A. Miller, DrPH, Gopal K. Singh, PhD, and Denise R. Lewis, PhD, Ben F. Hankey, ScD

Application of information technology to statistical analysis and data management systems:

Lynn A. G. Ries, MS, and Carol L. Kosary, MA

Demography, analytic epidemiology, and ecologic linkage studies:

Barry A. Miller, DrPH, Denise R. Lewis, PhD, and Gopal K. Singh, PhD

Technical support, video conferencing and publication distribution:

Elliott Ware, BSc

Contract administration:

Elizabeth (Betsy) P. Flagg, BA

Administrative support:

Sue Hoffman, BA, and Janis Paige

Statistical Research and Applications Branch (SRAB)

Essential corollaries to the development of cancer surveillance databases and cancer control interventions are the statistical analyses and mathematical modeling that contribute insight into the interpretation of these data. SRAB promotes and facilitates the use of these methods and models at NCI, in other federal agencies, as well as throughout the extramural research community. Research under the aegis of SRAB moves forward through sponsorship of extramural research activities, support for the development of software, and in-house analytic activity.

Areas of Staff Interest:

Program development:

Eric (Rocky) J. Feuer, PhD

Projecting the effect of cancer control practices on the cancer burden:

Eric (Rocky) J. Feuer, PhD, Kathleen A. Cronin, PhD, Barnali Das, PhD, Kevin W. Dodd, PhD, Angela B. Mariotto, PhD

Analytic approaches for the measurement of progress against cancer:

Eric (Rocky) J. Feuer, PhD, Kathleen A. Cronin, PhD, Barnali Das, PhD, Michael P. Fay, PhD, Angela B. Mariotto, PhD, Ram Tiwari, PhD, Linda W. Pickle, PhD

Geographic information systems, spatial analysis, and data visualization:

Linda W. Pickle, PhD, B. Sue Bell, PhD, Barnali Das, PhD

Program evaluation, meta-analysis and outcomes research:

William W. Davis, PhD, Kevin W. Dodd, PhD, B. Sue Bell, PhD

Survey methodology, design and analysis, and population risk assessment:

William W. Davis, PhD, Kevin W. Dodd, PhD

Development and management of statistical grant portfolio:

Caroline M. McCabe, Ram Tiwari, PhD

Administrative assistance:

Reginald B. Taborn, BA, Jennifer T. Myers

“I am proud to have been a part of the advances in statistical and computer technology that have fundamentally changed the way we report and interpret cancer statistics. Joinpoint methodology and the recently introduced delay-adjusted incidence rates improve our ability to detect changes in trends. U.S. prevalence estimates now come from a more representative group of SEER registries. Survival methods have been expanded as we debate the merits of analytic approaches, attempt to estimate ‘cure’ rates, and factor competing causes of death into survival estimates. Methods for estimating the lifetime and age-conditional risks of developing cancer have been improved, and can be used for risk communication and study planning. Statistical modeling of the influence of cancer control interventions on population data are enabling us to better analyze and project cancer trends and optimize opportunities for cancer control planning.”

“Happy 30th Anniversary to SEER. In my 16 years with the program, I have been delighted, surprised, and stimulated by the developments. I can’t wait to see what lies ahead!”

—Eric J. (Rocky) Feuer, PhD
Chief, Statistical Research and Applications Branch, NCI

The Registries

The Surveillance, Epidemiology, and End Results (SEER) Program of the National Cancer Institute (NCI) is an authoritative source of information on cancer incidence and survival in the United States. SEER began collecting data on cancer cases on January 1, 1973, in the states of Connecticut, Iowa, New Mexico, Utah, and Hawaii and in the metropolitan areas of Detroit and San Francisco-Oakland. In 1974–1975, the metropolitan area of Atlanta and the 13-county Seattle-Puget Sound area were added. In 1978, 10 predominantly Black rural counties in Georgia were added, followed in 1980 by the addition of American Indians residing in Arizona. Three additional geographic areas participated in the SEER Program prior to 1990: New Orleans, Louisiana (1974–1977, rejoined 2001); New Jersey (1979–1989, rejoined 2001); and Puerto Rico (1973–1989). NCI also funds a cancer registry that, with technical assistance from SEER, collects information on cancer cases among Alaska Native populations residing in Alaska. In 1992, the SEER Program was expanded to increase coverage of minority populations, especially Hispanics, by adding Los Angeles County and four counties in the San Jose-Monterey area south of San Francisco. In 2001, the SEER Program extended its coverage to include Kentucky and Greater California; in addition, New Jersey and Louisiana once again became participants.

The SEER Program currently collects cancer incidence and survival data from 14 population-based cancer registries and 3 supplemental registries covering approximately 26 percent of the U.S. population. Information on more than 3 million in situ and invasive cancer cases is included in the SEER database, and approximately 170,000 new cases are added each year within the SEER coverage areas. SEER registries routinely collect data on patient

demographics, primary tumor site, morphology, stage at diagnosis, first course of treatment, and followup for vital status. The SEER Program is the only comprehensive source of population-based information in the United States that includes stage of cancer at the time of diagnosis and survival rates within each stage. The mortality data reported by SEER are provided by the National Center for Health Statistics.

For the expansion registries (Kentucky, Greater California, New Jersey, and Louisiana), NCI funds are combined with funding from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR) as well as funding from the states. NCI staff work with the North American Association of Central Cancer Registries to guide all state registries to achieve data content and compatibility acceptable for pooling data and improving national estimates. The SEER team is developing computer applications to unify cancer registration systems and to analyze and disseminate population-based data. Use of surveillance data for research is being improved through Web-based access to the data and analytic tools, and linking with other national data sources. For example, a new Web-based tool for public health officials and policy makers, State Cancer Profiles, provides a user-friendly interface for finding cancer statistics for specific states and counties.

The SEER Program is considered the standard for quality among cancer registries around the world. Quality control has been an integral part of SEER since its inception. Every year, studies are conducted in SEER areas to evaluate the quality and completeness of the data being reported.

The following section briefly describes the SEER registries, their goals, and history.

Connecticut Tumor Registry

Principal Investigator

Anthony P. Polednak, PhD

Registrar of Tumor Records

Cathryn E. Phillips, CTR

Geographic Area

Entire State

“I was fortunate to always have a core of dedicated key staff who were challenged by the job as well as motivated by the fact that they could see the results of their efforts reflected in the many special studies and the publications of cancer data of which the registry was a part. Every cancer registry needs people like that. I was the beneficiary of the efforts of many registry staff, which made my job easier and ultimately was the reason I was able to have the longevity I did have.”

—John (Jack) T. Flannery, BA
Director, Connecticut Tumor Registry (retired)

The Connecticut Tumor Registry (CTR), part of the SEER Program since 1973, is one of the original SEER registries and examines cancer patterns in Connecticut. The registry is one of only five statewide-designated SEER sites in the United States with long-term cancer incidence and survival data.

The CTR is part of the Bureau of Community Health within the Connecticut Department of Public Health. All hospitals and clinical laboratories in Connecticut are required by state regulations (public health code) to report cancer cases to the registry, as well as information on followup and treatment. With statistical information on cancers diagnosed among Connecticut residents since 1935, CTR data cover a longer period than any other cancer registry in the United States. Data on about 500,000 cancers diagnosed since 1973 are included in the registry. A historical file is maintained of more than 204,000 tumors diagnosed between 1935 and 1972, the pre-SEER era.

The registry has reciprocal cancer-reporting agreements with adjacent states and several other states (including Florida). The registry may then identify those Connecticut residents diagnosed with cancer and/or obtaining cancer treatments in other states, improving accuracy when estimating cancer rates among Connecticut residents. Like other SEER registries, CTR participates in NCI-sponsored research studies. Samples of Connecticut cancer patients have been included in all of the periodic SEER “Patterns of Care” studies.

Web Site

<http://www.dph.state.ct.us/oppe/hptumor.htm>

Hawaii Tumor Registry

Principal Investigators

Marc T. Goodman, PhD, MPH
Laurence N. Kolonel, MD, PhD

Program Coordinator/Operations

Michael D. Green, CTR

Director

Brenda Y. Hernandez, PhD

Geographic Area

Entire State

The Hawaii Medical Association, Hawaii State Department of Health (DOH), and the local chapter of the American Cancer Society established the Hawaii Tumor Registry (HTR) in 1960. It is one of the original SEER registries, and has been part of SEER since 1973. Operated jointly by the Cancer Research Center of Hawaii at the University of Hawaii and the DOH, the HTR has statutory backing for the collection of cancer morbidity and mortality data by the DOH.

The HTR database contains more Native Hawaiians than any other registry nationwide. It also contains sizable numbers of Caucasian, Chinese, Filipino, and Japanese cases, as well as data on other smaller ethnic groups such as Koreans and Samoans. This racially diverse database has been invaluable in demonstrating ethnic variations in cancer incidence and survival. The main goals of the HTR are to (1) determine cancer incidence and monitor cancer trends with respect to demographic and social characteristics of the population; (2) determine survival experience for cancer patients and monitor cancer survival trends with respect to form of cancer, extent of disease, therapy, and parameters of other prognostic importance; (3) identify cancer risk factors by conducting special studies which disclose groups with higher or lower cancer risks; and (4) identify factors related to patient survival through special studies of referral patterns, diagnostic procedures, treatment methods, and other aspects of medical care.

Web Site

<http://planet-hawaii.com/htr/>

“SEER has been a lynchpin for the cancer center. I attribute the success of the center’s epidemiologic research program to the Hawaii Tumor Registry and the high quality it achieved after joining the SEER Program in 1973. HTR’s operational responsibilities, once directed by several of its founding organizations, have been consolidated under SEER, which has provided the resources and motivational guidance to improve coverage and followup for the state’s unique and ethnically diverse population.”

—Laurence N. Kolonel, MD, PhD
*Deputy Director, Cancer Research Center of Hawaii
Co-PI, Hawaii Tumor Registry*

“As a missionary for the Church of Jesus Christ of Latter-day Saints in 1949, I frequently visited a lady with a melanoma on her foot; after a hemipelvectomy, I saw the recurrences until she looked like a horny toad. The medical profession abandoned her. Her last words to me were ‘Elder Smart, in your future study of medicine, please study this disease.’”

—Charles Smart, MD
*Chief, Early Detection Branch, NCI
Director, Utah Cancer Registry (retired)*

“In 1973 when the UCR acquired funding from the SEER Program... we were ecstatic! This was our chance to contribute to the most comprehensive source of population-based data in the United States. Our Registry went from ‘small town’ to ‘uptown.’ The future is promising. The next step... from ‘uptown’ to ‘global,’ as our progressive data are utilized to help fight cancer worldwide.”

—Rosemary Dibble, CTR
*Director of Operations
Utah Cancer Registry*

Utah Cancer Registry

Principal Investigator (Acting)

Wallace Akerley, MD

Director of Operations

Rosemary Dibble, CTR

Geographic Area

Entire state

The Utah Cancer Registry (UCR) is a population-based cancer registry that has served the State of Utah since 1966. Cancer was defined as a reportable disease in Utah in 1948. Revised rules mandating the reporting of cancer in Utah were implemented in 1999. The UCR was designated as the official repository for such information and is affiliated with the University of Utah and its Health Sciences Center and the Utah Department of Health. The UCR is one of the original members of the SEER Program and has participated in that program continuously since 1973.

