

Annual Report

Illinois Health and Hazardous Substances Registry

July 2004 through June 2005



**A Report to Governor Rod R. Blagojevich
and the 94th General Assembly
from the
Illinois Department of Public Health
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1. EXECUTIVE SUMMARY

The Illinois Department of Public Health's Division of Epidemiologic Studies is responsible for developing and managing the Illinois Health and Hazardous Substances Registry (IHHSR). The registry was created by the Illinois Health and Hazardous Substances Registry Act (410 ILCS 525/1 *et seq.*), enacted on September 10, 1984, and currently has the following components: the Illinois State Cancer Registry (ISCR), the Adverse Pregnancy Outcomes Reporting System (APORS), the Occupational Disease Registry (ODR)(which further contains the Adult Blood Lead Registry [ABLR], Census of Fatal Occupational Injuries [CFOI] and the Occupational Safety and Health Survey [OSH]), the Environmental Public Health Tracking (EPHT) and a research and data utilization section. This is the registry's 19th annual report and it describes accomplishments and research activities from July 2004 through June 2005 (FY05).

Overall, IHHSR activities in FY05 were characterized by continued recovery of registry infrastructure and functions lost three years ago, and consistent expansion of registry operations for disease surveillance and support to research. Department leadership and the hard work and dedication of division staff enabled the IHHSR to accomplish its mission as outlined in the act, which includes the following activities:

1. Collect and maintain high quality reports on the incidence of cancer, adverse pregnancy outcomes, and occupational diseases and injuries;
2. Conduct epidemiologic assessments on public health outcomes and hazardous substances;
3. Provide a source of information for the public;
4. Monitor changes in incidence to detect potential public health problems to predict risks and to conduct cancer cluster investigations;
5. Use data to target intervention resources for communities and patients and their families;
6. Inform health professionals and citizens about risks, early detection and treatment of cancers found to be elevated in their communities; and
7. Promote high quality research to provide better information for disease prevention and control.

1.1 Illinois Health and Hazardous Substances Registry Goal

The goal of the registry, according to the act, is to develop and maintain a unified system for the collection and compilation of statewide information on cancer incidence, adverse pregnancy outcomes, occupational diseases and injuries, and hazardous exposures; for correlation and analysis of information on

public health outcomes and hazardous substances; and for use of this information in decision making and public health policy development.

1.2 Fiscal Year 2005 Main Accomplishments

- Received \$2,901,579 from federal and other non-general revenue sources to support activities of the Department's Division of Epidemiologic Studies. Currently, all components of IHHSR receive federal funding.
- Responded to 67 inquiries about perceived cancer or birth defect excesses in local communities. Sixteen of the inquiries were responded to with previously conducted reports for the areas in question. A total of 28 inquiries were answered with published cancer rates by county or epidemiologic reports; and for two inquiries, an in-depth evaluation was initiated with one completed and one ongoing.
- Collected reports on Illinois residents with 61,111 newly diagnosed cancer cases (2002), 13,911 adverse pregnancy outcomes (2003), 150 adult lead poisoning cases (2004), 9,081 representative non-fatal occupational disease and injury sample records (2004), 208 fatal occupational injuries (2004) and 1,270 fatal occupational illnesses (2004).
- Responded to 106 requests for general information about the registry, 128 requests for epidemiologic reports and published data, and 37 special data requests or collaboration from outside researchers.
- Prepared and submitted 11 grant proposals to support the registry's operations and research.
- Released five reports in the Epidemiologic Report Series and prepared two peer-reviewed journal articles. Prepared seven written reports for quality control studies of registry data.
- Participated in statewide health programs, provided data and information support as needed.
- Delivered 52 presentations at professional meetings.
- Achieved national "best in class" or "above average" status for all registry components that can be externally evaluated.

1.3 IHHSR Coordinating Council

The IHHSR Act created the Health and Hazardous Substances Coordinating Council comprising the following persons ex officio or their designees: dean of the School of Public Health of the University of Illinois at Chicago, the directors of the Illinois departments of Agriculture, Labor, Natural Resources, Nuclear Safety (now part of the Illinois Emergency Management Agency), Public Health, and of the Illinois Environmental Protection Agency. The council met on August 23, 2005 to hear division accomplishments, to discuss current issues, and to approve the fiscal year 2005 annual report.

1.4 Goals for Fiscal Year 2006

1. Continue to collect complete and quality data to monitor disease trends among Illinois residents.
2. Engage communities, partners, and stakeholders in data dissemination and utilization to reduce health disparities.
3. Respond to public concerns about disease clusters in various geographic areas in Illinois through increased geocoding.
4. Conduct activities stipulated or required by federal cooperative or research grants.
5. Pursue grants and other funding opportunities in order to sustain and enhance the division's programs.
6. Conduct epidemiologic studies with registry data to provide information to the public health community and policy makers. Initiate regular data linkage and side-by-side presentation with environmental health data.
7. Provide epidemiological data and information to federal, state, and local health education and intervention programs.
8. Work with the Department's Data Release and Research Committee to provide researchers with high-quality and timely registry data to support research advancing scientific knowledge and improving public health.
9. Provide enforcement agencies with health surveillance information to enhance their intervention and regulatory programs and to improve public health and safety.

10. Participate in national registry certification and data submission activities.
Maintain registry's best in class status and data usefulness.

2. PROGRAM DATA

Table 2.1 and 2.2 summarize the registry's data collection and dissemination activities for last year compared with data from the previous four years. In order to be consistent with the regular reporting schedule, numbers in Table 2.1 are expressed by calendar years during which cases were born, diagnosed or reported. There is normally a two-year time delay for cases being reported to IHHSR. Projections for the future year also are included.

| Table 2.1 Registry Data Collection | | | | | | |
|---|------------------|------------------|------------------|------------------|---------------------|--------------------|
| | Calendar 1999 | Calendar 2000 | Calendar 2001 | Calendar 2002 | Calendar 2003 | Estimated 2004 |
| ISCR Invasive Neoplasms (including bladder <i>in situ</i>) | 58,211 | 58,198 | 58,897 | 59,200 | 59,776 ¹ | 59,250 |
| Breast <i>in situ</i> | 1,739 | 1,964 | 2,009 | 1,911 | 1,968 ¹ | 2,022 |
| APORS Cases | 16,496 | 17,594 | 16,976 | 18,501 | 13,911 ² | 12,700 |
| Occupational Disease Cases | | | | | | |
| ABLR lead poisoning | | | | | | |
| New cases | 475 | 578 | 332 | 252 | 266 | 150 ³ |
| Prevalent reports | 1,652 | 2,224 | 2,236 | 1,462 | 1,016 | 725 ³ |
| Occupational Fatality Cases | 1,739 | 1,519 | 1,462 | 929 | 1,195 | 1,470 ³ |
| Injuries | 208 | 206 | 231 | 190 | 200 | 208 ³ |
| Illnesses | 1,531 | 1,313 | 1,231 | 793 | 994 | 1,270 ³ |
| Occupational Safety and Health Survey | | | | | | |
| Estimated Cases⁴ | 80,628 | 72,929 | 65,888 | 63,000 | 66,110 | 66,000 |
| Sprains, strains | 32,924 | 30,701 | 28,048 | 27,751 | 29,550 | 28,000 |
| Bruises, contusions | 6,692 | 5,456 | 4,898 | 4,300 | 5,820 | 5,400 |
| Cuts, lacerations | 4,935 | 5,689 | 4,849 | 5,700 | 5,060 | 5,300 |
| Fractures | 6,064 | 5,096 | 5,113 | 5,132 | 4,400 | 4,200 |
| Multiple injuries | 2,079 | 1,838 | 1,810 | 1,608 | 2,190 | 2,000 |
| Carpal tunnel syndrome | 1,447 | 1,500 | 1,884 | 1,480 | 1,850 | 1,500 |
| Heat burns | 879 | 769 | 871 | 1,345 | 950 | 900 |
| Tendinitis | 792 | 671 | 422 | 165 | 410 | 450 |
| Amputations | 389 | 696 | 658 | 453 | 540 | 500 |
| Chemical burns | 591 | 379 | 275 | 276 | 570 | 300 |
| Hazardous Substances (GIS)⁵ | | | | | | |
| Geocoding registry cases | All | All | All | All | All | All |

¹ Reporting is not complete for calendar year 2003.
² APORS stopped collecting data on children whose only criteria was admittance to designated patient unit (DPU) without other reportable medical conditions in May 2003.
³ Actual counts for 2004.
⁴ Estimated numbers based on Occupational Safety and Health sample survey.
⁵ For specific results of geocoding of APORS and cancer cases for the Hazardous Substance Registry, see section 6.

| Table 2.2 Registry Data Dissemination and Translation | | | | | | |
|---|-------|-------|-------|------|---------------------|-------------------|
| | FY 01 | FY 02 | FY 03 | FY04 | FY 05 | Estimated FY06 |
| Data Request | | | | | | |
| General information | 104 | 91 | 89 | 114 | 106 | 100 |
| Data and reports | 114 | 115 | 112 | 113 | 128 | 120 |
| Cluster evaluations | 13 | 8 | 4 | 1 | 1 | 1 |
| Confidential data for research | 10 | 15 | 8 | 9 | 16 | 15 |
| Quality Assurance Studies¹ | | | | | | |
| Casefinding Visits | | | | | | |
| APORS | | | | | 476 | 470 |
| ISCR | | | | | 395 | 300 |
| Cases added from casefinding visits | | | | | | |
| APORS | | | | | 12,812 ² | 10,000 |
| ISCR | | | | | 1,781 ³ | 1,100 |
| Internal Quality Control | | | | | | |
| APORS | | | | | 5 | 5 |
| ISCR | | | | | 17 | 15 |
| Public Use Files | 3 | 3 | 3 | 4 | 3 | 3 |
| Publications | | | | | | |
| Epi Report Series | 7 | 9 | 5 | 5 | 5 | 5 |
| Surveillance reports | 1 | 1 | 1 | 0 | 0 | 1 |
| Peer-Reviewed Publications | 3 | 0 | 2 | 2 | 2 | 1 |
| Brief reports | | | | | | |
| Newsletter articles | 4 | 4 | 0 | 0 | 0 | 0 |
| Reports using registry data | 21 | 8 | 9 | 19 | 13 | 5 |
| Oral/Poster Presentations | 42 | 46 | 31 | 63 | 52 | 50 |
| Grant proposals funded | 7 | 9 | 9 | 9 | 11 | 9 |
| ¹ At the recommendation of the IHHSR Coordinating Council, quality assurance study counts are being adjusted for FY05 to more accurately reflect the quantity of work performed and the outcome of that effort. ² Represents additional birth defects identified and confirmed through the active case verification process where the medical records of previously submitted cases were reviewed. ³ Represents cases missed during hospital reporting and identified during casefinding visits. | | | | | | |

3. ILLINOIS STATE CANCER REGISTRY

The Illinois State Cancer Registry (ISCR) is the only population-based source for cancer incidence information in Illinois. Cancer cases are collected through mandated reporting by hospitals, ambulatory surgical treatment centers, non-hospital affiliated radiation therapy treatment centers, independent pathology labs, dermatologists and through the voluntary exchange of cancer patient data with 13 other (mostly nearby) states, plus the Mayo Clinic in Rochester, Minnesota, and Barnes-Jewish Hospital in St. Louis, Missouri. Currently one Veteran's Administration (VA) facility in Illinois is reporting cases to ISCR and another military facility in Illinois that participates in the U.S. Department of Defense's registry reporting system also shares data with ISCR.

