



Illinois State Cancer Registry

Cancer Survivors Project

The Illinois State Cancer Registry (ISCR) has received Institutional Review Board (IRB) approval to participate in a nationwide study of cancer survivors in conjunction with the American Cancer Society. The purpose of the study is to examine behavioral, psychosocial, treatment and support factors that influence the quality of life and survival of long-term cancer survivors in the United States. Specifically, the aims of the study are to describe unmet needs of the cancer survivors; to identify factors that determine good quality of life; and, to examine factors that relate to the development and possible prevention of late effects.

The study will be conducted between January 1, 2001, and December 31, 2001. To be included in the study, individuals must be residents of Illinois; over the age of 18; have been diagnosed with invasive cancer of the female breast, prostate, colon, rectum, uterus, invasive or in-situ cancer of the bladder, or melanoma of the skin; and be alive at the time of initial contact. Approximately 3,000 Illinois residents diagnosis in 1991, 1996 or 1999 are expected to participate in the study.

Confidentiality

ISCR has updated the confidentiality protocol

for transferring electronic data. Any list that is E-mailed from ISCR to a reporting facility and contains patient identifiers will be encrypted using PGP software. The reporting facility must call ISCR for the password. Additionally, ISCR discourages the transmission of confidential patient data via fax unless the fax machine receiving the transmission is located in the registry office. Confidential information being sent by hard copy through the U.S. Postal Service should be in a sealed envelope inside a second sealed envelope.

Training

ISCR offers individualized training sessions to those performing tumor registry work. Training sessions can be customized to the specific needs of the reporting facility. This training is intended to help registrars comply with the state reporting requirements. Facilities that have recently had a change in personnel are encouraged to utilize this service. Additionally, regional workshops are scheduled to cover changes in reporting requirements or advanced cancer registration topics. For additional information, to schedule a training session, or to suggest a workshop topic, contact Jim Hofferkamp at 217-557-0184.



Adverse Pregnancy Outcomes Reporting System

APORS Receives CDC Funds to Improve Birth Defect Surveillance

The U. S. Centers for Disease Control and Prevention (CDC) awarded \$120,000 to the Adverse Pregnancy Outcomes Reporting System (APORS) in October 2000. APORS will use the funding to enhance surveillance of birth defects. This was the first federal funding obtained by APORS.

The three-year project will emphasize improvement of hospital reporting. All Illinois hospitals are mandated to report newborns who meet the APORS case definition. The funding will support the hiring of a quality control specialist/trainer who will coordinate and conduct studies to evaluate hospital reporting. Individual reports and summary reports will be provided to hospitals. In-depth follow back will be performed to assure missed cases are reported to APORS. On-site training will be provided to hospitals identified as needing improvement.

An epidemiologist will be hired to coordinate data analysis and dissemination. Two birth defect surveillance reports (trends in the prevalence in Chicago and Illinois, and mortality and county-specific prevalence) will be produced each year and disseminated to APORS reporters, local health departments, other state birth defect registries, CDC, and interested parties. The surveillance reports will continue to be available on the Illinois Department of Public Health's Internet site (www.idph.state.il.us/about/epi/apors.htm). Statewide prevalence data will be sent to CDC and to the National Birth Defect Prevention Network for incorporation into national statistics. APORS also will explore the possibility of generating downloadable public use birth defect files for the Department's Web site.

Surveillance data on neural tube defects (NTDs) will be provided to the Illinois Folic Acid Council, a statewide coalition promoting the consumption of folic

acid by women of childbearing age to prevent neural tube defects (spina bifida and anencephaly). The surveillance data can be used to target education efforts and to evaluate progress in reducing NTD occurrence. APORS will consult with the March of Dimes to identify additional data needs for surveillance of NTD. APORS will continue to work with local health departments and the Illinois Department of Human Services' High-risk Infant Follow-up Program to assure prompt counseling and intervention services for NTD-affected families take place. APORS will monitor the provision of follow-up services and prepare a summary report for dissemination to local health departments and to the Illinois Department of Human Services.