UCR data are used to monitor the burden of cancer in Utah and nationally and to facilitate scientific studies of the disease. Approximately 70 percent of Utah residents are members of the Church of Jesus Christ of Latter-day Saints, whose doctrine regarding consumption of tobacco, alcohol, and caffeinated beverages and other lifestyle issues may have influenced the occurrence of cancer in Utah. UCR data have been used in national patient care evaluation studies to monitor methods of diagnosis, treatment, and outcome of specific cancers. In addition, the registry assists hospitals and physicians in Utah with patient followup and provides a comprehensive review of how their treatment results compare locally, regionally, and nationally.

Web Site

<http://www.uuhsc.utah.edu/ucr/index.html>

New Mexico Tumor Registry/Arizona Cancer Registry

Principal Investigators

Charles R. Key, MD, PhD
Charles L. Wiggins, PhD

Program Manager

Dawn J. Hamilton, BS, CTR

Geographic Area

Entire states of Arizona and New Mexico

The New Mexico Tumor Registry (NMTR) was established in 1966 and began statewide population-based cancer registration in New Mexico and the Navajo Nation in 1969. The NMTR expanded its coverage to all Arizona American Indians in 1980 at the request of NCI and the Indian Health Service (IHS). The NMTR is one of the original member registries of the SEER Program and is a program of the University of New Mexico's Health Sciences Center. The NMTR identifies and collects information on all cancer cases diagnosed in the American Indian population of Arizona under a collaborative agreement between the NMTR, the IHS, and the Arizona Department of Health Services via the Arizona Cancer Registry (ACR). The ACR collects data on cancer cases in Arizona reported by hospitals, clinics, and physicians.

The NMTR's mission is to identify all cancer cases (excluding non-melanoma skin cancer) within its geographic boundaries and to collect, analyze, and maintain information on cancer according to rules and procedures mandated by the SEER Program. The NMTR's catchment population is dispersed over a large geographic area. To facilitate completeness and uniformity of case registration, the NMTR uses a "circuit-riding" system in which personnel from the central office travel throughout the state to collect information on cancer cases. The NMTR is a primary national data source in the Southwest for cancer incidence among Hispanics and a major source for data on cancer incidence among Native Americans. New Mexico has a higher percentage of Hispanics and American Indians than does any other state in the country. Incidence and mortality data from this registry are used extensively in epidemiologic studies to identify disease trends, patterns, and risk factors important in cancer prevention and control. The NMTR and affiliated collaborators have focused their research efforts on cancers of the lung, prostate, breast, cervix, digestive organs, and melanoma and have compiled an extensive bibliography of epidemiological studies of cancer.

Web Sites

<http://hsc.unm.edu/epiccpro/>

<http://www.hs.state.az.us/phs/phstats/acr>

One reason Dr. Key gave for his decision to focus on the development of a tumor registry for New Mexico was a conversation with a fellow faculty member and pathologist at the Albuquerque VA Medical Center who wanted to know why "all of the VA lung cancer patients have Anglo surnames and all of the stomach cancer patients have Spanish surnames."

Metropolitan Detroit Cancer Surveillance System

“I am truly blessed to have pursued my life’s ambition—researching for a cure to cancer—in the city where I was born, raised, and educated. I believe in cancer research. I have seen remarkable improvements in survival rates, treatment, and quality of life. It’s been a long road, but our work is not done yet.”

—Joanne Harris, CTR
Chief, Cancer Surveillance Unit
Metropolitan Detroit Cancer
Surveillance System

Principal Investigators

Ann G. Schwartz, PhD, MPH
Kendra Schwartz, MD, MSPH

Manager

Joanne Harris, CTR

Geographic Area

Michigan counties: Macomb, Oakland, and Wayne

The Metropolitan Detroit Cancer Surveillance System (MDCSS) was organized in 1949 as a central pathology registry to serve 25 hospitals in Wayne, Oakland, and Macomb counties. Population-based cancer reporting was initiated in 1969 with MDCSS’s participation in NCI’s Third National Cancer Survey. The Michigan Department of Community Health (MDCH) also appointed MDCSS to collect cancer data in the tricounty area for the statewide cancer reporting system. MDCSS has participated in the SEER Program since SEER’s founding in 1973. The program is part of the Barbara Ann Karmanos Cancer Institute (KCI) of the Wayne State University School of Medicine. KCI is an NCI-designated Comprehensive Cancer Center.

MDCSS’s charge is to register all newly diagnosed cancer cases in residents of the Detroit Metropolitan Area and provide active followup on all living patients. MDCSS data are used locally and for research purposes. Local physicians and hospitals often request updated information on patients for long-range planning, evaluation of treatment or equipment needs, and other purposes. Service agencies, professionals, and members of the general public seek information on patterns of cancer in the Detroit Metropolitan Area for educational and program planning purposes. The MDCSS database provides researchers the capability to describe groups of the Detroit area population in terms of cancer incidence, survival, stage of diagnosis, and treatment patterns. The database also informs more extensive studies that attempt to determine environmental, socioeconomic, dietary, and occupational exposures that may impact cancer patterns and to assess the impact of screening, early detection, and treatment on the length and quality of patient survival. The Detroit Metropolitan Area is well suited to such studies because of its diverse population and urban, industrial environment.

Web Site

<http://www.karmanos.org/epid/>

Iowa Cancer Registry

Principal Investigators

Charles F. Lynch, MD, PhD
Charles E. Platz, MD

Administrative Director

Kathleen M. McKeen

Geographic Area

Entire state

The Iowa Cancer Registry (ICR) is a population-based cancer registry that has served the State of Iowa since 1973. The ICR has been a member of the SEER Program since its inception in 1973. The ICR is affiliated with the Department of Epidemiology in the College of Public Health of the University of Iowa.

The goals of the ICR are to (1) assemble and report measurements of cancer incidence, survival, and mortality among Iowans; (2) provide information on changes over time in the extent of disease at diagnosis, therapy, and patient survival; (3) promote and conduct studies designed to identify factors relating to cancer etiology, prevention, and control; (4) respond to requests from individuals and organizations in the state of Iowa for cancer data and analyses; and (5) provide data and expertise for cancer research activities and educational opportunities.

The ICR uses traveling field representatives and other means to collect data and reports the incidence of newly diagnosed cancer cases and followup information to the SEER Program. Since 1973, the ICR is estimated to have provided 11.4 percent of the total SEER cases.

Web Site

<http://www.public-health.uiowa.edu/shri/>

Kathleen McKeen credits the late Dr. Howard Latourette, Director of Radiation Therapy and Medical Director of the University of Iowa Hospitals and Clinics Cancer Registry, with encouraging her to pursue work in the cancer registry field, noting, “He was a physician dedicated to helping his patients and to their well being, and he was an inspiration to all of his students and staff...He was a proponent of the cancer registry field and that interest was infectious to others.”

“The SEER Program is a tremendous research resource. It has been and continues to be at the heart of my research activities, having assisted with local, regional, national, and international epidemiologic studies as well as with cancer prevention and control activities. I am proud to be part of the SEER Program and anticipate many more years of quality cancer surveillance data that can be used to improve lives.”

—Charles F. Lynch, MD, PhD
Principal Investigator, Iowa SEER
Chair, SEER 30th Anniversary
Committee

well as the discovery of dedicated scientists and friends, than involvement in SEER.”

—Dee W. West, PhD
*Chief Scientific Officer
Northern California Cancer Center
Principal Investigator
Greater Bay SEER*

Greater Bay Area Cancer Registry

Principal Investigators

Dee W. West, PhD
Sally Glaser, PhD

Director, Registry Operations

Ray Gottfredson

Geographic Area

California counties: Alameda, Contra Costa, Marin, San Francisco, San Mateo, Monterey, San Benito, Santa Clara and Santa Cruz.

In 1969, NCI selected the San Francisco Bay Area to participate in its Third National Cancer Survey. The San Francisco Bay Area Registry became part of the original SEER registries in 1973. The registry was operated within the California Department of Health Services until 1982, when it moved to the Northern California Cancer Center.

Cancer reporting became mandatory in California in 1987. Legislation designated cancer as a reportable disease and created the statewide California Cancer Registry (CCR), subdivided into 10 regional registries. The regions share information about cases diagnosed outside their region of residence to ensure complete reporting within each regional cancer registry. Statewide implementation of cancer incidence data reporting by the 10 regional cancer registries was effective as of January 1, 1988. The registries for the San Francisco Bay Area (San Francisco, Alameda, Contra Costa, Marin and San Mateo counties), designated as Region 8 of the CCR, and the Santa Clara Region (Monterey, San Benito, Santa Clara and Santa Cruz counties), designated as Region 1 of the CCR, together are known as the Greater Bay Area Cancer Registry (GBACR). The four counties in the San Jose-Monterey area south of San Francisco were added to GBACR in 1992 as part of SEER's expansion to include more minority populations. These counties include a large Hispanic population.

The GBACR consists of two components: (1) Registry Operations, responsible for data collection and management, and (2) Surveillance Research, responsible for conducting research using cancer registry data and examining patterns of cancer incidence in the Greater Bay Area. The GBACR includes data on persons of diverse racial/ethnic and socioeconomic backgrounds.

Web Site

http://www.nccc.org/ResearchandTraining/research_gbareg.html

Cancer Surveillance System (Seattle)

Principal Investigators

Thomas L. Vaughan, MD, MPH
Stephen M. Schwartz, PhD

Manager

Mary Potts, RHIA, CPA, CTR

Geographic Area

Washington counties in the Seattle-Puget Sound area: Clallam, Grays Harbor, Island, Jefferson, King, Kitsap, Mason, Pierce, San Juan, Skagit, Snohomish, Thurston, and Whatcom

The Cancer Surveillance System (CSS), which collects population-based data on cancer incidence and survival in the 13 contiguous counties in northwestern Washington State, was established in 1974 under contract with the SEER Program. Until 1992, cancer data were reported to the CSS under voluntary agreements with hospitals, radiation and surgery centers, and pathology laboratories. In 1992, cancer diagnoses were required by law to be reported to the Washington State Department of Health's Washington State Cancer Registry. The CSS was designated as the contractor responsible for the collection of cancer information for CSS's reporting area. The CSS is a program of the Fred Hutchinson Cancer Research Center, one of NCI's Comprehensive Cancer Centers.

The cancer data provided by the CSS enable public health scientists and practitioners to (1) track trends in the incidence of all forms of cancer (surveillance), (2) identify and investigate patterns of cancer occurrence (epidemiology), and (3) monitor trends in mortality and survival from specific cancers (end results).

Additional CSS objectives are to conduct epidemiologic and cancer control studies using CSS- and SEER-generated data; perform casefinding and record review for studies that require collection of additional case information; develop new and improved methods of data collection, quality control, and data processing; train graduate students in biostatistics, epidemiology, and cancer control research; serve as a data and technical resource to area health care providers and institutions; provide information on cancer incidence and survival in the Puget Sound region to local health planners and other users of health statistics.

Web Site

<http://css.fhcrc.org>

“The SEER Program has provided a standard of excellence for the world. During the editing process for the latest version of Cancer Incidence in Five Continents, when evaluating the data submitted from registries, we frequently asked whether the data were of ‘SEER quality.’ ”

—David B. Thomas MD, DrPH
Former Principal Investigator
Seattle SEER

Metropolitan Atlanta and Rural Georgia SEER Program

“The strength of the SEER Program has come through a realization on the part of the staff that the real story is not in the numbers themselves, but in the lives behind those numbers. A database with information on several million cancers represents in reality several million people whose lives were forever changed by a diagnosis of cancer.”