Of the 193 reporting hospitals, only 14 continue to report manually, while the remaining 179 hospitals report electronically. Of the 71,335 individual abstracts submitted for the 2003 report year, only 1,317 (1.9%) were submitted manually. The majority of abstracts (98.1%) were submitted electronically

3.1 Review and Evaluation of Fiscal Year 2005 Goals

Maintain/Enhance Completeness of Reporting

Goals met

- An estimate of the completeness of Illinois cancer incidence reporting was published annually in the North American Association of Central Cancer Registries (NAACCR) Cancer in North America (CINA) and includes 2002.
- Monitored quarterly incidence to ensure completeness.
- Provided all reporting facilities quarterly Data Quality Indicator Reports for facility-specific historical-to-current submissions.
- Completed casefinding at 91 hospital-affiliated pathology labs and identified 343 missed cases.
- Completed casefinding at 25 radiation therapy facilities
- Completed casefinding at 190 hospitals and identified 1,064 missed cases.
- Completed casefinding at 17 dermatology clinics and identified 44 missed cases.

- Completed casefinding at 72 ambulatory surgical treatment centers and identified 330 missed cases.
- Performed follow-back to physicians' offices for all non-reported cases identified through hospital affiliated pathology labs casefinding for the 2002 and 2003 diagnosis years. This activity added 427 abstracts to the ISCR database.
- Completed death clearance for the 2002 diagnosis year with a death certificate only rate of 2.9 percent. The objective was to have a death certificate only rate of less than 3 percent.
- Maintained interstate data exchange with 13 other states and two large out of state hospitals: Barnes Hospital in St. Louis, Missouri, and Mayo Clinic in Rochester, Minnesota. A total of 3,452 previously unreported cases were added to the cancer database for the 2002 diagnosis year.

Maintain Timeliness of Reporting

Goals met

- Abstracting at two VA hospitals was not done because the VA facilities will not allow ISCR access to medical records due to HIPAA concerns. Some cases are being reported voluntarily by three VA hospitals that now have registrars.
- By December 2004, more than 99 percent of the unduplicated cases of cancer for the 2002 diagnosis year were available to be counted as incident cases by ISCR. The original goal was 95 percent.
- By December 2004, 90 percent of the expected unduplicated cases of cancer for the 2003 diagnosis year were available to be counted as incident cases by ISCR. The original goal was 90 percent.

Maintain Quality Control and Audit Activities

Goals met

- On a monthly basis, utilized National Program of Cancer Registries (NPCR) Cancer Surveillance Systems (CSS) inter-record edits to perform quality control review of all data received during the previous year.

- On a semi-annual basis, utilized the NAACCR methodology for accessing duplicates; and, on a monthly basis reviewed all new submissions against the current ISCR database to identify potential duplicate abstracts.
- Maintained an unresolved duplicate rate of less than 0.1 percent for cancer cases diagnosed during 1998-2002.
- Used the NAACCR Edits metafile to perform EDITS checks on cases diagnosed between 1995 and 2002 diagnosis years in preparation for the NPCR call for data.
- Used the NPCR CSS inter-record edits to perform quality control review of the 1995 through 2002 diagnosis years in preparation for the NPCR call for data.
- Completed a linkage of the 2002 vital records tape to the ISCR database to enhance the completeness of selected variables (gender, place of birth, race, maiden name and Spanish/Hispanic origin). The ISCR database was updated with 22,624 cases.
- Completed a comparison of sex and name for all cases added to the database since July 2003. There were 652 cases selected and 384 corrections made.
- Completed an Item-Specific Review for cancer cases diagnosed in 2002.
- Completed a reabstracting (reliability) audit for randomly sampled non-registry reporting facilities focusing on selected variables consistent with a previous NPCR audit performed in Illinois.
- Completed quality control review of the data pulled for the ISCR research and public data set files for the 1986-2002 diagnosis years.

Goals not met:

The evaluation of treatment data for 1995-2002 for the Illinois cancer control sites was not completed because the federal audit support position was not funded for the past fiscal year due to CDC funding restrictions.

Maintain Basic and Advanced Training

Goals met

- Presented six basic training sessions and 14 advanced training sessions for reporting facilities, targeting cancer reporters at different levels.
- Provided individual on site training for 43 cancer incidence reporters in various reporting facilities.
- Provided support for all new Illinois abstractors by performing review of their first 25 abstracts submitted, assisting with edits application and data submission, and ensuring understanding of abstracting and staging rules.
- Collaborated with the Cancer Registrars of Illinois, the Illinois Division of the American Cancer Society and the Chicago Area Cancer Registrar's Association to provide a Certified Tumor Registrar (CTR) prep class and a course titled Cancer 101.
- Handled 1,285 calls from cancer reporters with specific abstracting or computer questions.
- Several ISCR staff members attended the annual Cancer Registrar's of Illinois meeting in September 2004; one ISCR field staff member attended the annual National Cancer Registrar's Association meeting in April 2005; and, the ISCR trainer attended the annual North American Association of Central Cancer Registries meeting in June 2005.

Submit Cancer Data to NAACCR and CDC

Goals met

- In January 2005, a non-confidential analytic data file of 485,857 cancer incidence records for 1995-2002 was submitted to the U.S. Centers for Disease Control and Prevention (CDC). The records were accepted and will be included in the *United States Cancer Statistics, 2001* report.
- In December 2004, a non-confidential data file of 474,331 cancer incidence records for 1995-2002 was submitted to the NAACCR for the purpose of registry certification and inclusion in *Cancer in North America*, a yearly publication

Maintain Current Data Utilization Activities

Goals met

- Used MapInfo Professional© and MapMarker Plus© software to geocode cancer incidence data in November 2004 and added the geocoded data to the ISCR cancer database.
- Hired a data use coordinator who is responsible for all activities related to the release of confidential cancer data and serves as the data steward for the cancer registry.
- Individual hospital reports were prepared as requested by reporting facilities.
- Provided incidence information as requested to the Illinois Comprehensive Cancer Control Program.
- Provided general information to the public concerning perceived cancer cluster and conducted in-depth cancer cluster investigations as needed.
- Re-geocoded the entire ISCR database and stored the information in a separate data file to prevent corruption by ongoing cancer database conversions. Geocoded information was also added to the ISCR research files.

Goals not met

- Due to delays in the production of the public data file and the departure of the cancer epidemiologist, the Illinois cancer statistics report and the county-specific report for Illinois (1997-2001) were not produced the past year and the Web-based cancer inquiry system and IPLAN were not updated. The two reports are now available for new data at the IDPH Web site.
- The development of the hospital specific annual reports for the 2002 diagnosis year was not completed due to higher priorities for other projects.

3.2 Fiscal Year 2005 Major Accomplishments**3.2.1 North American Association of Central Cancer Registries Gold Certification**

NAACCR has developed a formal certification process to recognize excellence in cancer registration for its members, which include all

population-based cancer registries in the United States and Canada. At the annual meeting of NAACCR, held June 6-10, 2005, in Boston, Mass., ISCR was recognized as having met the *gold standard* – the highest standard for registry certification. To be awarded this honor, a registry must have completeness of case ascertainment 95 percent or better; 98 percent validity of information recorded for selected data variables (age, sex, race and state/county); death-certificate-only cases less than 3 percent; duplicate primary cases less than one per 1,000; and 99 percent of the records passing the NAACCR EDITS without error and data submissions within 24 months of the close of the accession year. **This is the seventh consecutive year that ISCR has received this highest quality certification.**

3.2.2 Sustained Excellence Award

The staff of the Illinois State Cancer Registry were recognized by the Illinois Department of Public Health with a Sustained Excellence Award in October 2004. Director, Dr. Eric E. Whitaker presented the award “in recognition of their exceptional teamwork and sustained excellence in achieving ‘Gold Certification’ for the Illinois State Cancer Registry in 2004.”

3.2.3 Established the Data Release and Research Committee

The Department established the Data Release and Research Committee in August 2004 modeled on established procedures and documents developed by the Illinois State Cancer Registry for release of confidential data.

3.2.4 Collaboration with State and National Organizations

3.2.4.1 Illinois Comprehensive Cancer Control Program - Illinois Department of Public Health. The Illinois Department of Public Health began working on the framework for the Department’s Comprehensive Cancer Control State Plan during the last year to identify cancer prevention and control priorities for Illinois that could be most effectively addressed through collaborative efforts; to develop a strategic plan outlining an organized approach to achieving the priorities; and to identify successful community education and intervention models that should be implemented. Several Division staff have met with the ICCCP staff during the last year to offer guidance in the development of the plan.

3.2.4.2 Vital Records – Illinois Department of Public Health. Death certificate data from the Division of Vital Records (VR) are matched with the registry database on an ongoing basis. Follow-back is performed on non-matched cancer cases and death information is added to match cases. Death information available from the VR death tape is also used to populate an Internet-based

death query system that is accessible through password and ID. This system is used by hospital-based cancer registrars to obtain follow-up information on cancer patients from their facilities.

The VR death tape also contributes to the ISCR database the following variables: gender, race, birthplace, Hispanic origin and maiden name. If the reported information for these fields is blank or unknown in the registry database and the information on the VR tape is known, the known information will replace the unknown information on ISCR. This practice has enhanced the ISCR data quality.

