



State of Illinois
Department of Public Health

Annual Report Illinois Health and Hazardous Substances Registry

July 2018 through June 2019

November 2019

Annual Report
Illinois Health and Hazardous Substances Registry
July 2018 through June 2019



A Report to Governor J.B. Pritzker
and the 101st General Assembly
from the
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Table of Contents

Acronyms	iii
1. Executive Summary	1
1.1 Illinois Health and Hazardous Substances Registry (IHHSR) Goal	1
1.2 Fiscal Year 2019 Highlights	2
1.3 Illinois Health and Hazardous Substances Registry Coordinating Council	3
1.4 Goals for Fiscal Year 2020	3
2. Program Data	4
Table 2.1 Registry Data Collection	4
Table 2.2 Registry Data Dissemination, Reports and Publications	5
3. Illinois State Cancer Registry	6
3.1 Review and Evaluation of Fiscal Year 2019 Goals	6
3.1.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry.....	6
3.1.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting.....	6
3.1.3 Provide Training for Reporting Facilities and for Central Registry Staff.....	7
3.1.4 Ensure Data Quality.....	7
3.1.5 Maintain Data Use Activities	8
3.1.6 Provide Adequate Program Management	9
3.2 Fiscal Year 2019 Major Accomplishments	9
3.2.1 North American Association of Central Cancer Registries Gold Certification	9
3.2.2 National Program of Cancer Registries (NPCR) Registry of Excellence	9
3.2.3 Initiation and Completion of a High-Profile Cancer Assessment in Willowbrook, Illinois	9
3.2.4 Collaboration with State and National Organizations	10
3.2.5 Quality Control Reports.....	11
3.3 Goals for Fiscal Year 2020	11
3.3.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry.....	11
3.3.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting.....	11
3.3.3 Provide Training for Reporting Facilities and for Central Registry Staff.....	12
3.3.4 Ensure Data Quality.....	12
3.3.5 Maintain Data Use Activities	12
3.3.6 Provide Adequate Program Management	13
4. Adverse Pregnancy Outcomes Reporting System	14
4.1 Review and Evaluation of Fiscal Year 2019 Goals	14
4.2 Fiscal Year 2019 Major Accomplishments	17
4.2.1 Cooperative Agreement with the U.S. Centers for Disease Control and Prevention (CDC).....	17
4.2.2 Cooperative Agreement with the March of Dimes (MOD)	17
4.2.3 Enhancement of the APORS Database	17
4.2.4 Improved Birth Defects Surveillance	17
4.2.5 Evaluation of Case Management Services Provided to APORS Cases	18
4.2.6 Linkages with Other Programs and Activities.....	18
4.2.7 Quality Control Reports.....	20
4.3 Goals for Fiscal Year 2020	21
5. Occupational Disease Registry	23
5.1 Adult Blood Lead Registry (ABLR)	23
5.1.1 Fiscal Year 2019 Accomplishments	23
5.1.2 Interventions Resulting From ABLR Notifications of Elevated Lead Results	23
5.1.3 Goals for Fiscal Year 2020	23
5.2 Census of Fatal Occupational Injuries and Illnesses (CFOI)	24

5.2.1	Review and Evaluation of Fiscal Year 2019 Goals	24
5.2.2	Goals for Fiscal Year 2020	24
5.3	Survey of Occupational Injuries and Illnesses (SOII) (formerly Occupational Safety and Health Survey)	244
5.3.1	Review and Evaluation of Fiscal Year 2019 Goals	24
5.3.2	Survey Process and Achievements for Fiscal Year 2019.....	25
5.3.3	Goals for Fiscal Year 2020	25
6.	Hazardous Substances Registry	26
6.1	Geocoding Process and Accomplishments.....	26
6.1.1	Geocoding Cancer and Birth Defects Data	26
	Table 6.1.1.1 Percentage of IHHSR Reports with Complete Geocoding as of November 2017	27
6.2	Goals for Fiscal Year 2019.....	27
7.	Cluster Inquiries and Assessments	27
7.1	Review and Evaluation of Fiscal Year 2019 Goals	27
7.2	Fiscal Year 2019 Accomplishments	27
7.3	Fiscal Year 2020 Objectives	28
8.	Research Program	29
8.1	Fiscal Year 2019 Major Accomplishments	29
8.1.1	Provision of Epidemiologic Support to IDPH Committees and Workgroups.....	29
8.1.2	Provision of Peer-Review Service to Scientific Publication	29
8.1.3	Provision of Epidemiologic Supervision and Tutoring.....	29
8.1.4	Publication of the Department-wide Illinois Morbidity and Mortality Bulletin (IMMB).....	29
8.1.5	Technical Assistance.....	29
8.1.6	IDPH Institutional Review Board	30
8.2	Scientific Publications in Fiscal Year 2019.....	30
8.3	Other Recent Reports or Publications That Used Registry Data.....	31
8.4	Epidemiologic Report Series.....	33
8.5	Fiscal Year 2019 Presentations by IDPH Division of Epidemiologic Studies Staff.....	34
8.6	Research Data Release and Collaborations	36
9.	Grants	38
9.1	Funded Grants	38
9.1.1	Survey of Occupational Injuries and Illnesses in Illinois (formerly Occupational Safety and Health Survey)	38
9.1.2	Census of Fatal Occupational Injuries in Illinois	38
9.1.3	Improvement of Birth Defects Surveillance Program	38
9.1.4	National Cancer Prevention and Control Program.....	39
9.1.5	Neonatal Abstinence Syndrome Surveillance	39