—John Young, Jr., DrPH, CTR
*Principal Investigator,
MARGA SEER*

Principal Investigators

John L. Young, Jr., DrPH, CTR
Jonathan M. Liff, PhD

Manager

Mary Streeter, RHIT, CTR

Geographic Area

Georgia counties:

Atlanta Registry: Clayton, Cobb, DeKalb, Fulton, and Gwinnett

Georgia Rural Registry: Glascock, Greene, Hancock, Jasper, Jefferson, Morgan, Putnam, Taliaferro, Warren, and Washington

The Metropolitan Atlanta and Rural Georgia (MARGA) SEER Program is comprised of the Atlanta registry and the Rural Georgia SEER registry. The Atlanta registry was included in NCI’s First, Second, and Third National Cancer Surveys and joined the SEER Program in 1975 as one of the original SEER registries. The registry is managed by the Georgia Center for Cancer Statistics (GCCS), a research unit within the Department of Epidemiology of the Rollins School of Public Health at Emory University in Atlanta, Georgia. Since its inception, the population covered by the Atlanta SEER registry has increased dramatically, but the geographical boundaries have not changed. In 1978, the GCCS also began operating the supplemental Rural Georgia SEER registry that records cancer incidence and mortality data for residents of the 10 rural, predominantly black counties southeast of Atlanta. SEER included this registry as part of its supplemental expansion to increase coverage for minority populations.

The GCCS has a strong working relationship with the Cancer Control Program of the Georgia Department of Human Resources, which maintains a statewide cancer registry funded by the Centers for Disease Control and Prevention (CDC). Collaboration between the two registries identifies MARGA-area patients who might be treated for cancer at other hospitals in Georgia.

The MARGA SEER registry is the oldest SEER registry in the Southeast. As a source of information for many blacks listed in the SEER Program, MARGA was one of the registries used as a research tool for the Black/White Cancer Survival Study, one of SEER’s Landmark Studies. The registry data are used by researchers at Emory University as well as in joint research activities with the American Cancer Society and the CDC.

Web Site

<http://www.sph.emory.edu/GCCS/>

Los Angeles Cancer Surveillance Program

Principal Investigators

Ronald K. Ross, MD
Dennis Deapen, DrPH
Leslie Bernstein, PhD
Wendy Cozen, DO

Director of Operations

Judith R. Boone, BA

Geographic Area

Los Angeles County

The Los Angeles County Cancer Surveillance Program (CSP), organized in 1970 and administered by the University of Southern California Keck School of Medicine, was initially part of the National Viral Cancer Program (a laboratory-based viral oncology program). It was developed with the voluntary cooperation of hospitals and other institutions, clinics, and medical laboratories equipped to diagnose cancer in Los Angeles County. Since 1972, the registry has been population-based, providing complete incidence data for Los Angeles County from that date.

In 1981, the CSP was legally mandated to collect information on all new cancer cases occurring among Los Angeles County residents. This information is used to monitor cancer incidence patterns and trends. The CSP became the regional registry for Los Angeles County in 1987 under the new statewide mandate for cancer surveillance through the California Cancer Registry. In 1992, when SEER was expanded to increase coverage of minority populations, the CSP became the largest registry of the SEER Program and added patient followup to its program. Its addition to SEER greatly increased program coverage of the Hispanic population. The CSP reports data in a county where over one-third of the residents are foreign-born. It is perhaps the most ethnically diverse county in the United States. Los Angeles County has a sizable Hispanic population, as well as a large group of Asian and Pacific Islander populations.

The CSP is one of the most productive cancer registries in the world in terms of scientific contributions toward understanding the demographic patterns and the etiology of specific cancers. The CSP has a bibliography of more than 420 publications contributed to scientific journals. The registry supports a large ongoing body of research funded mainly by the National Cancer Institute.

Web Site

http://www.usc.edu/schools/medicine/departments/preventive_medicine/divisions/epidemiology/research/csp/index.html

“Population-based cancer registration in Los Angeles County in 1969 was a vision of Brian E. Henderson, MD, who believed a rapid ascertainment system would enable cancer epidemiologists to conduct important research into the causes of human cancers. For 30 years now, this vision has inspired both researchers and cancer registry staff to ensure that the registry is heavily utilized for high-quality, leading-edge research. Participation in the SEER Program has expanded this research capability in association with the other member registries and the active support of the NCI staff.”

—Dennis Deapen, DrPH
*Director, Los Angeles Cancer Surveillance Program
Co-PI, Los Angeles SEER*

Cancer Registry of Greater California

“I finished graduate school with the goal of seeking other areas of work, but I came back to looking at the cancer registry again. At one point, I mentioned my dilemma to Dr. John Young who said to me, ‘Once the registry is in your blood, it will always be there.’ Yes, indeed, this is true! My life’s work has been fulfilling and challenging at the same time.”

—Lilia O’Connor, MBA,
RHIT, CTR
Director of Operations
California Cancer Registry

Principal Investigator

William E. Wright, PhD

Director of Operations

Lilia O’Connor, MBA, RHIT, CTR

Geographic Area

This includes the following California Cancer Registry (CCR) regions: Central California, Sacramento, Tri-County, Desert Sierra, Northern California, San Diego/Imperial, Orange County.

In 2001, the Cancer Registry of Greater California (CRGC) became one of four new expansion registries in the SEER Program. SEER added these seven remaining regional registries of the California Cancer Registry (CCR) to provide coverage for populations with limited existing cancer surveillance data but of high interest to public health decision makers. The California Department of Health (CDH) provides overall administration, while each regional registry is administered locally. In 1947, the CCR began as a CDH-conducted feasibility study for a centralized cancer registry based on hospital-reported data. The successful study led to a larger registry in the San Francisco Bay area and a registry in Los Angeles County. Since 1960, population-based cancer incidence data have been available in California, founded in part by CDC’s National Program of Cancer Registries.

The registries continued to develop over the years. The San Francisco Bay area registry became part of the original SEER registries in 1973. The Los Angeles Registry was established in 1972. Recognizing the enormous value of population-based cancer data from the San Francisco and Los Angeles areas, California enacted legislation in 1985 that officially established the CCR program, with 10 regional cancer registries supplying statewide population incidence data from 1988 forward. Region 1 (the San Jose-Monterey area) joined with Region 8 (San Francisco Bay Area) in the SEER Program in 1992, and the Los Angeles registry (Region 9) also joined that year. This left the seven remaining CCR regions to become part of the SEER Program as an expansion registry in 2001.

Web Sites

CCR: <http://www.ccrca.org/>

Central California: None Available

Northern California: None Available

Tri-County: <http://www.tccr.org/>

Sacramento: <http://www.cspeg3.org/>

Desert Sierra: <http://www.dscsp.com/>

San Diego/Imperial/Orange County: <http://www.epi.uci.edu/cspoc/>

Louisiana Tumor Registry

Principal Investigator

Vivien W. Chen, PhD

Catherine N. Correa, PhD, MPH

Registry Operations

Catherine N. Correa, PhD, MPH

Michelle B. Crouch, RHIA, CTR

Geographic Area

Entire state

Cancer registration in Louisiana began in 1947 at the Charity Hospital in New Orleans as part of the NCI's program on "end results." In 1974, as part of its SEER Program, the NCI provided funds for a population-based cancer incidence and survival registry covering the Greater New Orleans (Jefferson, Orleans, and St. Bernard parishes) area, which began the Louisiana Tumor Registry (LTR). In 1979, the LTR was transferred to Louisiana's Office of Public Health as part of a pilot program for statewide cancer registration. As part of this program, cancer in Louisiana became a reportable disease in 1982. The catchment area for the LTR expanded in 1983 to cover all 35 parishes of south Louisiana. Statewide coverage was achieved in 1988 when the remaining 29 parishes comprising north Louisiana were added to the LTR program.

Since 1995, the LTR has been a program of the Louisiana State University Health Sciences Center (LSUHSC) and is under the auspices of the LSUHSC School of Public Health. The LTR receives funding from the CDC's National Program of Cancer Registries. In 2001, the Louisiana Tumor Registry was selected as one of four new expansion registries to join the NCI's SEER Program. Data from the LTR represent cases of cancer that occur in a state with a large population of rural African-Americans, a unique Acadian/Cajun population and a population marked by high cancer mortality rates and high poverty levels.

By law, the LTR collects, analyzes, and disseminates information on cancer in Louisiana. Its purpose is to gather statistical data "...to aid in the assessment of cancer incidence and survival, possible causes of specific cancers, and other related aspects of cancer in Louisiana." The LTR computes cancer incidence rates by age, race, sex, geographic area, and other demographic characteristics to identify cancers that are problematic for Louisiana residents and groups that are at particularly high or low cancer risk. Statewide incidence and mortality are monitored over time. The LTR conducts special studies, often in collaboration with other researchers and institutions. Areas of research include identification of risk factors, racial disparities in cancer occurrence and survival, and patterns of care. The LTR data are used in cancer research, in the planning and implementation of cancer prevention and control programs in Louisiana, and to evaluate the effectiveness of such programs.

Web Site

<http://www.lcltfb.org/registry.htm>

"When I first compiled cancer statistics for a hospital registry as a graduate student, I was amazed at its wealth of data. Dr. Pelayo Correa, co-founder of the Louisiana Tumor Registry, inspired and challenged me to pursue my career in population-based cancer registration—a valuable resource for epidemiologic research and the cornerstone for cancer control. Since joining the Louisiana registry, my goal has been to achieve SEER data quality—the gold standard in the world. We are proud and excited to become a SEER expansion registry and feel privileged to work with a group of very dedicated colleagues."

—Vivien W. Chen, PhD
Principal Investigator
Louisiana Tumor Registry

“New Jersey is a challenging place to study cancer. On several occasions, I have had to face upset citizens, and I have helped put together a ‘Cancer Cluster SWAT Team.’ Complying with SEER data requirements is easy in comparison, especially since this is our second attempt at it...I have this fantastic dream that SEER will need me as a translator in Lyon and I will have to make the trip to IARC. France is one of my favorite places, and this would fulfill a career goal to be involved with international health. It’s too bad the staff in Lyon speak English so well!”

—Betsy Kohler, MPH, CTR
Director, New Jersey State
Cancer Registry

New Jersey State Cancer Registry

Principal Investigator

Betsy A. Kohler, MPH, CTR

Program Manager

Susan Van Loon, RN, CTR

Geographic Area

Entire State

With oversight by the New Jersey Department of Health and Senior Services, the New Jersey State Cancer Registry (NJSCR) was established by state legislation in 1977 that made cancer a reportable disease. The registry has been recording the incidence of cancer for the State of New Jersey since 1979. Additional legislation in 1996 provided for penalties for non-reporting of cancer cases. The NJSCR received funding from the SEER Program from 1983 to 1989. It received funding from the CDC’s National Program of Cancer Registries in 1994. It is one of four states to be included in the SEER 2001 expansion program.

The purpose of the NJSCR is to: (1) monitor cancer trends in New Jersey, (2) promote scientific research to increase survival, (3) respond to NJ residents on cancer issues and concerns, (4) educate the public, (5) provide information for policy planning in cancer prevention and control, and (6) share and compare cancer data with other states and the nation.

The NJSCR has reciprocal reporting agreements with neighboring states as well as Florida and Maryland. New Jersey residents often travel to nearby metropolitan centers for treatment at renowned cancer centers, and reciprocal agreements assure that duplicate cases are not created.