With funding from CDC, and in collaboration with VR, ISCR completed a pilot testing and an analysis of the possibility of keying the death certificate locally. This analysis was performed to determine the feasibility and validity of using the CDC developed Super MICAR software for coding Illinois deaths and using death certificate addresses for geocoding. Death certificates are currently keyed by an outside vendor and access to an electronic file of death certificate information is only available several months after the end of the death year. This could adversely affect the ongoing certification of the cancer registry. The analysis showed that the entire death certificate could be keyed locally with an accuracy of 90 percent on the coding of the cause of death and 90 percent on the geocoding of the person's address. Discussion is ongoing within the department regarding methods to increase accessibility to an electronic death file.

3.2.4.3 American Cancer Society (ACS) – Illinois Division. ISCR provided customized cancer incidence data for the publication *Illinois Cancer Facts & Figures, 2004*. The publication has been widely distributed in Illinois to cancer control programs and health professionals. ISCR staff also serve on the cancer registry subcommittee of the Cancer Incidence and End Results (CIER) Committee and of the Data Collection and Reporting Task Force. This subcommittee is responsible for organizing and presenting an annual cancer registrar educational workshop, a basic training session and a certified tumor registrar preparation course.

3.2.4.4 University of Illinois at Chicago. ISCR is collaborating with the University of Illinois to build a core capacity to conduct rapid case ascertainment (RCA) activities to facilitate early identification and recruitment of breast cancer patients to an epidemiologic study funded by the National Cancer Institute (NCI). The study, "Breast Cancer Care in Chicago," is exploring how women are diagnosed with breast cancer at the various stages of disease and why women receive different kinds of treatment for their cancer. Patient accrual for this study began in May 2005.

3.2.4.5 North American Association of Central Cancer Registries. ISCR provided data to NAACCR in response to the call for data and registry certification process. The data were used to generate cancer descriptions in North America publications. Staff also participated in various NAACCR committees and workgroups, contributing knowledge and expertise to this volunteer organization.

3.2.4.6 National Program of Cancer Registries (NPCR). ISCR submitted data to the CDC National Program of Cancer Registries call for data. All malignant tumors, whether *in situ* or invasive, were included. The annual submission satisfies the program requirements for reporting registry progress to CDC and contributes information to the national cancer surveillance effort.

3.2.4.7 Illinois Breast and Cervical Cancer Program (IBCCP). ISCR provided ongoing data support for this federally-funded program, which focuses on developing comprehensive education, outreach and screening for breast and cervical cancer.

3.2.4.8 CDC's Patterns of Care Study. The purpose of this international study is twofold: to collect complete treatment data information on a sample of cases from population-based registries for breast, colon and prostate cancer, and to compare national treatment and outcomes between the United States and Europe. Data collection for this project was completed in September 2004. Analysis of the data and preparation of articles for submission to professional journals is ongoing.

3.2.5 Quality Control Activities and Reports

In FY05, staff completed 395 casefinding visits. The following reports were prepared in FY05:

- 3.2.5.1** Leonard, D. *An Analysis of Methods for Identifying Subject Reference Duplication in Health Care Databases*. A project completed as a thesis for a Master of Science degree from the School of Information Technology, Illinois State University, May 2005.
- 3.2.5.2** Parrish, P. *Assessment of Duplicate Records for 1998-2002 Diagnosis Year*. Quality Control Report Series 04:02, Springfield, Ill.: Illinois Department of Public Health, November 2004.
- 3.2.5.3** Parrish, P. *Evaluation of Multiple Primaries for Melanoma Skin Cancers for 1986-2004 Diagnosis Year*. Quality Control Report Series 04:03, Springfield, Ill.: Illinois Department of Public Health, November 2004.
- 3.2.5.4** Koch, L. *Linking Illinois State Cancer Registry Records With Vital Records Death Master File to Enhance Data Completeness*. Quality Control Report Series 05:01, Springfield, Ill.: Illinois Department of Public Health, December 2004.
- 3.2.5.5** Koch, L, Parrish, P. *Geocoding Results for Sangamon County for the Illinois State Cancer Registry*. Quality Control Report Series 05:02, Springfield, Ill.: Illinois Department of Public Health, January 2005.
- 3.2.5.6** Parrish, P. *Item-Specific Completeness Report for 2002 Diagnosis Year*. Quality Control Report Series 05:03, Springfield, Ill.: Illinois Department of Public Health, January 2005.
- 3.2.5.7** Snodgrass, J. *Abstract Submission Completeness By Reporting Facilities for the 2002 Diagnosis Year: The Results of Quality Control Casefinding*. Quality Control Report Series 05:04, Springfield, Ill.: Illinois Department of Public Health, March 2005.

3.3 Goals for Fiscal Year 2006

Maintain/Enhance Completeness of Reporting

- Estimate the completeness of Illinois cancer incidence reporting for 1995-2003 diagnosis years using the revised NAACCR methodology.

- On a quarterly basis, compare observed-to-expected Illinois cancer incidence cases (diagnosis years 2003-2004) and monitor case reporting to ensure completeness.
- On a quarterly basis, provide facility-specific data quality Indicator Reports comparing facility-specific observed-to-expected case submissions and comparing information on facility-specific historical to current submissions.
- Complete casefinding visits at all reporting facilities in Illinois.
- Perform follow-back to physicians' offices for all non-reported cases identified through hospital-affiliated pathology casefinding for the 2003 diagnosis year and add a complete abstract to the ISCR database.
- Maintain the death certificate only rate of less than 3 percent for the 2003 diagnosis year.
- Complete processing of interstate data exchange files including application of Illinois specific edits metafile, inter-edits and add cases to the database.

Maintain Timeliness of Reporting

- Achieve 90 percent of the expected unduplicated cases of cancer for the 2004 diagnosis year and 95 percent of the expected unduplicated cases for the 2003 diagnosis year that will be available to be counted as incident cases by ISCR.
- Match Dianon Laboratories (electronic pathology report file) to the ISCR database for non-reported cases.
- Identify and contact out of state labs regarding implementation of electronic submission of lab based pathology reports to ISCR.

Maintain Quality Control and Audit Activities

- On a quarterly basis, utilize the National Program of Cancer Registries (NPCR) CSS inter-record edits to perform quality control review of all data received during the previous quarter.
- On a semi-annual basis, utilizing the NAACCR methodology for accessing duplicates, review all new submissions against the current ISCR database to identify potential duplicate abstracts.

- Maintain an unresolved duplicate rate of less than 0.1 percent for cancer cases diagnosed during 1998-2003.
- Using the NAACCR EDITS metafile, perform an EDITS check on cases diagnosed between 1998 and 2003 in preparation for the NAACCR call for data.
- Complete a linkage of the 2003 vital records tape to the ISCR database to enhance the completeness of selected variables (gender, place of birth, race, maiden name and Spanish/Hispanic origin).
- Complete a comparison of sex and name for all cases added to the database since July 2004
- Using the NPCR CSS, inter-record edits, perform quality control review of the 1995 through 2003 diagnosis years in preparation for the NPCR call for data.
- Complete an item-specific review for cases diagnosed in 2003.
- Perform quality control review of data pulled for the ISCR research and the public data set for diagnosis years 1986-2003.
- Complete a reabstracting (reliability) audit for randomly sampled non-registry reporting facilities focusing on variables consistent with a previous National Program of Cancer Registries audit performed in Illinois.
- Complete a review and comparison of staging scheme information for breast, lung, colon and prostate cases submitted for diagnosis years 1995-2003.

Maintain Basic and Advanced Training

- Present six basic training sessions for reporting facilities.
- Present six advanced training sessions for reporting facilities.
- Provide individual training for incidence reporters as requested.
- Provide support for new Illinois abstractors by performing review of the first 25 abstracts submitted, by assisting with edits application and data submission, and by ensuring understanding of abstracting and staging rules.

- Collaborate with the Cancer Registrars of Illinois, Illinois' division of the American Cancer Society and the Chicago Area Cancer Registrar's Association to provide a Certified Tumor Registrar (CTR) prep class and a course titled Cancer 101.
- Maintain dedicated phone line support and update tracker for each call.
- Provide ongoing educational opportunities for staff at local, regional and national meetings.

Submit Cancer Data to U.S. Centers for Disease Control and Prevention (CDC)

- Submit a non-confidential analytic data file of cancer incidence records to CDC per recommended guidelines.

Maintain Current Data Utilization Activities

- Prepare individual hospital reports as requested by submitting facilities.
- Provide incidence information on cancer in Illinois as requested by the Illinois Comprehensive Cancer Control Program.
- Produce the annual Illinois cancer statistics report for the 2003 diagnosis year.
- Produce the annual Illinois cancer report card (1998-2003).
- Prepare three electronic public use data sets (state, county and ZIP code) by March 2006 (1986-2003) for electronic transmission and access through the Department's Web site (www.idph.state.il.us).
- Provide an electronic data file (1986-2003) for use by the Department in local health planning (IPLAN).
- Continue to provide general information to the public concerning perceived cancer clusters and conduct in-depth cancer cluster investigations as needed.
- Update Web-based cancer inquiry system with data from 1997-2003.
- Geocode data received since October 2004 and add geocoding information to the ISCR database using MapInfo Professional© and MapMarker Plus© software.
- Coordinate all activities related to applications for access to confidential cancer data from researchers.

- Coordinate ISCR participation in special studies requiring patient consent/contact and collaborative projects requiring linkage with outside data sets.

4. ADVERSE PREGNANCY OUTCOMES REPORTING SYSTEM

The Adverse Pregnancy Outcomes Reporting System (APORS) collects information on Illinois infants born with birth defects or other abnormal conditions. The purpose of APORS is to conduct surveillance on birth defects, to guide public health policy in the reduction of adverse pregnancy outcomes, and to identify and refer children who require special services to correct and prevent developmental problems and other disabling conditions.

Mandated statewide data collection began in August 1988. All licensed Illinois hospitals are required to report adverse pregnancy outcomes to APORS. In addition, APORS receives reports from four hospitals in St. Louis, Missouri, that are part of the southern Illinois perinatal network. A few Indiana and Iowa hospitals also report Illinois children.

APORS cases meet one or more of the following criteria.

- The infant is diagnosed prior to hospital discharge as having a positive drug toxicity for any drug or shows signs and symptoms of drug toxicity or withdrawal;
- the infant is diagnosed with a congenital anomaly; a congenital infection; endocrine, metabolic or immune disorder; or blood disorder;
- the infant has a birth weight of less than 1,500 grams; or
- a neonatal or fetal death has occurred.