Increasing other uses of birth defects data for prevention and intervention is another project goal. In the project's first year, APORS staff will explore ways to directly link birth defect surveillance data to the state's early intervention program. APORS staff will encourage data requests for epidemiologic research by independent investigators. A procedure has been established for providing confidential data to outside researchers. APORS staff will visit university schools of public health or medical schools to introduce state birth defect data and to encourage its use by faculty members and students.

Not all birth defects are identified prior to or at birth, and many anomalies are identified during the first two years of life. This is especially true for heart, circulatory, gastrointestinal, and musculoskeletal defects. As a result, not all birth defects occurring in Illinois children are reported to APORS. The program will maintain its present system of hospital reporting of newborn cases and begin identifying cases diagnosed up to age 2 beginning in Chicago.



Occupational Disease Registry

Costs of Fatal Occupational Injuries

The National Safety Council provides estimates of the average cost of fatal injuries to illustrate the impact on the nation's economy.¹ The costs are a measure of the dollars spent and income not received because of accidental fatalities. It is estimated that each fatal accident occurring costs society \$900,000. This figure does not include any time lost by uninjured workers who were directly or indirectly involved in injuries nor any incurred property damage.

The Illinois Census of Fatal Occupational Injuries (CFOI) program receives reports of more than 200 confirmed cases of fatal occupational injuries during each calendar year in Illinois, which translates to an estimated cost of \$180 million per year. Although each case is unique, the following is an example of a fatal occupational injury case that could be very close to reality.

An employee, 45 years of age with 23 years at a building construction company, had completed replacing all the ceiling tiles, except in one corner of the room where paint cans and rollers were waiting for the painters due in the following day. It was already 4:15 p.m., and he still had three tiles to replace and the work area to clean. After maneuvering the man-lift close to the paint supplies, he began to place the ceiling tiles. After successfully placing one tile in position and removing the second, he extended over the man-lift's guard rail and toppled 15 feet into the buckets on the ground. Electricians on assignment in the building observed the fall and came to the area finding the employee nonresponsive. They called emergency personnel who arrived within 15 minutes.

Medical personnel rushed the employee to the hospital where the physician pronounced the employee dead. Autopsy reports showed the cause of death to be skull fracture with subsequent damage to the brain and a cervical fracture with minor contusions and lacerations.

Subsequent investigation of the incident determined that the man-lift was in good operational order, and the employee was trained on the use of the man-lift. The employee attempted to gain access to the corner by maneuvering the scissor man-lift next to the five-gallon buckets of paint rather than lower the lift and move the paint supplies out of the way. Because of the distance to the wall, the employee overreached, became top heavy, and toppled from the man-lift.

A good safety training program could prevent such a tragedy. Training teaches workers to move objects, to work safely, and not to overreach. Training also teaches the individual to assess the situation and to take no chances. Often, an individual gets in a hurry to complete a task and does not realize that he/she is placing himself/herself in danger.

Although the huge economic cost of fatal occupational injuries can be determined, any loss of life that is preventable is an indication of failure of safety programs. Simple safety programs for ensuring the use of seat belts and the proper placement of equipment, and following appropriate safety steps need to be implemented and enforced.

¹National Safety Council Cost of Unintentional Injuries 1999 [Http://nsc.org/lrs/statinfo/estcost9.htm](http://nsc.org/lrs/statinfo/estcost9.htm)



The REGISTRY NEWSLETTER is published by the Division of Epidemiologic Studies, Illinois Department of Public Health, 605 W. Jefferson St., Springfield, IL 62761, 217-785-1873, TTY (hearing impaired use only) 800-547-0466.

George Ryan, Governor
John R. Lumpkin, M.D., Director of Public Health
Tiefu Shen, M.D., Chief, Division of Epidemiologic Studies
Jan Snodgrass, Illinois State Cancer Registry
Trish Egler, Adverse Pregnancy Outcomes Registry
Roy Maxfield, Census of Fatal Occupational Injuries

**Printed by Authority of the State of Illinois
P.O. #541187 1.3M 12/00**

**Illinois Department of Public Health
Division of Epidemiologic Studies
605 W. Jefferson St.
Springfield, IL 62761**