Noteworthy for the NJSCR is the use of geographic information systems (GIS) for mapping of cancer data for cancer control and research purposes. The use of GIS by the NJSCR for cancer surveillance is considered a SEER Landmark Study.

Web Site

<http://www.state.nj.us/health/cancer/njsr1b.htm>

Kentucky Cancer Registry

Principal Investigator

Thomas C. Tucker, PhD, MPH

Director of Registry Operations

Frances Ross, CTR

Geographic Area

Entire state

The Kentucky Cancer Registry (KCR) began as a voluntary reporting system in 1986. In 1990, the State General Assembly passed legislation that formally established KCR as the population-based central cancer registry for the state. Mandatory reporting to KCR officially began January 1, 1991. The KCR operates as a division of the University of Kentucky's Markey Cancer Control Program.

All Kentucky acute care hospitals and their associated outpatient facilities are required to report each case of cancer to KCR. In 1994, the legislation that requires the reporting of cancer cases was modified to include reporting from all health care facilities that either diagnose or treat cancer patients. These additional facilities include freestanding treatment centers, nonhospital (private) pathology laboratories, and physician offices. Also in 1994, KCR received funding from the Centers for Disease Control and Prevention (CDC) through the National Program of Cancer Registries (NPCR). Since 1995, KCR has collected uniform, high quality data on approximately 21,000 new primary cases of cancer that occur in Kentucky residents each year.

In 2001, KCR was selected as one of four expansion registries to become part of NCI's SEER Program. Data from KCR represent cancer cases that occur in a poor rural state with a large Appalachian population, high cancer mortality rates, and low literacy rates. Such data were inadequately represented in the SEER database before KCR joined the SEER Program.

KCR data have been used to plan and evaluate a wide variety of cancer control activities. In addition, the research data set has been used by investigators to study lung, breast, colorectal, prostate, and cervical cancer. KCR data have been used in basic science, clinical, and population-based research projects as well.

Web Site

<http://www.kcr.uky.edu/>

Gilbert H. Friedell, MD, was the first director of the Markey Cancer Center at the University of Kentucky. It was his vision to develop a population-based cancer registry for the state that would provide timely and accurate information for both cancer control and research. He also wanted the registry to meet the standards of quality and excellence exemplified by the SEER registries. In 2001, under the direction of Thomas C. Tucker, PhD, MPH, and Frances Ross, CTR, the Kentucky Cancer Registry joined the NCASEER Program as one of its expansion registries.

"I am very proud that our vision of a population-based cancer registry for the state of Kentucky has become a reality."

—Gilbert H. Friedell, MD
*Director Emeritus
Markey Cancer Center*

Alaska Native Tumor Registry

Principal Investigator

Anne P. Lanier, MD, MPH

Program Manager

Jeannine Maxwell, BS, CTR

Geographic Area

American Indian/Alaska Native residents of Alaska at the time of diagnosis

Now a full member of the SEER Program, the Alaska Native Tumor Registry (ANTR) was initiated in 1974 in collaboration with the NCI and the Centers for Disease Control and Prevention. Analysis of five-year cancer incidence (1969-73) and cancer mortality data (1960-69) demonstrated that cancer patterns among Alaska Natives (AN) differed from those in the rest of the U.S. These data confirmed the need for a separate cancer registry for this population. Joseph Fraumeni, Jr., MD, and William Blot, PhD, then at NCI, DCE, should be credited with providing support for Alaskan investigators to conduct the preliminary studies and initiation of a registry utilizing data from 1969 forward. The initial registry focused on incidence; no data on staging, treatment, and follow-up were included. From the outset, the ANTR followed procedures and policies of the NCI SEER Program, and the registry received technical assistance from SEER over a number of years. No outside funding was provided from 1984-88. During that time, the registry served as a hospital registry for the Alaska Native Medical Center (ANMC), a referral hospital in Anchorage for most AN with major illnesses. In 1989, an interagency agreement between the NCI, the ANMC (data collection and registry management), and the University of New Mexico SEER Program (technical and management assistance) was implemented. Data were collected retrospectively for all AN diagnosed with cancer statewide from 1969 on, and the information collected on each patient was that required of all SEER registries. Since 1989, the ANTR has received ongoing support from the SEER Program. In 1999, the ANTR became a member of the SEER Program as a supplemental registry site, increasing coverage of minority populations in SEER.

Since start-up the ANTR has had a cooperative relationship with the SEER Program in Seattle to identify AN patients who are treated there. There is now collaboration with the Alaska Cancer Registry whose first year of data collection began in 1996.

Since inception ANTR has made available detailed data specific to AN. Summary reports and publications have provided aggregate data in multiple reports including 15-, 25- and 30-year (1969-98) summaries. ANTR now currently provides an annual cancer databook update. In 1999, the ANTR also completed a survival analysis, "Alaska Native Cancer Survival Report," for patients diagnosed 1969-94, and more recently a mortality study for the years 1994-98. All reports are distributed statewide to medical providers, tribal health board members, and key lay and tribal personnel, as well as made available in peer-reviewed publications.

Web Site

Not Available

Information Management Services, Inc.

The SEER Program has used the services of a contracting firm to provide support in the areas of data management, data analysis, quality assurance, publication support, and systems engineering throughout the history of the Program. These services include support directly to the SEER Program participants, as well as support for ancillary research utilizing the SEER data or conducted by the SEER Program participants.

Information Management Services, Inc. (IMS), founded in 1973, is a corporation specializing in computer support services for biomedical research. IMS has provided computer support to the NCI SEER Program for the past 19 years under several contracts. Over this timeframe, the IMS role has expanded to include systems engineering, quality control, and additional areas within SEER special studies.

IMS processes the SEER data submissions, which requires data quality control checks, creation of standard analytic variables, and generation of several analytic databases for use by the NCI and outside researchers. IMS also supports the conversion of data between versions of coding systems such as the Extent of Disease (EOD) and International Classification of Diseases (IOD). The company provides statistical analysis support of SEER data, as well as associated databases such as the NCHS mortality data. This includes support for the annual publication of the NCI Cancer Statistics Review through the generation of the tables and graphs. In addition, IMS supports the production of the statistics for and the publication of SEER Monographs and journal articles and provides data management and analytic support for other projects utilizing the SEER data, such as the SEER-Medicare

linkage project and SEER special studies such as patterns of care for specific types of cancer.

IMS has designed and developed multiple systems for the SEER Program, including the Edits programs and Quality Assurance systems. IMS developed the SEER*Prep, SEER*Stat, and JoinPoint analysis packages for use with SEER data. The progressive maturation of the SEER systems has resulted in a series of high-powered tools for use by the SEER registries, NCI staff, and other researchers. SEER systems are recognized internationally and have been distributed to thousands of researchers. Currently, IMS is working on development of a unified SEER data management system that can be deployed to each of the SEER registries. This new system will be able to replace systems developed independently by individual registries, many of which are reaching the end of their natural lifespan. While facilitating enhanced registry function and providing standardized data elements and computer algorithms, the new SEER data management system will allow each registry to add additional data items and customize aspects of the data management system function.

IMS Key Personnel:

Project Managers: Janis Beach, AA, David Roney, BS, and David Annett, BS

Project Leaders: Marie Topor, BS (1982–1986), Lisa Kahle, BA (1986–1988), Don Green, BS (1988–1992), and Jennifer Stevens, BS (1992–present)

Lead software designers and developers: Scott Depuy, BS, and Steve Scoppa, BS

Early Years of SEER Quality Control

“It was in June 1953 when I took a part-time job in the cancer registry at the **University Hospital, University of Michigan**, where I was attending classes. I had never heard of a cancer registry before, but thought it might be interesting. Initially, I worked days as a part-time abstractor and coder in the registry. Sometimes I wondered how dependable the data were as we staged disease with only word-of-mouth guidelines. I didn’t know then that some day I would know the answer. With that mastered, I went on nights, working as a machine operator—putting the data on punch cards, printing reports on the tabulating machine, and putting out a professional-looking annual report. I loved the work, so when I graduated, I continued to work there nights on a part-time basis. I also found full-time employment, traveling around to medical record departments of hospitals installing medical record report systems.

“The University of Michigan was involved in a federal program called the **End Results (Survival) Group**, and it was my job to prepare the data for them...In July 1961, I joined the End Results Group at NIH under the direction of **Dr. Sidney Cutler**. In 1973, NIH decided to integrate the End Results Group and the Third National Cancer Survey into one program and call it **SEER** (Cancer Surveillance, Epidemiology, and End Results Reporting). Dr. Cutler was the first director of the SEER Program. In 1975, **Dr. John L. Young** became our Director, holding this position until 1988.

“The SEER Program was the beginning of a great adventure. Instead of a few individual hospital registries, it involved all hospitals in specific geographic areas from whole states like Connecticut and Utah to metropolitan areas like Detroit and the San Francisco Bay area. We had to quickly develop a **SEER Uniform Coding Manual** and began training the cancer registrars in this huge program. We also had to develop a methodology for quality control. Were they finding all the cases? Were the cases abstracted completely? Were they coded correctly? Nothing on such an ongoing gigantic scale had been done before. It was exciting being in the forefront of this new growth in cancer research along epidemiological lines—designing codes, forms, and methods for checking the data.

“My question back in the early 50s, as to how dependable the data were without any written staging guidelines, was finally answered. Not so good! A committee was set up to develop the **Extent of Disease** codes, comprised of **Drs. Ryan, Latourette, Platz, and Schmitz along with Mildred Weiss and myself** (the worker bees). We drew on all the earlier staging systems used by physicians, such as Duke’s staging for colon cancer and Jewitt’s for bladder cancer. This first step in the direction of uniformity in staging by registrars gave us the impetus for developing our staging code for all sites! It never stopped. There was the 13-digit Extent of Disease code, the 2-digit Summary Staging Guide code (1977), the 1983-87 4-digit codes. And so it goes—a never ending job that is still ongoing. I learned a lot, and I enjoyed every minute of it.

Self-Instructional Manuals for Registrars

“In the mid-1960s, both Dr. E. T. Krementz and I were consultants for the tumor registry at Charity Hospital, New Orleans, LA. We both spent a great deal of time helping there, but it was almost a losing battle, as the budget did not permit paying the employees very much, and except for a few stalwarts who stayed, the turnover was high. Most of the young people who were hired were the wives of residents. These were bright women, but it took most of them the better part of a year to learn all they had to know to be helpful as tumor registrar workers...It was facing these problems that the idea of a self-training program was conceived. At Tulane, we had worked with Dr. Virginia Zechert of Georgia on self-instructional programs...This was the time the Cancer, Heart Disease, and Stroke Program was developed by the Federal Government. With the help of the local group, a research grant was submitted to train people to work in tumor registries...The program was designed to take a high school graduate who could type and in ten weeks that were self-taught, the individual could learn on the job what had taken almost a year in the past...Recognizing the importance of this project, the National Cancer Group at NIH decided to take over the project so the results at the various Tumor Registries under the SEER Program would have compatible results. Fortunately they placed Evelyn Shambaugh in charge...Thus, trying to solve a local problem, a system was developed that now is used worldwide and has been a great help in evaluating treatment of various malignancies.”

—Robert F. Ryan, MD

The Next Generation of SEER Quality Improvement and Education

“I fell in love with my job almost thirty years ago. I was a hospital-based registrar in Wisconsin at a time when there was no ICD-O, no TNM, no standards for data collection, and no organized program of instruction—everything had to be learned on the job. But the concept of cancer registration appealed to me because I was learning something new every day. One day, a new, red book appeared on my desk: the International Classification of Diseases for Oncology. I wanted to be involved in developing a book like that.