4.1 Review and Evaluation of Fiscal Year 2005 Goals

Improve Casefinding

Goals met

- APORS has initiated rule changes to expand the case age for birth defects to include diagnoses made prenatally and during the first two years of life. The draft rule, after several rounds of revisions, is currently under legal review.
- Conducted training for hospital staff regarding case identification.

- Matched APORS newborn cases with hospital discharge data to identify missed newborn cases.
- Matched APORS newborn cases with vital records (VR) birth data to identify missed newborn cases. The memoranda of understanding are under legal review.
- Matched APORS newborn cases with VR death data to identify missed birth defects cases.
- Performed active case verification with new casefinding by performing hospital chart review.

Improve Quality of APORS Data

Goals met

- Evaluated the accuracy of hospital reporting in terms of timeliness and accuracy; provided hospital-specific feedback and used results to identify hospital training needs.
- Evaluated the quality of the active case verification process in terms of timeliness and accuracy; provided individual-specific feedback and used results to identify staff training needs.
- Provided ongoing in-service training to hospitals that have been identified as problem reporters in terms of timeliness, accuracy or case completeness.

Improve Program Effectiveness

Goals met

- Efforts were made to use APORS surveillance data to improve access to health services and early intervention services. Data sharing agreements need to be executed with the University of Illinois Division of Specialized Care for Children and the Illinois Department of Human Services (IDHS) Early Intervention Program.
- Based on the University of Illinois at Chicago (UIC) School of Public Health's assessment, APORS developed an action plan to improve program outreach; the plan was included as a part of the assessment published by UIC.
- Evaluated the timeliness of APORS reporting and reported processing to identify areas for improvement through training and automation.

- Maintained linkages with key organizations such as the Illinois perinatal networks, the Illinois Perinatal Statewide Quality Council, the Greater Illinois Chapter of the March of Dimes, the Illinois Folic Acid Campaign and the National Birth Defects Prevention Network, and provided data to these organizations for use in their efforts to promote birth defect prevention.

4.2 Fiscal Year 2005 Major Accomplishments

4.2.1 Cooperative Agreement with the U.S. Centers for Disease Control and Prevention

In August, APORS completed its first year of a five-year cooperative agreement with the U.S. Centers for Disease Control and Prevention (CDC) to enhance Illinois birth defects surveillance and service referral. A shortened second year was completed in June 2005.

4.2.2 Hospital Training

In-service training for medical staff was conducted at 60 hospitals throughout the state. The purpose of the training was to promote the reporting of infants exposed to or diagnosed with hepatitis B and to review APORS reporting. Case identification and timeliness of reporting were emphasized.

4.2.3 Improved Birth Defects Surveillance

APORS continued its hybrid of passive case reporting as a starting point to identify potential birth defect cases. Cases within the APORS Birth Defects Surveillance (ABDS) system were electronically sent to regional field staff, who then performed reviews of the infants' medical charts, verified the presence of birth defects, eliminated false positives and collected additional diagnoses. In FY05, the abstractors reviewed 6,883 birth defects reported by hospitals and eliminated 805 false positive diagnoses; this resulted in 6,078 verified, passively reported diagnoses. Abstractors clarified a further 77 diagnoses and added 6,734 new diagnoses. As a result, 12,812 birth defects were verified, an 86 percent increase over passive hospital reporting.

4.2.4 Prevention Activities

APORS staff began distributing birth defect prevention information via news release and at health conferences. In April, a joint Illinois Department of Public Health (IDPH) and IDHS news release encouraged women of childbearing age to take folic acid. Several radio and television stations ran stories based on the release. Information booths were staffed at two conferences: the Breastfeeding Conference held in Springfield and the Prevention Conference held in suburban Chicago. County neural tube defects surveillance data and risk factor information was provided to 10 high-risk local health departments (Chicago and Cook, DeKalb, DuPage, Kane, Lake, Madison, McHenry, Peoria and Winnebago counties).

4.2.5 Linkages with Other Programs and Activities

4.2.5.1 Perinatal Programs. APORS continued to identify infants for the Illinois Department of Human Services' perinatal management and high-risk infant tracking program. More than 12,000 infants were referred from local health department nurse visits. Physical and psychological development monitoring and counseling for parents are provided through the nurse visits. APORS also identified infants for the IDPH Division of Infectious Diseases' congenital syphilis and perinatal hepatitis B programs, which ensure that all infants with congenital syphilis and infants prenatally exposed to or diagnosed with a hepatitis B infection are offered services. Data on all infants born with cleft lip and/or palate were supplied to the Department's Division of Oral Health's craniofacial anomaly program to ensure these infants receive appropriate services.

4.2.5.2 Interagency Committee on Maternal and Child Health Programs. In a joint effort with the IDPH newborn metabolic screening program, the Interagency Committee on Maternal and Child Health (MCH) Programs was created. With consistent and active contributions from APORS, the committee's goals are: 1) educating committee members on programs and issues relevant to maternal and child health; 2) educating others (i.e. public health professionals, health providers, other agencies) about MCH programs/services; and 3) identifying opportunities for integrating prevention activities.

- 4.2.5.3 Perinatal Health System of Illinois.** The Perinatal Health Statewide Quality Council serves in an advisory capacity to APORS. Neonatologists, perinatal center administrators and other professionals assist the program regarding medical aspects of adverse pregnancy outcome surveillance. The APORS manager serves on the council.
- 4.2.5.4 March of Dimes.** The March of Dimes is coordinating the Illinois Folic Acid Campaign to increase awareness that consumption of folic acid will prevent neural tube defects (NTDs). APORS is providing quarterly surveillance data on NTDs and other data reports to assist the March of Dimes in targeting its activities. The campaign will continue in FY06.
- 4.2.5.5 National Birth Defects Prevention Network (NBDPN).** APORS participated in the National Birth Defects Prevention Network with the registry manager serving on the state data committee.
- 4.2.5.6 Perinatal Networks.** APORS maintained communications with the perinatal network administrators to facilitate hospital reporting of APORS cases. APORS staff sought guidance from the perinatal administrators in matters related to hospital training.
- 4.2.5.7 U.S. Centers for Disease Control and Prevention.** APORS submitted quarterly reports on neural tube defects as part of CDC's and the National Birth Defects Prevention Network's efforts to monitor trends in the disease.

4.2.6 Quality Control Reports

There were no quality control reports completed in FY05.

4.3 Goals for Fiscal Year 2006

Improve Casefinding

- Conduct training for hospital staff regarding case identification.
- Match APORS newborn cases with hospital discharge data to identify missed newborn cases.
- Match APORS newborn cases with vital records (VR) birth data to identify missed newborn cases.

- Match APORS cases with VR infant death data to identify birth defect cases.
- Perform active case verification with new casefinding by performing hospital chart review.

Improve Quality of APORS Data

- Evaluate the accuracy of hospital reporting in terms of timeliness and accuracy, provide hospital-specific feedback and use results to identify hospital training needs.
- Evaluate the quality of the active case verification process in terms of timeliness and accuracy, provide individual-specific feedback and use results to identify staff training needs.
- Geocode new APORS cases and increase the percentage of cases geocoded to the exact street level to 97 percent.
- Provide ongoing in-service training to hospitals that have been identified as problem reporters in terms of timeliness, accuracy or case completeness.

Improve Program Effectiveness

- Use APORS surveillance data to improve access to health services and early intervention services.
- Use APORS surveillance data for birth defects prevention.
- Use the University of Illinois at Chicago School of Public Health's assessment and action plan to make program improvements and to make regulatory changes that enhance birth defect surveillance.
- Evaluate the timeliness of APORS reporting and report processing to identify areas, if any, where timeliness can be improved.
- Maintain linkages with key organizations, such as the Illinois perinatal networks, the Illinois Perinatal Statewide Quality Council, the Greater Illinois Chapter of the March of Dimes, the Illinois Folic Acid Campaign and the National Birth Defects Prevention Network.
- Coordinate the implementation of an APORS case-reporting module that will be a component of the new system for hospitals to report birth and death related data to IDPH.

5. OCCUPATIONAL DISEASE REGISTRY

The Occupational Disease Registry (ODR) has three components: the Adult Blood Lead Registry (ABLR), the Census of Fatal Occupational Injuries (CFOI) and the Occupational Safety and Health Survey (OSH).

5.1 Adult Blood Lead Registry

ABLR collects data on cases of elevated blood lead levels of 25 micrograms per deciliter (mcg/dl) and above for adults 16 years of age and older and notifies federal enforcement agencies to trigger inspections and/or interventions. Currently, this program is funded through a purchase order for data with the U.S. Centers for Disease Control and Prevention (CDC). Due to funding limitations no verification or quality checks are conducted.

5.1.1 Fiscal Year 2005 Accomplishments

Goals met

- Received 66 percent of the ABLR laboratory reports electronically.
- Notified federal Occupational Safety and Health Administration (OSHA) within 10 days of any company found to have employees with blood lead levels above 60 micrograms per deciliter of blood.
- Notified OSHA quarterly of any company that had employees with elevated blood lead levels above 40 micrograms per deciliter of blood.
- ABLR data were sent to the CDC's National Institute for Occupational Safety and Health (NIOSH) on a quarterly basis.

5.1.2 Interventions Resulting from ABLR Notifications of Elevated Lead Results

ABLR reported to OSHA the names of 35 companies with employees who had blood lead levels greater than 40 micrograms per deciliter of blood. OSHA conducted two site evaluations in Illinois during FY 2005 because of ABLR referrals. The results of the investigations resulted in fines totaling \$2,000 for the two companies in violation of OSHA rules.

5.1.3 Goals for Fiscal Year 2006

- Receive more than half of the ABLR laboratory reports electronically.
- Notify OSHA within 10 days of any company found to have employees with blood levels above 60 micrograms per deciliter of blood.

- Notify OSHA quarterly of any company that has employees with elevated blood lead levels above 40 micrograms per deciliter of blood.
- Notify CDC's NIOSH on a quarterly basis of those cases that were entered into the registry.

5.2 Census of Fatal Occupational Injuries (CFOI)

Fatal work injuries can often be traced to hazardous working conditions or unsafe work practices. The U.S. Bureau of Labor Statistics (BLS) developed the Census of Fatal Occupational Injuries (CFOI) as a cooperative venture between the states and the federal government to gather data about these events. The Illinois Department of Public Health has participated in CFOI since 1993. The data compiled by the CFOI program are published each year and contain information on the workers involved and the events surrounding each fatality.