“My first exposure to SEER was around 1980, when **Evelyn Shambaugh** made a presentation to our state registrars association as president of the National Tumor Registrars Association. Evelyn was very down-to-earth, despite the fact that she worked at the SEER Program at the National Cancer Institute. I knew about SEER from the SEER Self Instructional Manuals and the Summary Staging Guide, both impressive compilations of registry knowledge, and it was very nice meeting in person one of the authors of these vital references. She encouraged me to become active at the national level. I took her invitation to heart and became active in the NTRA. A short while later, I met **Constance Percy**, the author of that red ICD-O and later its 1992 second edition. Both women were serving their profession by being active in registrar associations.

“By the late 1980s, I was working for a computer software vendor, doing trainings and dealing with many state data requirements and conversion programs. One day in 1995, I got a call from a friend saying that SEER was looking for a new quality control staff person, and by the beginning

of the following year, I was a federal employee, a long way from that hospital in Wisconsin, following in the footsteps of **Evelyn, Connie, Jennifer Seiffert** and **Barbara Lyles**.

“I believe that I was meant to come to SEER, to be a resource to both hospital-based and central registry cancer data collectors. I helped to write the third edition of that red ICD-O book that had fascinated me so long ago. My colleagues **Carol Hahn Johnson, Margaret Adamo**, and I have taken advantage of cutting edge technology for the benefit of registrars who need many types of training. We have shifted from paper and printed books to electronic files. The next version of the SEER Program Code Manual will be software-based. The Extent of Disease coding system used by SEER is the foundation for the Collaborative Staging System that will be implemented in all registries in the U.S. in 2004. The Self-Instructional Manuals have evolved into a series of web-based training modules through the creativity and technical expertise of the Atlanta SEER registry staff.

“We have made a conscious shift from retrospective quality control to continuous quality improvement. We have emphasized consistency in coding and data analysis through education of registrars. Our data quality studies are web- or software-based, and through the data quality profiles, the SEER regions have become more cohesive in the way they collect data.

“I’ve been in the registry business almost thirty years, and I am still learning something new every day.”

—**April Fritz, BA, RHIT, CTR**
Quality Control Manager, SEER, NCI

Lifetime Achievement Awards

The following individuals have made remarkable and unique contributions to the SEER Program. Their vision, persistence, and high standards have helped to make SEER the success it is today.

Charles R. Key, MD, PhD

Charles Key has been a principal investigator for the SEER Program since its inception. In 1969, he joined the University of New Mexico (UNM) School of Medicine, Department of Pathology. Dr. Key became Medical Director of the New Mexico Tumor Registry (NMTR) as it was expanding from a pilot program to a statewide population-based cancer registry. He also is a Professor both of Pathology and of Family, Community, and Emergency Medicine at UNM, and is Co-Director of the Epidemiology and Cancer Control Program at the UNM Cancer Research and Treatment Center (CRTC). Dr. Key was Acting Chair of the UNM Department of Pathology from 1992–1994 and Interim Director of the UNM Cancer Research and Treatment Center from 1995–1996.

Dr. Key earned both his MD and PhD (Pathology) from the University of Oklahoma. He has been a member of the Board of Directors (now called the Leadership Council) of the state and local American Cancer Society (ACS) for more than 30 years. Dr. Key received the ACS New Mexico Division's National Award, the ACS New Mexico Harold Runnels Memorial Award, the New Mexico Department of Health Community Health Promotion Award, the UNM Board of Regents' Meritorious Service Medal, and the ACS New Mexico Lifetime Achievement Award.

Dr. Key was a pioneer in documenting striking differences in cancer incidence and mortality among New Mexico's American Indian, Hispanic, and non-Hispanic white populations. His research has focused on using NMTR data in descriptive studies of patterns of cancer incidence, extent of disease at diagnosis, choice of treatment, and outcomes. Dr. Key participated in initial discussions that led to the establishment of the SEER Program and has been an important influence in the development of cancer surveillance and control efforts among Southwest American Indians and Alaska Natives. He currently heads numerous research projects in pathology, oncology, cancer control and smoking cessation, skin cancer in New Mexico, cancer incidence in American Indians and Hispanics, genetic research, familial cancers in multi-ethnic populations, and breast and cervical cancer surveillance.

John L. Young, DrPH, CTR

John Young is a world-renowned expert on cancer reporting systems. He has more than 35 years experience in both the public and private sectors in the areas of national cancer databases and epidemiological research and was the Director of NCI's SEER Program from 1975 to 1988. Dr. Young has traveled the globe as a consultant to the World Health Organization, the International Agency for Research on Cancer (IARC), the International

Union Against Cancer, and the governments of Canada, Cyprus, Egypt, India, Israel, Japan, Jordan, Palestine, Saudi Arabia, and Turkey. His vast expertise has enabled many countries to establish central cancer reporting systems.

In 1989, Dr. Young became Chief of the Cancer Surveillance Section of the California Department of Health Services. He was responsible for management and operation of the California Cancer Reporting System, comprised of 10 regional cancer registries and a central California Cancer Registry. In 1996, Dr. Young joined the staff of the North American Association of Central Cancer Registries (NAACCR) as Director of Cancer Surveillance and Control. Since 1998, he has been Professor of Epidemiology at the Rollins School of Public Health, Emory University, and Director of the Georgia Center for Cancer Statistics. This Center manages the Metropolitan Atlanta and Rural Georgia SEER Program.

Dr. Young holds a BA degree from Baylor University, and both an MPH degree in biostatistics and a DrPH degree in biostatistics and epidemiology from the University of North Carolina at Chapel Hill. Interestingly, he also is a Certified Tumor Registrar. Dr. Young is widely published in the areas of cancer epidemiology and has edited seven major monographs published by NCI and the International Agency for Research on Cancer (IARC). He has been active in the International Association of Cancer Registries (IACR) and is a past president of both the IACR and the NAACCR. Among his many honors and awards is the Calum S. Muir Memorial Award from the NAACCR, its premier award named for the pioneer in international cancer registration.

Dr. Young has been an inspirational mentor to many in the SEER Program and a vocal champion for its continued funding and expansion. On the occasion of SEER's 20th anniversary, he advised the assembly on three battles that lay ahead. One was the battle of complacency after having such a high level of success; the second was the battle of the budget, which will always be a challenge. Then he said, "The third battle will be that of facing with courage those who will wish to shoot the messenger. Our data will not

always show the progress that we hope and strive to see. There will be those who wish to mold the data to fulfill their own agenda and will threaten our efforts with resistance. Truth, however, must remain truth regardless of how unpopular or politically damning it might be."

Lynn A. Gloeckler Ries, MS

Lynn Ries has been a health statistician in the SEER Program at NCI for 31 years. She is a native of Washington, D.C. who lived in the state of Washington while attending graduate school and simultaneously worked on detail from NCI at the Fred Hutchinson Cancer Research Center. Her long years with SEER has given her extensive experience in the analysis and interpretation of the SEER database and an in-depth knowledge of the data content and coding rules for the SEER Program. Ms. Ries offers insights that are unique and valuable to the overall understanding of the SEER mission.

Ms. Ries began work as a mathematician in the Biometry Branch at NCI in 1972. During that time, she provided programming and data analysis support for the End Results Group, a precursor to the SEER Program. In 1974, Ms. Ries requested an assignment at Fred Hutchinson while earning an M.S. in Biomathematics at the University of Washington. As Ms. Ries states, "It was an excellent training opportunity to learn statistics and to learn how a cancer registry operates." Shortly after her return to Bethesda in 1976, she joined the newly reorganized Demographic Analysis Section. She has been involved with the SEER Program in many ways, "from Project Officer to writing coding manuals to analysis of data."

Ms. Ries is a member of several North American Association of Central Cancer Registries' (NAACCR) committees and subcommittees, and is a member of the Benign Brain Tumor Committee of the National Coordinating Council for Cancer Surveillance, as well as a member of the Collaborative Stage Working Group. She collaborates annually with the American Cancer Society, the Centers for Disease Control and Prevention, and the NAACCR on the Annual Report to the Nation on the Status of Cancer. The sixth report was released in September 2003.

Ms. Ries' many honors and awards include a number of NIH Awards of Merit, NIH Director's Awards, the SEER 20th Anniversary Award for Contributions to the SEER Program, and a NAACCR Distinguished Service Award. Her research interests include childhood cancer, prognostic factors and cancer survival, time trends in incidence and mortality rates, and clinical relevance of conditional survival rates. She has authored over 100 publications on these and other topics related to cancer surveillance.

John T. Flannery, BA

John (Jack) Flannery, who has a BA in Business Administration from the University of Connecticut, began his work with the Connecticut Tumor Registry (CTR) in 1962 as a Research Analyst. By 1977, he had risen to be Director of the CTR and eventually, in 1982, the co-principal investigator for the Connecticut SEER contract. Mr. Flannery retired in 1997 after 35 years of service with the CTR and the Connecticut Department of Public Health.

Over the years, Mr. Flannery's responsibilities varied in the CTR, and the tools available to his team changed dramatically as well. One of his early responsibilities was submission of data to the End Results Group (ERG) of NCI, a precursor to the current SEER Program. Key punch cards (180,000) were used to code CTR data, and the editing process required to convert the CTR to NCI format, update the data, then box and send the information to NCI required two months of the staff's time.

During his early years with the CTR, Connecticut was one of the few areas in the United States that recorded population-based cancer incidence data, and the only area with data as far back as 1935. Frequent demand for the information motivated the CTR staff to obtain and classify complete and accurate cancer data and to submit timely reports. Marketing the CTR also was a major responsibility for Mr. Flannery, and he spent time developing good working relationships with Yale University, the University of Connecticut, the American Cancer Society, and the Connecticut media, thus assuring a "strong resource of external support which was frequently called upon," according to Mr. Flannery.

Mr. Flannery acknowledges the dedicated CTR staff who were "motivated by the fact that they could see the results of their efforts reflected in the many special studies and the publications of cancer data of which the CTR was a part."

Calvin Zippin, ScD

Calvin Zippin had dreamed of going to medical school but graduated with a degree in mathematics and science from the New York State College for Teachers (now SUNY Albany). He became a research assistant at the Sterling-Winthrop Research Institute, an affiliate of a large international pharmaceutical company. His work there on correlations between biological activity and the chemical structure of synthesized chemical compounds, laboratory experiments, and statistical analyses led to several publications as well as a scholarship and research assistantship in biostatistics at Johns Hopkins University, where he took many medical courses and earned his ScD.

Dr. Zippin's next destination was the University of California (UC), where he's been for 50 years—first in Berkeley at the School of Public Health and then at the School of Medicine in San Francisco. In 1955, Dr. Zippin was named head of the cancer registry in the Cancer Research Institute (CRI) at UC-San Francisco and appointed to the Department of Preventive Medicine. With this appointment, he achieved his childhood dream of entering the field of medicine.

The CRI was invited to contribute cancer end results data to the Third National Cancer Conference held in Detroit in 1956. This led to the Institute's participation in the SEER Program. The CRI established a cancer registry training program in the early 1960s and, eventually, provided quality control and training services to the SEER Program, in addition to conducting feasibility studies and other research, with Dr. Zippin serving as principal investigator for the SEER Quality Control Unit.