5.2.1 Review and Evaluation of Fiscal Year 2005 Goals

Goals met

- Published a summary report of the 2003 fatal occupational injury data by October 2004.
- Provided information on fatal occupational injuries to the BLS, the funding source, no later than four months after the death.

5.2.2 Goals for Fiscal Year 2006

- Publish a summary report of the 2004 fatal occupational injury data by October 2005.
- Provide information on fatal occupational injuries to the BLS, no later than four months after the death.
- Meet the new deadlines for data completion set out by the BLS.

5.3 Occupational Safety and Health Survey (OSH)

The Occupational Safety and Health Survey (OSH) focuses on surveillance of non-fatal workplace injuries and illnesses. The Illinois OSH is supported through a cooperative agreement between the states and the U. S. Bureau of Labor Statistics. The Illinois data are pooled with that from other states to provide the total injury and illness rate for each industrial group at the national level. Because of Illinois' participation, the data are also published annually at the state level to give information on incidence rates for the type of injury, body part of the injury, the source of the injury and the event causing the injury.

5.3.1 Review and Evaluation of Fiscal Year 2005 Goals

Goals met

- Submitted data files on all reported occupational injuries and illnesses of the surveyed companies to the U.S. Bureau of Labor Statistics (BLS).
- Published a summary report of the occupational injuries and illnesses data to enable safety organizations and companies to identify causes and to produce training programs aimed at preventing them; and made summarized, but industry-specific, data available to companies and industrial groups.
- Collected, coded, and entered all 2003 data prior to BLS deadlines.

5.3.2 OSH Survey Process and Achievements for Fiscal Year 2005

In January 2004, ODR sent survey forms to 6,070 companies for 2003 data. OSH staff began receiving completed forms the following week with the highest volume arriving in mid-February. Six weeks after the initial mailing, receipt of reports had dropped off to approximately eight per day. A second request for data was sent to 2,806 non-responding companies on March 24, 2004. A third request, on April 24, 2004, went to 1,763 non-responding companies. In May 2004, non-responding companies were contacted by telephone to solicit data. Through staff diligence, the overall response rate was 96 percent, significantly surpassing the BLS standard of 85 percent.

5.3.3 Goals for Fiscal Year 2006

- Continue all activities in FY05 and maintain the high standards achieved by the program.

6. ENVIRONMENTAL PUBLIC HEALTH TRACKING

Environmental Public Health Tracking (EPHT) is the ongoing collection, integration, analysis and interpretation of data about environmental hazards, exposure to environmental hazards, and human health effects potentially related to exposure to environmental hazards. It includes dissemination of information learned from these data to federal, state and local agencies as well as to the public. The Illinois EPHT program was created in 2003 with federal funds; it is part of CDC's efforts to develop a national public health network that will 1) be standards-based; 2) allow direct electronic data reporting and linkage within and across health effect, exposure and hazard data; and 3) interoperate with other public health systems. Because of the program's focus on environmental hazards, exposure and their relationships with health outcomes,

Illinois' EPHT is a natural extension of the IHHSR's original unfunded Hazardous Substances Registry.

6.1 Review and Evaluation of Fiscal Year 2005 Goals

Goals met or partially met

- The initial legislation inventory has been completed. The inventory of databases has been completed for health effects data and is ongoing for environmental hazard data.
- Specialized training on Geographic Information Systems (GIS) usage and geocoding was provided to EPHT staff by the IDPH GIS Section. Additional advanced GIS training has been scheduled for the Environmental Health Specialist. An educational session about displaying data was provided to members of the planning consortium.
- The planning consortium set priorities for the linkage of databases for EPHT as follows: cancer, birth defects, childhood lead poisoning and asthma.
- The linkage and analysis for the DuPage County demonstration project has been completed.
- Staff developed Intranet and Internet (<http://www.idph.state.il.us/about/epi/epht.htm>) Web sites for EPHT information. They also developed a secure Web portal community for planning consortium members.

6.2 EPHT Progress and Achievements for Fiscal Year 2005

6.2.1 Geocoding Cancer and Birth Defects Data.

Population-based data for the Illinois State Cancer Registry and the Adverse Pregnancy Outcomes Reporting System were geocoded using an in-house software program (Map Marker 9.3 © and Map Info Professional© Version 6.5).

The records were assigned geocodes using the North American Datum (NAD) 83 standard, which is the most recent available. NAD is the base set of coordinate readings used to assign latitude and longitude coordinates in the United States. The new standard reflects emerging knowledge about the shape of the earth and corrects for large numbers of surveying errors accumulated in the old datum (NAD27).

The process includes: address standardization; verification of ZIP code based on city; assignment of ZIP +4 based on address; assignment of census tract or block numbering area (BNA); assignment of block group;

and assignment of latitude and longitude codes, including specificity level of the code or reason the record could not be coded.

The Illinois State Cancer Registry utilized rollover funds from CDC to hire temporary employees to verify address information that did not code to the address level when processed through the MapMarker© software. A 4.6 percent improvement in address level geocoding was accomplished through this project. With minimal cost and effort, the completeness of geocoding to the address level was increased to 89.3 percent.

The level of completeness for each geocode element varied little by year of diagnosis (see range in Table 6.2.1.1). A detailed quality assessment of the geocoding results for cancer data has been completed and will serve as a reference document for researchers using geocoded registry data.

| Table 6.2.1.1 Percentage of IHHSR Reports with Complete Geocoding as of November 2004 | | | |
|--|--------------------------|--------------------------|---------------------------|
| Range of Percentage Complete by Diagnosis Year | | | |
| | Average all years | Lowest | Highest |
| Cancer Reports (n=914,618 cases for diagnosis years 1986-2002) | | | |
| ZIP code | 99.9 | 99.9 | 99.9 |
| ZIP +4 code | 99.5 | 99.3 | 99.7 |
| Census Tract or BNA ¹ | 97.2 | 95.7 | 97.9 |
| Lat/Lon code ² | 99.9 | 99.9 ³ | 100.0 ³ |
| address specific | 89.3 | 87.1 | 91.2 |
| centroid ZIP +4 | 0.5 | 0.3 | 0.7 |
| centroid ZIP +2 | 2.1 | 1.8 | 2.7 |
| centroid ZIP | 8.1 | 5.8 | 10.7 |
| APORS Reports (n= 249,452 cases for birth years 1989-2004) | | | |
| ZIP code | 99.8 | 99.0 | 99.5 |
| ZIP +4 code | 94.3 | 92.5 | 96.0 |
| Census Tract or BNA ¹ | 98.7 | 97.2 | 99.7 |
| Lat/Lon code ² | 98.7 | 97.2 ³ | 99.7 ³ |
| address specific | 93.0 | 91.5 | 94.4 |
| centroid ZIP +4 | 1.3 | 0.8 | 1.7 |
| centroid ZIP +2 | 1.7 | 1.3 | 2.4 |
| centroid ZIP | 2.7 | 1.5 | 4.4 |
| ¹ BNA – block-numbering areas are small statistical subdivisions of a county for grouping and numbering blocks in non-metropolitan counties where local census statistical area communities have not established census tracts (accounts for 10-12 percent of these numbers). Accuracy is based on the specificity of the address specific matches. ² Latitude and longitude ³ The number is not equal to the sum of all centroid ZIP and address specific percentages because they did not all occur in the same year. | | | |

6.2.2 GPSI Intern

EPHT was successful in its application for a Graduate Public Service Intern (GPSI) through the University of Illinois at Springfield. The internship is for a period of two years and will be used to help with software development and database design.

6.2.3 National Workgroups

Division staff participated in two national EPHT workgroups: Program Marketing and Outreach, and Systems and Network Development.

6.2.4 Cost Extension Application

EPHT submitted a 10-month cost extension application to CDC, which, if approved, would extend the end of this funding cycle until July 31, 2006. Original objectives are still due at the end of current funding year. CDC provided a list of allowable objectives for the cost extension period.

6.2.5 Collaborative Efforts

A neonatologist from Indiana University contacted EPHT to discuss a bi-state study of possible relationships between groundwater contamination by agricultural chemicals and certain types of birth defects. This would also involve the U.S. Geological Survey (USGS) as a source of groundwater monitoring data. Discussions are ongoing to determine the feasibility of such a study.

6.3 Goals for Fiscal Year 2006

- Identify and characterize sources of asthma exacerbation data.
- Identify and characterize air-monitoring data for ozone and particulate matter.
- Investigate the compatibility of asthma exacerbation data with ozone and particulate matter measures in the bi-state East St. Louis/St. Louis area.
- Submit a plan for the staged development of a standards-based Environmental Public Health Tracking System to CDC.

7. CLUSTER INQUIRIES AND EVALUATIONS

7.1 Review and Evaluation of Fiscal Year 2005 Goals

All goals were met

- Responded to all inquiries with information and educational materials regarding cancer diseases.
- Completed all cluster evaluations within six months of the written request.

7.2 Fiscal Year 2005 Accomplishments

The Division responded to **all** inquiries about perceived cancer clusters by providing information and educational materials regarding cancer diseases. One study initiated in July 2003 was in progress at the end of FY04 and ultimately completed in November 2004.

In FY05, the Department received 67 calls concerning perceived cancer excesses. The response protocol requires staff to first discuss general epidemiologic information about cancer with the caller, explain the cluster protocol and expected outcomes, and send educational materials when appropriate. For 16 of these calls, previous cancer cluster evaluations were already available to answer the concerns. Staff used published cancer rates by county, epidemiologic reports and data from the public data files (n=28) or general information about the frequency of cancer or causes of cancer to help address the callers' concerns. Two written requests were received to conduct in-depth cluster evaluations. One evaluation was completed within 14 weeks and the other evaluation involves numerous ZIP code areas, some without population data, and is expected to be completed by September 2006.

In a cluster evaluation, the study areas are defined by geography, usually a county or ZIP code area. The number of cancer cases observed in the study area is compared with the number of cancer cases expected for the population of that area. The expected numbers are derived from the age-, sex- and race-specific incidence rates in an area of Illinois with a similar population density as the study area. Applying appropriate statistical methods, the data are compared to see whether the observed incidence is higher than the expected. All reports are public documents and are available on request. The one completed evaluation is summarized in the table below.

Table 7.2.1 Cancer Cluster Evaluations Completed in Fiscal Year 2005

| Name (ZIP) | Cancer Type | Obs.^a | Exp.^b | Years of Study | Comment |
|-----------------------|---|------------------------------|-------------------------|-----------------------|--|
| Chicago (60601-60611) | all glioblastomas | 24 | 17 | 1991-2000 | |
| Ottawa (61350) | all males all females thyroid (age 15-34) | 677 697 7 ^c | 676 693 2 | 1991-2000 | The incidence of thyroid cancer is relatively high between the ages of 15 and 39 years. Other than ionizing radiation, the causes of thyroid cancer are unknown. From recent epidemiologic studies, factors suspected to be associated with thyroid cancer include benign thyroid nodules and goiter, hormonal and reproductive variables, dietary intake and genetic factors. |

^aObserved number of cases.

^bExpected numbers are based on the age-, sex- and race-specific incidence rates in an area of Illinois with a similar population density as the study area.

^cObserved number is statistically different from the expected number at $p < .01$

7.3 Work in Progress

- Evaluations of the cancer incidence in the Blue Island area (numerous ZIP code areas) will be initiated as soon as population data can be obtained.

7.4 Fiscal Year 2006 Objectives

- Respond to all inquiries with information and educational materials regarding cancer diseases.
- Complete cluster evaluations within 12 months of the written request.

8. RESEARCH PROGRAM

The research section of the Illinois Health and Hazardous Substance Registry represents a crucial link between data collection and data dissemination and between raw data and ready-to-be digested information. Through various formats, registry data were summarized, tabulated, analyzed, and presented to policy makers, health professionals and the general public.

8.1 Fiscal Year 2005 Major Accomplishments

8.1.1 Creation of Best Practice

The Department's Division of Epidemiologic Studies researchers continue to play leadership roles in advancing research on surveillance and registry operations. Two registry algorithms created by Division researchers: the algorithm to assign Hispanic ethnicity based on race, name and birthplaces, and the algorithm to evaluate confidentiality levels of large micro data files have been recognized by the National Association of Central Cancer Registries as the best practice. The two algorithms were validated by the organization and accepted as registry standards. All central cancer registries in North America are recommended to apply these algorithms to their data. A draft paper has been prepared to publish the algorithms in a peer-review journal.

8.1.2 Participation in Department-wide Activities

Division staff participated extensively in the Department's Data Release and Research Committee, the Reduction of Health Disparity team, the Committee on Data Standards, the Committee on Public Use Files, the Cervical Cancer Task Force, and Reform and Renewal Public Health Team 7: Using Data for Public Health Decision making. Five staff are currently serving on these committees in various capacities.

8.1.3 Community Outreach

In response to community requests, Division staff conducted on-site consultations and presentations in the following communities and groups:

- Downers Grove, at the invitation of the Citizens' Advisory Group. Private wells in parts of Downers Grove and Lisle have been found to be contaminated by solvents believed to have come from nearby industrial sites. Division staff answered questions from the audience.

- Dan Ryan Expressway Reconstruction Health Consultation Group, at the request of the Illinois Department of Public Health and the Illinois Department of Transportation. The focus of this group is to provide advice on the planned expressway reconstruction project in Chicago to reduce the potential health impact to nearby residents. The group meets regularly at the University of Chicago campus.

8.2 Scientific Publications in Fiscal Year 2005

The following articles were prepared and/or in the process of publication.

- 8.2.1** Leonard DR, Rariden RL, Beccue B, Shen T. Attempts to Minimize Manual Review During Registry Duplication. *J Reg Management* (in process)
- 8.2.2** Howe HL, Lake A, Shen T. Method to Access Identifiability in Electronic Data Files. *Am J. Epidemiology*.

8.3 Other Reports or Publications That Used Registry Data

- 8.3.1** Ellison JH, Wu XC, Howe HL, McLaughlin CC, Lake A, Firth R, Sullivan SK, Roney D, Cormier M, Leonfeller S, Kosary C (eds). *Cancer in North America, 1998-2002. Volume Three: NAACCR Combined Incidence Rates*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. April 2005.
- 8.3.2** Ellison JH, Wu XC, Howe HL, McLaughlin CC, Lake A, Firth R, Sullivan SK, Roney D, Cormier M, Leonfeller S, Kosary C (eds). *Cancer in North America, 1998-2002. Volume One: Incidence*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. April 2005.
- 8.3.3** Ellison JH, Wu XC, Howe HL, McLaughlin CC, Lake A, Firth R, Sullivan SK, Roney D, Cormier M, Leonfeller S, Kosary C (eds). *Cancer in North America, 1998-2002. Volume Two: Mortality*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. April 2005.
- 8.3.4** Ellison JH, Wu XC, Howe HL, McLaughlin CC, Lake A, Firth R, Sullivan SK, Roney D, Cormier M, Leonfeller S, Kosary C (eds). *Cancer in North America, 1998-2002. Volume Four; Cancer Incidence in U.S. Hispanic/Latino Populations*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. April 2005.
- 8.3.5** Greenlee R. *Variation in Cancer Stage at Diagnosis by Area-Level Poverty and Urban/Rural gradient in CINA Deluxe 1995-2001*. North American Association of Central Cancer Registries, Inc. March 2005.

- 8.3.6** Greenlee R. *Evaluation of Methods to Estimate and Compare Race/Ethnicity Specific Cancer Incidence Rates Using Combined Central Cancer Registry Data*. Springfield, Ill.: North American Association of Central Cancer Registries, June 2004.
- 8.3.7** Athas W. *Quality Assessment of CINA Deluxe, 1995-1999 Morphology Data*. Springfield, Ill.: North American Association of Central Cancer Registries, May 2004.
- 8.3.8** Howe HL. *Evaluation of NHIA Submissions for 1997-2001*. Springfield, Ill.: North American Association of Central Cancer Registries, October 2004.
- 8.3.9** Wu XC, Chen VW, Martin HJ, Roffers SD, Groves FD, Correa CN, Hamilton-Byrd E, Jemal A. Subsite Specific Colorectal Cancer Incidence Rates and Stage Distributions among Asians/Pacific Islanders in the United States, 1995-1999. *Cancer Epidemiol Biomarkers Prev* 2004;13(7):1215-22.
- 8.3.10** Jemal A, Clegg LX, Ward E, Ries LAG, Wu XC, Jamison PM, Wingo PA, Howe HL, Anderson RN, Edwards BK. Annual reports to the nation on the status of cancer, 1975-2001, with a special feature regarding survival. *Cancer* 2004;101:3-27.
- 8.3.11** Perkins CI, Hotes J, Kohler Ba, Howe HL. Association between breast cancer laterality and tumor location, United States, 1994-1998. *Cancer Causes and Control*. 2004;15(7):1215-22.
- 8.3.12** Aldrich TE. Review: Quality Assessment of CINA Deluxe, 1995-1999 Morphology Data, 2004. *J Reg Management* 2004;31(3):111.
- 8.3.13** U.S. Cancer Statistics Working Group. *United States Cancer Statistics, 2001 Incidence and Mortality*, Atlanta Georgia: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; 2004.

8.4 Epidemiologic Report Series

The following reports were released in the Department's Epidemiologic Report Series; all reports are available to the public upon request.

- 8.4.1** Maxfield R, Shen T. Survey of Workplace Nonfatal Injuries and Illnesses Illinois, 2002. Epidemiologic Report Series 04:01 Springfield, Ill.: Illinois Department of Public Health, May 2004.

- 8.4.2** Qiao B, Shen, Snodgrass JL. Illinois Cancer Statistics Review, 1986-2001. Epidemiologic Report Series 04:05 Springfield, Ill.: Illinois Department of Public Health, November 2004.
- 8.4.3** Maxfield R, Shen T. Occupational Railroad Fatalities, Illinois, 1992-2002. Epidemiologic Report Series 04:06 Springfield, Ill.: Illinois Department of Public Health, November 2004.
- 8.4.4** Wamack J, Maxfield R, Shen T. Census of Fatal Occupational Injuries, Illinois, 2003 Epidemiologic Report Series 04:07 Springfield, Illinois.: Illinois Department of Public Health, November 2004.
- 8.4.5** Qiao B, Shen T, Snodgrass JL. Illinois County Cancer Statistics Review, Incidence, 1997-2001. Epidemiologic Report Series 05:01 Springfield, Ill.: Illinois Department of Public Health, January 2005.

8.5 Fiscal Year 2005 Presentations by Division Staff

| Title | Event | Date |
|---|---|-------------|
| ISCR-CTR Prep Workshop (collaboration between ISCR, ACS, CRI and Chicago Area Cancer Registry Association) | One-day workshop for registrars planning on taking the cancer registry certification exam (Harvey) | July 2004 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Carle Foundation Hospital (Urbana) and Gibson Area Hospital (Gibson City) | July 2004 |
| Macon County Concerns of Birth Defects Occurrence | Macon County Health Department and representatives from Illinois Environmental Protection Agency and Macon County Board of Health | July 2004 |
| Cancer Surveillance and Registration | Graduate students at the University of Illinois at Chicago School of Public Health | August 2004 |
| ISCR and the Internet Cancer Query System | ISCR brief demonstration at the Illinois Public Health Information Network (I-PHIN) kick-off meeting. | August 2004 |

| Title | Event | Date |
|---|---|----------------|
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Children's Memorial Hospital (Chicago); Christ Hospital and Medical Center (Oak Lawn); Evanston Hospital; Highland Park Hospital; Hope Children's Hospital (Oak Lawn); Lake Forest Hospital; OSF St. Anthony Medical Center (Rockford); Provena Covenant Medical Center (Urbana); Rockford Memorial Hospital; Rush-Presbyterian, St. Luke's Medical Center (Chicago); St Joseph Hospital (Chicago); St. James Hospital and Health Centers (Chicago Heights); and Swedish American Hospital (Rockford) | August 2004 |
| EPHT Planning Consortium Quarterly Meeting | Illinois Department of Transportation (Springfield) | August 2004 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Barnes-Jewish Hospital (St. Louis), Cardinal Glennon Children's Hospital (St. Louis), Hinsdale Hospital, Ingalls Hospital (Harvey), Northwest Community Hospital (Arlington Heights), St. Alexis Medical Center (Hoffman Estates), St. John's Mercy Medical Center (St. Louis), St. Louis Children's Hospital (St. Louis), and Silver Cross Hospital (Joliet) | September 2004 |
| ISCR New Abstractor On-Site Training | Springfield Clinic (Springfield) Memorial Hospital (Chester) | September 2004 |
| ISCR Advanced Workshop: Abstracting Collaborative Stage and Identifying and Abstracting Benign Brain Tumors | Good Samaritan Hospital (Mt. Vernon), LaSalle Building (Chicago), Penta Building (Springfield), Memorial Medical Center (Springfield) | September 2004 |