Joanne Harris, CTR

Joanne Harris, Certified Tumor Registrar (CTR) and Chief of the Cancer Surveillance Unit of the Metropolitan Detroit Cancer Surveillance System (MDCSS), began her cancer-fighting career 40 years ago as a clerk at the Michigan Cancer Foundation (now Karmanos Cancer Institute). Today, she manages the day-to-day operations of this SEER Program in Detroit.

Ms. Harris has been with MDCSS since it began in 1973. An abstractor at the time, she was promoted to Supervisor of Abstracting in 1975. Further promotions included to Manager of Data Collection in 1979 and to Associate Director, Cancer Surveillance Section in 1982. She received her CTR certification in 1983 and was promoted to her current position in 1984.

Ms. Harris finds her work fulfilling and challenging and speaks highly of her colleagues, both locally and nationally.

Kathleen M. McKeen

Kathleen McKeen's career in cancer surveillance spans 44 years at the University of Iowa. The success of the Iowa program is directly related to her expertise, dedication, and commitment to the Cancer Registry profession and to the state, national, and international surveillance communities. In 2001, Ms. McKeen was recognized for this dedication when she received the Calum S. Muir Memorial Award presented by the North American Association of Central Cancer Registries, its premier award named for the pioneer in international cancer registration.

Ms. McKeen, associated with the State Health Registry of Iowa since 1978, has been its Registry Director since 1982. As Registry Director, she coordinates the activities of nearly 50 staff, and interacts with local, state, and national agencies to assure proper assembly and dissemination of cancer

registry data. Prior to joining the program in 1978, Ms. McKeen directed the University of Iowa Hospitals and Clinics, Cancer Registry. She began her career at the University Hospital Registry in 1959, which was then a member of the End Results Program of the Biometry Branch at NCI, with NCI's Third National Cancer Survey Program which was a precursor to the SEER Program.

Ms. McKeen credits the late Dr. Howard Latourette for encouraging her to pursue work in the cancer registry field. She also acknowledges Drs. Charles Platz, Peter Isacson, and John Young for offering their knowledge and support that aided in the advancement of her career in the cancer registry field.

Rosemary Dibble, CTR

Rosemary Dibble, Certified Tumor Registrar (CTR) and Director of Operations for the Utah Cancer Registry (UCR), first learned of the UCR in 1970 while working the night shift as a statistical medical records clerk at LDS Hospital in Salt Lake City. The mother of three, she worked at night so she could raise her children in the daytime while continuing her career in medical records.

Charles Smart, MD, founder of the UCR, worked alongside Ms. Dibble completing his records and invited her to join the fledgling UCR staff. Her initial duties included identifying cases, abstracting at nonregistrar hospitals and laboratories in Utah, coding and merging cancer cases, publishing the first Cancer in Utah report, establishing new hospital registries, and more. Little staff and funding were available for these activities.

In 1973, the UCR received funding from the SEER Program. These funds enabled Ms. Dibble and UCR staff to initiate quality control activities at hospitals and laboratories, attend SEER coding and educational workshops, conduct statewide seminars for hospital registrars, and share knowledge and procedures with other SEER-funded registries.

As her 30-plus year career progressed, Ms. Dibble became involved in the National Cancer Registrars Association, the American College of Surgeons, and the North American Association of Central Cancer Registries. She has contributed significantly to the development of quality statewide and national databases, certifications for registrars and registries, educational opportunities, cutting-edge software and analysis programs, and more. She sees a promising future for cancer registries and says the next step is to go “global, as our progressive data are utilized to help fight cancer worldwide.”

Evelyn M. Shambaugh, MA, CTR

Ms. Evelyn Shambaugh was the Head of Quality Control for SEER’s Cancer Statistics Branch from 1989–1999 for SEER’s Demographic Analysis Section from 1977–1989. Ms. Shambaugh received her MA in statistics at the University of Maryland. She became a Certified Tumor Registrar in 1990. Ms. Shambaugh has led several committees for the National Cancer Registrars Association. She also chaired the (North) American Association of Cancer Registries Committee for a Uniform Data Standard for more than 10 years.

Ms. Shambaugh received several awards in recognition and appreciation of Sustained High Quality Work Performance over her four decades of service at the NCI. She also received an NIH Director’s Award in 1991 and the National Cancer Registries Association Literary Award in 1995. Ms. Shambaugh has authored or co-authored 23 publications, including the SEER Self-Instructional Manuals for Tumor Registrars.

SEER Leadership Recognition

The following individuals are recognized for their significant contributions to the SEER Program, either in its operations, use of data, or applications research. Their remarkable dedication has helped to bring SEER to the leading edge of data management, usage, and statistical reporting.

Scientific and Administrative

Edward J. Sondik, PhD

Edward Sondik serves as Director for the National Center for Health Statistics (NCHS), one of the Centers for Disease Control and Prevention. NCHS is the principal health statistics agency of the United States, with a wide-ranging program of research and analysis in health and vital statistics, epidemiology, and related health and statistical sciences. NCHS works cooperatively with the SEER Program by providing data needed for SEER reporting and research evaluation. Dr. Sondik directs a wide-ranging program of vital statistics and survey research to monitor the health of Americans, to anticipate and plan for future data needs and to develop the technologies and analytic tools necessary to meet the Nation's health statistics needs. He serves on the Interagency Committee on Statistical Policy, whose membership consists of the leaders of the designated federal statistical agencies, and is Senior Advisor to the Secretary of Health and Human Services (HHS) on Health Statistics, providing technical and policy advice on statistical and health information issues. In this capacity, he also serves on the HHS Data Council, the body that reviews DHHS data policy and related issues. Dr. Sondik received BS and MS degrees in electrical engineering from the University of Connecticut and a PhD in electrical engineering from Stanford University. From 1971 to 1976, he was on the faculty of the Department of Engineering-Economic Systems at Stanford University. From 1976 to 1982,

he was on the staff of the National Heart, Lung, and Blood Institute of the National Institutes of Health. In 1982 he joined NCI and held several posts from Chief of the Biometrics and Operations Research Branch to Deputy Director of the Division of Cancer Prevention and Control, as well as Acting Director, NCI.

Barbara K. Rimer, DrPH

Barbara Rimer is Deputy Director for Population Sciences at the Lineberger Cancer Center, and a Professor in the Department of Health Behavior and Health Education at the University of North Carolina (UNC). Before coming to UNC, she was Director of the Division of Cancer Control and Population Sciences at NCI. Previously, Dr. Rimer was Acting Deputy Director of the Duke Comprehensive Cancer Center and Director of Population Science for Behavioral Research at Fox Chase Cancer Center. Dr. Rimer received her DrPH in Health Education at the Johns Hopkins School of Hygiene and Public Health. She also has served on the IOM Committee on Health Communication for Diverse Populations and chaired the National Cancer Advisory Board. She has received several awards including the American Cancer Society Distinguished Service Award, NIH Director's Award, and the DHHS Secretary's Award for Distinguished Service. Dr. Rimer is a member of several journal editorial boards, and she has authored and co-authored more than 200 publications, including four books, four health education manuals, and 40 book chapters.

Dr. Rimer is known nationally for her research on cancer risk communication, cancer control, and breast cancer screening. Much of her current research focuses on developing and evaluating cancer prevention and screening interventions, particularly interventions that aid patient decisionmaking.

Joseph F. Fraumeni, Jr., MD

Joseph (Joe) Fraumeni, Director of the Division of Cancer Epidemiology and Genetics (DCEG) at NCI, is known nationally for his research on environmental and genetic determinants of cancer. Dr. Fraumeni joined NCI in 1962 and became Head of the Ecology Studies Section in 1966, Chief of the Environmental Epidemiology Branch in 1975, and Director of the Epidemiology and Biostatistics Program in 1979. Dr. Fraumeni received an MD at Duke University and an MSc in epidemiology at Harvard School of Public Health. He completed a medical residency at Johns Hopkins Hospital and Memorial Sloan-Kettering Cancer Center. Dr. Fraumeni has received several awards, including the Lilienfeld Award from the American College of Epidemiology, the John Snow Award from the American Public Health Association, the James D. Bruce Award from the American College of Physicians, the Dr. Nathan Davis Award from the American Medical Association, and the Charles S. Mott Prize from the General Motors Cancer Research Foundation. Dr. Fraumeni is an elected member of the National Academy of Sciences and the Institute of Medicine. He is an Adjunct Professor of Epidemiology at the Harvard School of Public Health, the Uniformed Services University of the Health Sciences, and George Washington University School of Public Health and Health Services. Dr. Fraumeni has authored and co-authored more than 300 publications.

Peter Greenwald, MD, DrPH

Peter Greenwald is the Director of the Division of Cancer Prevention at NCI. Under his direction, research on cancer prevention and cancer control plus the application of technology and disease surveillance are combined in pursuit of a significant reduction in cancer incidence, morbidity, and mortality. Dr. Greenwald received his MD degree from SUNY College of Medicine and earned his DrPH degree at Harvard School of Public Health, where he focused on cancer epidemiology. He is certified in both Internal and Preventive Medicine. He arrived at NCI from New York State in 1981, having run the state's epidemiology, cancer control, and cancer registry program.

Among his responsibilities are the development and conduct of cancer prevention clinical trials, which focus on the areas of diet and cancer and chemoprevention. His research work relates primarily to human cancer prevention trials, cancer epidemiology, and cancer control. He is the author of more than 200 scientific papers.

Larry G. Kessler, ScD

In 2002, Larry Kessler was appointed Director of the Office of Science and Technology at the FDA's Center for Devices and Radiological Health (CDRH), where he directs the efforts of the laboratories of CDRH and the Standards Coordination Program. The Office of Science and Technology plays a crucial role in identifying key scientific questions and solutions concerning device safety and effectiveness. In June 1995, Dr. Kessler joined the FDA's CDRH as the Director of the Office of Surveillance and Biometrics. Under his leadership, the Office implemented the Medical Device Reporting

(MDR) regulation for user reporting of adverse events, developed a program for reducing the burden on industry for repetitive reporting, and completed a pilot program for a sentinel system for ease of reporting of adverse events. From 1984 to June 1995, Dr. Kessler served as chief of NCI's Applied Research Branch, an interdisciplinary research unit within NCI's Surveillance Program that performed applied research on modeling and statistics for understanding cancer rates and trends, economics and health services research on cancer prevention and control, and applied nutrition research and surveillance. He has published more than 100 peer-reviewed journal articles, as well as numerous book chapters and government reports.

Dr. Kessler's research has concentrated on applications of quantitative methods and health services research to problems in surveillance and public health. He received his Doctor of Science (ScD) from the Johns Hopkins University, School of Hygiene and Public Health in 1978.

Earl Pollack, ScD

Earl Pollack was Chief of the Biometry Branch at the National Cancer Institute (NCI) from 1977 to 1985. He has authored and co-authored several publications, including several papers based on SEER data. Dr. Pollack co-authored the first SEER publication: *NCI Monograph 57, SEER Program Incidence and Mortality, 1973–1977*, which launched routine reporting and use of the database.