| Title | Event | Date |
|--|---|----------------|
| ISCR Advanced In-Service: Abstracting Multiple Primary Tumors | Illinois Department of Public Health (Springfield) | September 2004 |
| ISCR Advanced Workshop: Abstracting Collaborative Stage and Identifying and Abstracting Benign Brain Tumors | Delnor Hospital (Geneva), James R. Thompson Center (Chicago), St. Anthony's Hospital (Rockford) | October 2004 |
| ISCR New Abstractor On-Site Training | Oak Brook Surgery Center (Oak Brook) | October 2004 |
| Overview of EPHT Program, Progress and Future Direction | Illinois Environmental Health Association's Annual Educational Conference (Peoria) | October 2004 |
| Key Themes and Messages | Poster presentation at 2004 National Environmental Public Health Tracking Workshop (San Francisco, California) | October 2004 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Children's Memorial Hospital (Chicago), Ingalls Hospital (Harvey), Norwegian American Hospital (Chicago), Mercy Hospital & Medical Center (Chicago), Riverside Medical Center (Kankakee), St. Anthony Hospital (Chicago), Silver Cross Hospital (Joliet), Trinity Hospital (Chicago) and University of Chicago Hospitals | October 2004 |
| Cancer Burden in Illinois | National Comprehensive Cancer Control Leadership Institute's Illinois State Meeting (Chicago) | October 2004 |
| ISCR Reporting Requirements and Different Career Paths for Cancer Registrars | Morraine Valley Community College (Palos Hills) | November 2004 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Illinois Masonic Medical Center (Chicago), Northwestern Memorial Hospital (Chicago) and University of Iowa Hospital (Iowa City, Iowa) | November 2004 |

| Title | Event | Date |
|---|--|---------------|
| Update for Citizens' Advisory Group | Presentation to 75-member Citizens' Advisory Group (Downers Grove) | November 2004 |
| Collaborative Staging | Chicago Area Cancer Registrars' Association quarterly meeting (Maywood) | November 2004 |
| Cancer 101 | Ingalls Hospital (Harvey) | November 2004 |
| ISCR Advanced Workshop: Abstracting Collaborative Stage and Identifying and Abstracting Benign Brain Tumors | Illinois Department of Public Health (Springfield) | December 2004 |
| Cancer Burden in Illinois | American Cancer Society and CDC Joint Cancer Leadership Institute Meeting (Chicago) | December 2004 |
| Cervical Cancer Incidence and Mortality in Illinois | Illinois Cervical Cancer Elimination Task Force | December 2004 |
| Basic ISCR Reporting Requirements | Hammond-Henry Hospital (Geneseo), Anderson Hospital, (Maryville) Carbonodale Memorial Hospital | December 2004 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Little Company of Mary Hospital (Evergreen Park), and St. Francis Hospital and Health Center (Blue Island) | December 2004 |
| ISCR New Abstractor On-Site Training | Illinois Metro Radiation Therapy Center (Fairview Heights) | December 2004 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Little Company of Mary Hospital (Evergreen Park), and St. Francis Hospital and Health Center (Blue Island) | December 2004 |
| ISCR-Basic Training Workshop | Sarah Bush Hospital (Mattoon), South Suburban Hospital (Hazel Crest) | January 2005 |

| Title | Event | Date |
|--|---|---------------|
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Evanston Hospital, Lutheran General Hospital (Park Ridge), OSF St. Francis Medical Center (Peoria), and Rush Medical Center (Chicago) | January 2005 |
| Actively Passive Birth Defect Ascertainment Supplementing Passive Case Ascertainment with Active Case Verification | Poster presentation at the National Birth Defects Prevention Network 8 th Annual Meeting (Scottsdale, Arizona) | January 2005 |
| ISCR New Abstractor On Site Training | Northshore Endoscopy (Lake Bluff) | January 2005 |
| ISCR Reporting Requirements and Different Career Paths for Cancer Registrars | Presentation to MPH graduate class at University of Illinois – Springfield | January 2005 |
| Issues related to tracking health disparities | Bromen Regional Medical Center (Normal) and Provena Covenant Medical Center (Urbana) | January 2005 |
| Applied Epidemiology | Presentation to MPH graduate class at University of Illinois - Springfield | February 2005 |
| ISCR Basic Training Workshop | Penta Building (Springfield) | February 2005 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | Bromen Regional Medical Center (Normal) and Prevena Covenant Medical Center (Urbana) | February 2005 |
| Cancer Burden Challenges to the Illinois Cancer Registry | Presentation to American Cancer Society (Chicago) | February 2005 |
| ISCR New Abstractor On-Site Training | Danville Polyclinic, Hopedale Hospital, Ottawa Hospital | February 2005 |
| APORS Case Identification and Completion of Reporting Forms (in-service training) | CGH Medical Center (Sterling), FNH Memorial Hospital (Freeport), and Illinois Masonic Medical Center (Chicago) | March 2005 |

| Title | Event | Date |
|---|---|------------|
| ISCR New Abstractor On-Site Training | St. Anthony's (Chicago), Jersey Hospital (Jerseyville), Trinity Hospital (Rock Island), Orland Park Surgery Center | March 2005 |
| APORS Case Identification and Completion of Reporting Forms-- (In-Service training) | St. John's Hospital (Springfield) | April 2005 |
| Ways to Advance EPHT through State and Local Partnership | National Environmental Public Health Tracking Conference (Atlanta, Georgia) | April 2005 |
| Illinois EPHT Legislative Tracking Software | National Environmental Public Health Tracking Conference (Atlanta, Georgia) | April 2005 |
| Cancer burden challenges to the Illinois Cancer Registry | SIU Health Service Journal meeting (Springfield) | April 2005 |
| ISCR Reporting Requirements and Different Career Paths for Cancer Registrars | Southern Illinois Collegiate Common Market (Herrin) | April 2005 |
| New Abstractor On-Site Training | OSF St. Francis Medical Center (Peoria) | April 2005 |
| Abstracting Staging and Treatment Workshop, ISCR | Anderson Hospital (Maryville), Clay County Hospital (Flora), St. James Hospital (Chicago Heights), LaSalle Building (Chicago) | May 2005 |
| ISCR Reporting Requirements and Different Career Paths for Cancer Registrars | College of DuPage, Health Information Management students | May 2005 |
| EPHT Planning Consortium Quarterly Meeting | Penta Building (Springfield) and remote WebEx sites | May 2005 |
| Abstracting Staging and Treatment Workshop, ISCR | Memorial Hospital (Carbondale), Penta Building (Springfield), Trinity Hospital (Moline) | June 2005 |
| ISCR New Abstractor On-Site Training | Community General Hospital (Sterling) | June 2005 |

8.6 Research Data and Collaborations

| Principal Investigator (Affiliation) | Title | Date | Funding Source |
|---|--|----------|---|
| Rosalind Ramsey-Goldman, Dr.Ph. Northwestern University, Feinberg School of Medicine | Project Title: Exposure to Immunosuppressive Drugs and Cancer Risk in Systemic Lupus Erythematosus (SLE) | 08/25/04 | National Arthritis Foundation and NCI/NIH |
| Laura Rogers, M.D., M.P.H., Southern Illinois University School of Medicine | Exercise and Rural Breast Cancer Survivors (Sangamon County) | 07/22/04 | SIU School of Medicine Internal Grant |
| Diane Johner | Gastroschisis in Macon County Macon County Health Department | 07/04 | |
| Sandy Reno, Will County Community Economic Development | Drug Exposed Infants in Will County | 12/28/04 | |
| Elizabeth Colloton, Chicago Department of Public Health, Office of Epidemiology | Drug Exposed Children in ZIP Codes 60636 and 60621 | 12/07/04 | |
| Jeff Peddycoart, IDHS | Children in APORS by Race and Ethnicity | 10/27/04 | |
| Adam Rappapat, Illinois Spina Bifida Association | Rates of Spina Bifida by Survival Status | 08/05/04 | |
| Belinda Waller, IDHS | Demographic and Diagnostic Information for APORS Cases by Selected ZIP Codes | 07/15/04 | |
| Katrina Armstrong, M.D., M.S.C.E., University of Pennsylvania | Segregation and Racial Disparities in Prostate Cancer | 10/29/04 | NCI |

| Principal Investigator (Affiliation) | Title | Date | Funding Source |
|--|---|-------------------|-----------------------|
| Steven Saunders, M.D., M.P.H., Illinois Department of Human Services | <ul style="list-style-type: none"> • Fetal Alcohol Syndrome • Neural Tube Defects • Frequency of Congenital Anomalies, Very-Low Birth Weight, and all APORS Cases • Frequency of Drug Exposed Infants • African-American Women Delivering Very-Low Birth Weight Infants in Selected Chicago Areas • Diagnoses Among Infants and Fetal Death | 07/04 to 06/05 | CDC |
| Gary Marsh, Ph.D., University of Pittsburgh | The Cohort Mortality and Cancer Incidence Studies of the Rahway, NJ Facility | 02/18/05 | Merck Pharmaceuticals |
| Elizabeth Colloton, Chicago Department of Public Health, Office of Epidemiology | Chromosomal Anomalies in Chicago | | CDC |
| Brooke Kinniburgh, Epidemiology Fellow, IDHS | Fetal Alcohol Syndrome | 04/07/05 | |
| Gwen Smith, Bureau of Maternal and Child Health Promotion, IDHS | Neural Tube Defects (Chicago) | 03/21/05 | |
| Lynn Rosenberg, S.C.D., Boston University/Slone Epidemiology Center | The Black Women's Health Study: A follow-up study | 12/08/04 | NIH/NCI |
| Maya Shahani,, University of Illinois at Chicago | Craniofacial Anomalies | | CDC |