SEER Alumni

G. Marie Swanson, PhD, MPH

Marie Swanson is a nationally recognized epidemiologist who has been involved in cancer research and surveillance for over 25 years. Since 2001, she has been dean of the Mel and Enid Zuckerman Arizona College of Public Health and a professor of epidemiology and biostatistics at that school. Prior to that appointment, she was the first director

of the Cancer Center at Michigan State University (MSU), one of the few centers in the United States that focuses on cancer prevention, early detection, treatment, and supportive care to rural populations. The University of Arizona has noted that "Under her leadership, the Cancer Center has brought multifaceted educational outreach to more than 40 counties across Michigan, has developed a nationally recognized program in palliative and end-of-life care and has established strong, interdisciplinary research programs." Dr. Swanson received her doctorate in sociology from Wayne State University in 1974 and a master's in public health in epidemiology from the Johns Hopkins University in 1983. Dr. Swanson's many honors and awards have included the Lifetime Achievement Award from the Sisters' Network, a national African American women's breast cancer survivor organization, and a Distinguished Service Award from the American College of Epidemiology.

The author of more than 120 publications in peer-reviewed journals, Dr. Swanson has conducted research on occupational cancer risks, particularly ethnic and racial diversity in cancer risk, and is a noted expert on breast cancer. She has taken active roles in the work of boards and associations, including the American College of Epidemiology, the International Association of Cancer Registries, and local and national boards of the American Cancer Society.

David B. Thomas MD, DrPH

David Thomas received his medical degree from the University of Washington in 1963 and his DrPH from Johns Hopkins University in 1972. He has been associated with the SEER Program since 1975, when he began work at the Fred Hutchinson Cancer Research Center in Seattle. He served as principal investigator for the SEER contract and head of the Epidemiology Program at the Fred Hutchinson Center for many years. Dr. Thomas has worked extensively and internationally in the areas of cancer epidemiology (including breast and cervical cancer),

tobacco-related cancers, steroid contraceptives, and cancer screening. From 1978 to 1992, for example, he coordinated a collaborative study for the World Health Organization in 11 countries on five continents. The study assessed the effects of steroid contraceptives and other factors on risks of gynecological and liver cancers.

In 1988, Dr. Thomas began a randomized trial regarding breast self-examination in Shanghai, China. He also conducted a study in Seattle that showed that radiographic densities and certain types of calcifications on mammograms in women under age 50 can be used to identify women at increased risk of subsequent breast cancer. In 2002, Dr. Thomas published a commentary that argued strongly for selective rather than universal cancer registration in the United States.

Donald F. Austin, MD, MPH

Dr. Donald (Don) F. Austin is the Associate Director for Cancer Prevention and Control at the Oregon Health Sciences University (OHSU) Cancer Institute. He also is Professor of Public Health and Preventive Medicine at OHSU. In the past, Dr. Austin has served as a Commissioned Cancer Control Officer for the Kentucky State Department of Health, a Medical Epidemiologist for the California Department of Health, and a Medical Officer at the Centers for Disease Control and Prevention. He also was Chief of the California Tumor Registry from 1974–1988 where he served as a SEER principal investigator for 12 years. Dr. Austin received his MD from the OHSU Medical School. He later received an MS in Microbiology from OHSU and an MPH in Epidemiology from the University of California at Berkeley, both in the same year. Dr. Austin is Chair of the Tobacco Free Coalition of Oregon. He also served on the American Cancer Society's Board of Directors from 1994–1997 and was President of the North American Association of Central Cancer Registries from 1988–1991. In recent years, Dr. Austin has focused on teaching and fostering the development of young researchers and public health

professionals. He also has undertaken some small research projects examining quality of care (mostly cancer related) and cancer epidemiology. Dr. Austin is an activist for public policy development in Oregon and is involved in forming collaborations between OHSU and the Oregon State Health Department, including the Breast and Cervical Cancer Program and the Oregon State Cancer Registry.

Constance L. Percy, MSPH

Ms. Constance (Connie) L. Percy, an internationally known expert in cancer nomenclature and classification, worked for NCI for 30 years, where the SEER cancer registries became her focus. Ms. Percy received her Masters of Science in Public Health from Columbia University. She was active in founding the International Association of Cancer Registries (IACR). She has received several awards and honors, including the most distinguished member of the National Cancer Registry Association award in 1994, the North American Association of Central Cancer Registries' Calum S. Muir Memorial award for outstanding contribution in the field of cancer registration in 1997, and two Public Health Service awards for superior service. She has authored or co-authored more than 40 papers on topics such as cancer registration, classification and nomenclature of neoplasm, accuracy of death certificates, and medical nomenclature. Ms. Percy contributed to the development of the Manual of Tumor Nomenclature and Coding, the first building block for cancer nomenclature; and the first, second and third editions of International Classification of Diseases for Oncology (ICD-O).

Linda K. Weiss, PhD

From 1991 to 1996, Dr. Weiss served as Assistant Director of the Epidemiology Division and Co-Investigator of Detroit SEER at the Karmanos Cancer Institute (then the Michigan Cancer Foundation), becoming a Wayne State University faculty member in 1995. In 1996, she assumed

positions of Director and principal investigator of the SEER Program and Co-Director of the Epidemiology Program. Her research during this time period focused on breast and ovarian cancer, and primarily on a long-term multi-site epidemiological study of exogenous hormone use and risk of breast cancer; several publications have been generated from this latter study. Dr. Weiss received her MA in anthropology and her PhD in biological anthropology from Wayne State. In 2000, she joined the NCI, where she is currently Chief of the Cancer Centers Branch.

Charles E. Platz, MD

For more than two decades, the Iowa Cancer Registry has consulted Charles Platz on questions about pathology and quality assurance of pathology data. Dr. Platz is Professor Emeritus of Surgical Pathology at the University of Iowa College of Medicine. Before coming to the University of Iowa, he was an Associate Professor of Pathology at the University of Chicago. Dr. Platz received his MD at the University of Chicago, where he also completed his pathology residency. He has served on several advisory groups and committees including the National Cancer Institute's Specimen Resources Committee since 2000. Dr. Platz also was a member of the Breast Cancer Surveillance Consortium Expansion Review Panel, the College of American Pathologists Bladder Cancer Task Force, the SEER Research Advisory Committee, the SEER Medical Advisory Group, and the North American Association of Central Cancer Registries "ASK NAACCR" advisory service. He has been an invited lecturer at numerous meetings, including multiple SEER workshops. Dr. Platz also has authored or co-authored more than 50 publications.

Dr. Platz's current research interest is histopathology of neoplastic diseases and its clinical and/or epidemiologic importance. Some examples of his ongoing research include: (1) a study of discrepancies between registry data on bladder cancer and pathologic evaluation results, and (2) a study of how clinical testing is affecting diagnosis and reported incidence of prostate cancer.

Clark W. Heath, Jr., MD

Clark Heath is a former Vice President for Epidemiology at the American Cancer Society (ACS) and the first director of what has become the (Metropolitan) Atlanta SEER Registry. He has authored and co-authored many publications based on SEER data, including a number of studies of environmental and hormonal factors and their influence on cancer. Dr. Heath has expertise in the areas of cancer epidemiology and geographic cancer clusters. He was active in the early years of the National Coordinating Council for Cancer Surveillance.

Dolores Mary Bell, CTR

For 38 years, Dolores Bell served the Karmanos Institute and its predecessor, the Michigan Cancer Foundation. She worked in the division of epidemiology, the Metropolitan Detroit Cancer Surveillance System, and the National Cancer Institute's SEER registry. She was a certified tumor registrar, passing the exam in 1983 when it was first offered, and held the positions of supervisor of coding, associate director of registry, manager of editing and follow-up units. Her supervisor Joanne Harris noted, "Dolores was a devout Christian and dedicated worker in her church, among them being the Workers of Mary and St. Vincent de Paul Society at St. Alexander's in Farmington. She was committed to quality, well respected by the entire staff, dedicated, very giving, patient, understanding, and had impeccable work standards. She was a mentor to many and a wonderful friend."

Dolores Mary Bell passed away peacefully at her home on October 10, 2001, following an illness. She is survived by seven children, 14 grandchildren, and two great grandchildren.

Friends and Colleagues

Charles Smart, MD

Charles Smart chose surgery as a viable option while at Temple University Medical School and ultimately became a prominent surgeon in Salt Lake City. In 1961, while a research fellow at UCLA, he participated in the Cancer Chemotherapy Drug Evaluation Program, funded by the Cancer Chemotherapy National Service Center. This center was a stimulus for the development of the End Results Group, forerunner of the SEER Program. In 1965, he became Cancer Coordinator at UCLA and as director of the cancer registry, participated in the development of computer programs to analyze end results. In 1966, Dr. Smart decided to use those computer programs for measurement and analysis of the magnitude of the cancer problem in Utah and contiguous parts of the surrounding states, and the Utah Cancer Registry was founded. This registry became population-based in 1970 and was accepted in 1973 as one of the original registries in the SEER Program. It became the source of many studies, including linkage with the genealogical files of the Mormon Church for genetic research. During his tenure as chief of the cancer division and assistant director of the American College of Surgeons (ACoS) from 1977 to 1982, ACoS popularized the computerization of hospital cancer registries, which greatly enhanced the SEER Program in gathering cases from the community. Dr. Smart then joined NCI as Chief of the Early Detection Branch and found SEER data an invaluable source for many scientific papers showing the relationship of early stage invasive disease and longer survival.

Throughout more than fifty years involved in medical study and care, Dr. Smart considers that his “greatest contribution to the quality of life and care of cancer patients has been in the area of prevention and early detection based largely upon SEER and other registry data.”

Pelayo Correa, MD

Pelayo Correa, a world-renowned gastric cancer researcher, is a Boyd Professor in the Department of Pathology at the Louisiana State University (LSU) Health Sciences Center and Deputy Director of LSU’s Stanley S. Scott Cancer Center. He is a founding member of the SEER Program’s Louisiana Tumor Registry (LTR), and has provided scientific guidance to the LTR for more than 20 years. Dr. Correa was born and educated in Columbia, South America, and graduated from the Medical School of the Universidad de Antioquia. He completed his pathology training at Emory University in Atlanta and at the Armed Forces Institute of Pathology in Washington, DC. After returning to Columbia, Dr. Correa helped to establish the Medical School at the Universidad del Valle in Cali. In 1962, Dr. Correa created the Cali Tumor Registry with a small grant from the Anna Fuller Fund and help from his mentor, NCI’s Dr. Bill Haenszel. The Cali Registry was unique in Latin America and provided data for the International Association of Cancer Registry publication, *Cancer Incidence in Five Continents*. Dr. Correa moved to the United States in 1970 and was a visiting scientist at NCI from 1970 to 1973 before becoming a professor at the LSU Medical Center.

Dr. Correa has published hundreds of scientific papers on cancer epidemiology and was a pioneer in recognizing the effects of the *Helicobacter pylori* inflammatory process in carcinogenesis. He has earned many honors and recognitions throughout his career, including having received a Presidential Appointment to the NCI’s National Cancer Advisory Board, on which he served from 1992 to 1998.

Gilbert H. Friedell, MD

Gilbert Friedell, a graduate of the University of Minnesota Medical School in 1949, received his pathology training in Boston, MA. He was the first director of the Markey Cancer Center at the University of Kentucky, serving from 1983 until 1990. He then became the Director for Cancer Control at the Center. During his tenure at the Center, he served as a founding director of the Kentucky Cancer Registry (1990–2000), the co-director of the Kentucky Cancer Program (1983–1998), and the principal investigator of the Region 9 Cancer Information Service for Kentucky, Tennessee, and Arkansas (1993–1998). Dr. Friedell is a nationally recognized leader in development of community-based cancer control programs. In 1998, he received the National Humanitarian Award of the American Cancer Society and the Susan G. Komen Foundation Individual Community Service Award. In 1996, he received an award for outstanding contributions in the field of cancer registration from the North American Association of Central Cancer Registries, and was presented with a certificate of appreciation at a United States Congressional briefing for his support of the creation of the CDC's National Program of Cancer Registries, a complementary registry program to the SEER Program.