| Principal Investigator (Affiliation) | Title | Date | Funding Source |
|--|--|---|--|
| Lillian Pezzin, Ph.D., J.D., Medical College of Wisconsin | Incident Breast Cancer | 02/18/05 | NIH/NCI |
| Lisa Dye, M.Ed., March of Dimes, Illinois Chapter, and Center for Birth Defects and Development Disability | Rapid Ascertainment of Neural Tube Defect Occurrence by Quarter | 09/04 12/04 03/05 06/05 | CDC |
| U.S. Centers for Disease Control and Prevention | Patterns of Care Study | Data collection completed 9/04 | CDC |
| March of Dimes, Illinois Chapter | Neural Tube Defects and High-Risk Areas in Illinois | 10/04 | |
| Paul Levine, M.D., George Washington University | Cancer Patterns in Gulf War Era Veterans | 11/07/03 (ongoing into 2005) | CDC, Association of Schools of Public Health, and Department of Veterans Affairs |
| National Birth Defect Prevention Network | Preterm Birth Study | 10/04 | |
| Monica Peek, M.D., M.P.H., Rush University Medical Center | County Sponsored Mobile Mammography Van Services for Low-Income Women | 03/03/05 | |
| World Health Organization | International Cleft Lip Study | 11/04 | |
| Luc Anselin, Ph.D., University of Illinois at Urbana-Champaign | Cancer Exploratory Spatial Data Analysis and Spatial Statistics | 05/24/05 | ATPM/CDC |
| Clifford Ko, M.D., M.S., M.S.H.S., University of California at Los Angeles | Improving the Care and Outcomes in Ovarian Cancer: A Population- Based Evaluation | Partial application on file 6/05 | CDC |

| Principal Investigator (Affiliation) | Title | Date | Funding Source |
|--|---|---|--|
| Christopher Masi, M.D., Ph.D., University of Chicago | The Geographic Distribution of Breast Cancer and Other Cancers in Cook County, Illinois | April 2004, data released 04/28/05 | UC |
| Laura Rogers, M.D., M.P.H., Southern Illinois University School of Medicine | Exercise and Rural Breast Cancer Survivors (State- Wide) | 05/31/05 | |
| Louise Wideroff, Ph.D., NCI | Evaluation of the Accuracy of Family History of Cancer Data in Population Surveys | April 2004, data released 12/08/04 | NIH |
| Fahui Wang, Ph.,D., Northern Illinois University | Spatial Clusters of Late- Stage Cancers in Illinois and Association with Healthcare Access | January 2004, released 02/02/05 | U.S. Department of Health and Human Services |
| Dick Warnecke, Ph.D., University of Illinois at Chicago | Neighborhood and Individual Effects on Stage at Diagnosis | 11/04 | NCI |
| Meir Stampfer, M.D., Dr.Ph., Brigham and Women's Hospital (Boston, Massachusetts) | Health Nurse's Study | Ongoing | NIH |
| NOTE: Following are definitions of acronyms used in the above table: American Cancer Society (ACS), U.S. Centers for Disease Control and Prevention (CDC), North American Association of Central Cancer Registries (NAACCR), National Cancer Institute (NCI), National Institutes of Health (NIH), and Association of Teachers of Preventive Medicine (ATPM) | | | |

9. GRANTS

The table below summarizes the division grant awards for FY2005:

| Grant | Agency | Status |
|---|---------------|---------------|
| Occupational and Health Survey in Illinois (continuation) | BLS | Funded 08/04 |
| Census of Fatal Occupational Injuries in Illinois (continuation) | BLS | Funded 08/04 |

| Grant | Agency | Status |
|---|--------|--------------|
| Adult Blood Lead Epidemiology and Surveillance (continuation) | CDC | Funded 07/04 |
| Cooperative Agreements for the Development of State-Based Birth Defects Surveillance Programs and the Use of Surveillance Data for Public Health Programs (continuation) | CDC | Funded 07/04 |
| Cooperative Agreements for the Development of State-Based Birth Defects Surveillance Programs and the Use of Surveillance Data for Public Health Programs (roll-over from 2004 Project Year) | CDC | Funded 05/05 |
| Perinatal Hepatitis B Program (submitted by IDPH, Division of Infectious Disease) (continuation) | CDC | Funded 12/04 |
| National Cancer Prevention and Control Program-National Program of Cancer Care (continuation) | CDC | Funded 07/04 |
| National Cancer Prevention and Control Program-National Program of Cancer Care (roll-over from PY03) | CDC | Funded 02/05 |
| National Environmental Public Health Tracking Program (continuation) | CDC | Funded 08/04 |
| National Environmental Public Health Tracking Program (roll-over from PY 03) | CDC | Funded 07/04 |
| U. S. Public Health Services-Indian Health Services (new) | CDC | Funded 02/05 |
| NOTE: Full titles of acronyms used in the above table are U.S. Centers for Disease Control and Prevention (CDC), Bureau of Labor Statistics (BLS), and Illinois Department of Public Health (IDPH). | | |

9.1 Activities of Funded Grants

The Division of Epidemiologic Studies received a total of \$2,901,579 in grant awards in fiscal year 2005.

9.1.1 Occupational and Health Survey in Illinois

The Department received \$117,784 in August 2004 from the U.S. Bureau of Labor Statistics to support the seventh year of the Occupational and Health Survey (OSH) in Illinois. This project is described in Section 5.

9.1.2 Census of Fatal Occupational Injuries in Illinois

The Department received \$75,496 in October 2004 from the U.S. Bureau of Labor Statistics to support the 13th year of the Census of Fatal Occupational Injuries (CFOI) in Illinois. This project is described in Section 5.

9.1.3 Adult Blood Lead Epidemiology and Surveillance

In July 2004, CDC contracted with the Department to provide quarterly data to the CDC, Adult Blood Lead Epidemiology, and Surveillance program. The Department received \$22,744 to provide the data for the fourth year of this agreement. The progress for this project is described in Section 5.

9.1.4 Improvement of Birth Defects Surveillance Programs.

In July 2004, the Department was awarded \$150,000 from CDC for year two (10 months) of a new five-year project period to evaluate, improve and expand the state birth defects surveillance program (APORS). The progress for this project is described in Section 4.

In May 2005, the Department received permission to rollover \$23,139 from PY04. These funds will be used to print additional educational material about prevention of birth defects and will be handed out at the Illinois State Fair and other public meetings.

9.1.5 Perinatal Hepatitis B Program

The division received \$20,000 in December 2004 to continue expansion of APORS surveillance and data collection to include perinatal hepatitis B and to develop a tracking system to identify newborn infants requiring follow-up immunization services. The progress for this project is described in Section 4.

9.1.6 National Cancer Prevention and Control Program

In July 2004, CDC awarded the Department \$6.88 million in funding for the third year of the National Cancer Prevention and Control Program. This grant combines three previous separate grants: the National Breast and Cervical Cancer Early Detection Program, the National Comprehensive Cancer Control Program and the National Program of Cancer Registries (NPCR). The division received \$1,438,372 for the NPCR component, which is in its ninth year. NPCR continues to focus on four aspects of the existing program: achieve 95 percent completeness of reporting; expand the quality control program; redesign the database

in a PC environment; and collect, code and computerize treatment data and occupation and industry information. The program for this project is described in Section 3.

In February 2005, the Department received permission to rollover \$358,805 from PFY03. These funds will be utilized to accomplish four major goals: collect treatment information for cancer records missing treatment information; demonstrate that the data entry of various fields from the death certificate when combined with available electronic information from the death certificate and electronic coding of the cause of death will get the information to ISCR death certificate only staff more quickly and eliminate the need for copying more than 7,500 death certificates each year; geocoding; and, provide infrastructure support for rapid case ascertainment.

9.1.7 National Environmental Public Health Tracking Program

In July 2004, the division was awarded an additional \$162,846 in rollover funds from year one to expand activities for year three. Details about the expanded activities are in Section 6

In August 2004, the Department was awarded \$617,956 by CDC to establish an enhanced environmental public health tracking system in Illinois. The division's share was \$529,893 with the remainder going to the Department's Division of Environmental Health. Details of the progress of activities are in Section 6.

9.1.8 U. S. Public Health Services – Indian Health Services

In February 2005, the division received \$2,500 of new funds from the U. S. Public Health Services through CDC to match names of American Indian and Alaska Natives on the Indian Health Services database with cases on ISCR to identify cases that may have been misclassified as non-Native. Details about the activities are in Section 3.

10. CANCER REPORTING FACILITIES THAT HAVE NOT COMPLETED REPORTING FOR THE 2004 YEAR BY JULY 1, 2005.

Due to substantial standard-setter delays in the implementation of national standards changes for the 2004 diagnosis year, an extension was given for reporting 2004 diagnosis year cases until October 1, 2005.

11. ACRONYMS

Acronyms Used in the Illinois Health and Hazardous Substances Registry Annual Report

| | |
|--------|---|
| ABLR | Adult Blood Lead Registry |
| ACS | American Cancer Society |
| APORS | Adverse Pregnancy Outcomes Reporting System |
| ATPM | Association of Teachers of Preventive Medicine |
| BLS | Bureau of Labor Statistics |
| BNA | Block Numbering Area |
| CDC | Centers for Disease Control and Prevention |
| CFOI | Census of Fatal Occupational Injuries |
| CINA | Cancer in North America |
| CRI | Cancer Registrars of Illinois |
| CTR | Certified Tumor Registrar |
| DCO | Death Certificate Only |
| DOD | Department of Defense |
| EPHT | Environmental Public Health Tracking |
| FY | Fiscal Year |
| GIS | Geographic Information Systems |
| GPSI | Graduate Public Service Intern |
| ICCCP | Illinois Comprehensive Cancer Control Program |
| IDHS | Illinois Department of Human Services |
| IDPH | Illinois Department of Public Health |
| IHHSR | Illinois Health and Hazardous Substance Registry |
| ISCR | Illinois State Cancer Registry |
| HIPAA | Health Insurance Portability and Accountability Act |
| MCH | Maternal Child Health |
| NAACCR | North American Association of Central Cancer Registries |
| NAD | North American Datum |
| NBDPN | National Birth Defects Prevention Network |
| NCI | National Cancer Institute |
| NIH | National Institutes of Health |
| NIOSH | National Institute for Occupational Safety and Health |
| NPCR | National Program of Cancer Registries |
| NTD | Neural Tube Defects |
| ODR | Occupational Disease Registry |
| OSH | Occupational Safety and Health Survey |
| OSHA | Occupational Safety and Health Administration |
| POC | Patterns of Care |
| PY | Project Year |
| RCA | Rapid Case Ascertainment |
| UIC | University of Illinois at Chicago |
| USGS | U.S. Geological Survey |
| VA | Veteran's Administration |
| VR | Division of Vital Records |