Dr. Friedell officially retired in 1998, but he continues his work in cancer control. He is a primary or contributing author on more than 200 scientific papers. Literacy issues have been a particular concern of his in dealing with the underserved population of Appalachia.

Ilona Kay Gebhard, BA, CTR

As Kay Gebhard states, “Working in cancer registries selected me.” While studying for a Masters in Art History, she worked part-time for an environmental chemist in the Preventive Medicine Department at the University of Iowa and accepted a position with the Iowa Tumor Registry when he left the university. Ms. Gebhard “learned about cancer registries from the ground up.” She became interested in cancer

surveillance and was influenced by Drs. Charles Platz and Chuck Lynch of the Iowa Tumor Registry to examine the pathology of cancer and the need to collect consistent and accurate data, leading to her full career as a quality control (QC) specialist for registry data. Ms. Gebhard's next move was to the University of California, San Francisco (UCSF), giving her the opportunity to work more closely with SEER and to educate those collecting and coding data about the importance of quality control in assuring data's usefulness for research. During this time, cancer surveillance became personal because of her own diagnosis of breast cancer, and she became involved with translational studies and an active patient advocate group. She provided some training for this group and did a presentation on SEER registries and QC studies.

Ms. Gebhard then moved to the New Mexico Tumor Registry to apply her QC expertise for two years before finally moving to the North American Association of Central Cancer Registries (NAACCR), where she is currently Program Manager for Education and Training. “I felt it was a challenge to bring my experience and knowledge to a larger group but still maintain an affiliation with SEER.” She maintains a close relationship with key SEER staff to assure she is up-to-date on current QC results, ensuring her training complies with current standards. “Working with NAACCR has given me the chance to broaden my knowledge and make a contribution to good cancer surveillance practices.”

Carol Kruchko

Carol Kruchko is the President of the Central Brain Tumor Registry of the United States (CBTRUS). The CBTRUS was incorporated in 1992 following a two-year feasibility study of a central registry for all brain tumor cases. Until that time, standard data reporting in the U.S. had been limited to malignant cases only. Benign brain tumors, however, can impose the same costs to society. CBTRUS began with three collaborating registries in Utah, Massachusetts, and Connecticut. It has grown in size and, with the passage of the Benign Brain Tumor Registry

Act, collection of data on benign brain tumors has become part of routine cancer surveillance.

Ms. Kruchko notes, “I became fascinated with the inner workings and the magnitude of collecting cancer data. Figuring out where CBTRUS could fit in was like fitting in another piece of an ever-evolving puzzle. CBTRUS data analyses provide aggregate information of population-based data on the incidence of all primary brain and central nervous system tumors in the United States.” CBTRUS complements current cancer registration in the U.S. and adds to collection efforts by making brain tumor data more meaningful (easily used and understood) to clinicians, researchers and patients through its reports and manuscripts. Currently, CBTRUS’ role has expanded to include helping the member organizations of the National Coordinating Council for Cancer Surveillance with the implementation of the collection of nonmalignant (benign) brain tumors mandated to start in 2004.

SEER Leaders

Dee W. West, PhD

Dee West is the Acting Executive Director of and Chief Scientific Officer at the Northern California Cancer Center (NCCC). He also is consultant/ advisor to the U.S. Agency for International Development Mideast Cancer Consortium, the Lucile Markey Cancer Center Cancer Control Program, the Population Sciences Program at the University of California at San Francisco Cancer Center, and the National Cancer Institute. Before coming to the NCCC, Dr. West was a Director and principal investigator at the Utah Cancer Registry and an Associate Professor in the Department of Family and Community Medicine at the University of Utah Medical Center. Dr. West received his PhD in Medical Sociology/Epidemiology from the State University of New York at Buffalo. He currently serves on the Steering Committee for the State of California Cancer Control Plan and chairs the National Coordinating Council for Cancer Surveillance. Dr. West has chaired the Evaluation and Selection Committee for Establishing Regional Cancer Registries in California and the Steering Committee for the Cooperative Family Registry for Breast Cancer Studies. He is a past President of the North American Association of Central Cancer Registries, and has received the prestigious Calum S. Muir Memorial Award. Dr. West has authored or co-authored more than 80 publications since 1975.

Dr. West has conducted research focusing on a wide range of cancer surveillance, control, treatment, and quality-of-life issues. He is principal investigator for the SEER study at the NCCC and for Northern California Cooperative Family Registry. Dr. West also is a co-investigator for several SEER Special Studies.

Laurence N. Kolonel, MD, PhD

Laurence (Larry) Kolonel is Deputy Director of the Cancer Research Center of Hawaii and Director of its Cancer Etiology Program. Since 1993, Dr. Kolonel has been principal investigator of the SEER Program-funded Multiethnic Cohort Study,

which evaluates the role of diet in various cancers in the multiethnic populations of Hawaii and Los Angeles. Dr. Kolonel received his MD from Harvard University and his MPH and PhD (Epidemiology) from the University of California at Berkeley. He is Board Certified in General Preventive Medicine and is a Professor at the University of Hawaii's School of Public Health. He also has been a Visiting Professor of Family, Community, and Preventative Medicine at Stanford University. Dr. Kolonel is Associate Editor of several journals, including *Cancer Research*, *Nutrition and Cancer*, and *Cancer Epidemiology Biomarkers and Prevention*. He has authored and co-authored more than 200 publications.

Dr. Kolonel is known internationally for his research in nutritional epidemiology and cancer. His research interests have focused on understanding the striking variations in cancer incidence and survival among the various ethnic populations in Hawaii. His early work led him to concentrate on the role of diet and other lifestyle factors in the etiology of cancer. Dr. Kolonel has written, "We have a particular interest in the interaction of diet with genetic susceptibility in determining cancer risk. Building on past accomplishments, we feel that the potential for understanding the etiology of cancer through studies of ethnic and migrant populations has never been greater."

Lilia C. O'Connor, MBA, RHIT, CTR

Lilia O'Connor has 32 years of experience working for central cancer registries in California. She currently works at the Public Health Institute (PHI) as Director of Operations for the California Cancer Registry (CCR). Before coming to the PHI, Ms. O'Connor was Director of Registry Operations at the Northern California Cancer Center (NCCC). She has an MBA and is a Certified Tumor Registrar and a Registered Health Information Technician.

Ms. O'Connor has recently been re-elected Treasurer of the North American Association of Central Cancer Registries, one of several positions of leadership and service she has held during her professional career in cancer surveillance.

Betsy A. Kohler, MPH, CTR

Betsy Kohler has worked in cancer epidemiology for 25 years at the New Jersey Department of Health and Senior Services. At first she worked on epidemiologic studies, as an interviewer on the National Bladder Cancer Study, and then moved into data analysis and study design. This fueled her interest to continue her graduate studies and she obtained a paid leave of absence to study cancer epidemiology. She earned an MPH in Epidemiology and completed all course work for a DrPH by the time NJ became affiliated with SEER. Putting her dissertation on hold, she became the Registry Operations Manager of the New Jersey State Cancer Registry.

Since 1994, Ms. Kohler has been the Director of Cancer Epidemiology Services, which includes not only the registry but also Cancer Surveillance, the research unit dedicated to epidemiologic investigations, citizen response, and data analysis. Ms. Kohler has been active in the North American Association of Central Cancer Registries, and is currently serving her second term on the Board of Directors. She is the principal investigator on the SEER contract, and New Jersey's cooperative agreement with CDC's National Program of Cancer Registries.

Regarding her career, Ms. Kohler states, "New Jersey is a challenging place to study cancer. I have had to meet with upset citizens, and have been asked to help put together a 'Cancer Cluster SWAT Team.' Complying with SEER data requirements is easy in comparison."

The USC Team

Population-based cancer registration in Los Angeles County was a vision of **Brian E. Henderson, MD**, in 1969, when he founded a population-based cancer surveillance system with rapid case ascertainment that would help investigators achieve research breakthroughs into the causes of human cancers. Dr. Henderson recognized that the size and diversity of the Los Angeles County population would allow study of common as well as less common cancers, of persons of all ages, and of certain racial and ethnic groups for which little or no research findings were available. By 1972, the Los Angeles Cancer Surveillance Program was essentially complete, thanks to the work of **Thomas M. Mack, MD**, **Malcolm Pike, PhD**, **Susan Preston-Martin, PhD**, **John Hisserich, PhD**, and other dedicated staff, as well as grant support from NCI. The registry recruited an epidemiologic research team that, just one year later in 1973, published five peer-reviewed articles in medical journals. Since then, the pace of research output at the Los Angeles Program has increased steadily to nearly one published paper per week. Dr. Mack was Director and **Mr. Herman Menck** was Deputy Director of the Los Angeles Program from the mid-1970s to the mid-1980s.

In 1987, the Los Angeles Cancer Surveillance Program joined the new California Cancer Registry, and the resources and capabilities of the registry were expanded. In addition to many operational changes, a new leadership team took the reins at this time. This team included **Ronald K. Ross, MD**, as Director; **Leslie Bernstein, PhD** as Scientific Director; **Dennis Deapen, DrPH**, as Executive Director; and Judith Boone, BS, as Director of Registry Operations. Many other staff members also must be thanked for collecting the cancer surveillance information and assuring its accuracy and completeness. Many of these staff members now have more than 20 years of service at the Program, including **Jane Sanchez**, **Bernice Lenoir**, **Karen Kishi**, **Cynthia Conant**, **Judith Boone**, **Dianne Kerford**, **Shirley Miyashiro**, **Tony Bautista**, and **Ginger Chui**. Furthermore, cancer registrars

representing every hospital in the county have been active participants since 1987.

Today Drs. Henderson, Pike, Mack and Preston-Martin are still active users of the Los Angeles SEER Registry. They and other researchers have found that the high quality and timeliness of this Registry's data allow them to develop, test, and re-test hypotheses. The Los Angeles Registry staff takes pride in the fact that its data are used extensively for cancer research and cancer control activities. Registry staff constantly strive to produce better data more rapidly. Many staff members are active in developing new techniques and registry methods and in training and providing services for other cancer registries.

Anne P. Lanier, MD, MPH

A native of the Midwest, Anne Lanier began her sojourn in Alaska in 1967, serving for several years as a general medical officer in the Commissioned Corps with the Alaska Area Native Health Service. After additional training, including work with Dr. Leonard Kurland at the Mayo Clinic Department of Epidemiology in Rochester, MN, she became interested in accurately documenting the patterns of cancer among the Alaska Native population, and she returned to Alaska in 1975. Local interest from Tom Bender, MD, MPH, of CDC's Alaska Epidemiology Program, and from Drs. Joe Fraumeni and Bill Blot of NCI, enabled her to conduct preliminary mortality and then incidence studies, which led to the initiation of the Alaska Native Tumor Registry (ANTR).

Dr. Lanier received her MD at Washington University School of Medicine in St. Louis, Missouri. She has held a number of positions within Alaska for the CDC, including Director of the Arctic Investigations Laboratory and Epidemiologist for the Alaska Area Native Health Service. She is currently the Director, Alaska Native Epidemiology Center in Anchorage. She has received the DHHS Distinguished Service Award and the Alaska Public Health Association's Meritorious Health Service Award.



NATIONAL[®]
CANCER
INSTITUTE