Acronyms

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

ABLR	Adult Blood Lead Registry
ACS	American Cancer Society
AHRQ	Agency for Healthcare Research Quality
APORS	Adverse Pregnancy Outcomes Reporting System
BLS	Bureau of Labor Statistics (U.S. Department of Labor)
CDC	U.S. Centers for Disease Control and Prevention
CFOI	Census of Fatal Occupational Injuries
CINA	Cancer in North America
FY	Fiscal Year
GIS	Geographic Information System
IARC	International Agency for Research on Cancer
IBCCP	Illinois Breast and Cervical Cancer Program
ICCCP	Illinois Comprehensive Cancer Control Program
IDHFS	Illinois Department of Healthcare and Family Services
IDPH	Illinois Department of Public Health
IHDDI	Illinois Health Data Dissemination Initiative
IHHSR	Illinois Health and Hazardous Substance Registry
IMMB	IDPH's Illinois Morbidity and Mortality Bulletin
IRB	Institutional Review Board
ISCR	Illinois State Cancer Registry
MMWR	CDC's Morbidity and Mortality Weekly Reports
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 of Occupational Safety and Health
NPCR	National Program of Cancer Registries
ODR	Occupational Disease Registry
OSH	Occupational Safety and Health Survey
OSHA	Occupational Safety and Health Administration
SEER	Surveillance of Epidemiology and End Results
SOII	Survey of Occupational Injuries and Illnesses
VA	Veteran's Administration
VR	Division of Vital Records

1. Executive Summary

The Illinois Department of Public Health's (IDPH) 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 includes 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 Survey of Occupational Injuries and Illnesses (SOII)], and a research and data dissemination section. This is the registry's 33rd annual report and it describes major registry activities and accomplishments from July 2018 through June 2019 (FY19).

The mission of the IHHSR includes the following:

- collect and maintain statewide reports on the incidence of cancer, adverse pregnancy outcomes, and occupational diseases and injuries;
- conduct epidemiologic analyses and health assessments at the state and local levels;
- provide a source of information for the public;
- monitor changes in incidence to detect potential public health problems, trends, and progresses;
- use data to help target intervention resources for communities, patients, and their families;
- inform health professionals and citizens about risks, early detection, and treatment of cancers in their communities; and
- promote high quality research to provide better information for disease prevention and control.

1.1 Illinois Health and Hazardous Substances Registry (IHHSR) Goal

The basic goal of the registry, according to the Act, is to develop and to 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 to use this information in decision making and public health policy development.

1.2 Fiscal Year 2019 Highlights

- Received \$1.64 million from federal funds and nearly \$27,500 from other non-general revenue sources, mostly through competitive processes, to support activities of the IDPH Division of Epidemiologic Studies
- Collected detailed case reports on Illinois residents with 63,135 newly diagnosed cancer cases (2017), 12,388 children with adverse pregnancy outcomes (2017), 2,580 adult lead poisoning cases (2018), 37,400 representative non-fatal occupational disease and injury sample records (2017), and 163 fatal occupational injuries (2017)
- Responded to 15 requests for general information about the registry, 43 requests for epidemiologic reports and registry data, and 19 special data requests or collaborations from outside researchers
- Responded to nine inquiries about perceived cancer excesses in local communities and neighborhoods, including a comprehensive cancer assessment in Willowbrook, IL in response to community concerns about ethylene oxide emissions from a Sterigenics facility in the area.
- Prepared and submitted five grant proposals to support the registry's operations and research
- Released one research paper in the Illinois Morbidity and Mortality Bulletin, one report in the Epidemiologic Report Series, and prepared six written reports for quality control studies of registry data
- Authored or co-authored four scientific papers for peer-reviewed journals
- Data released by the registry were used in 19 published studies by outside researchers
- Actively participated in national and statewide health programs; provided data, information, and epidemiologic support as needed
- Referred Illinois children with adverse birth outcomes to programs that provide follow-up services
- Referred six employees from six employers with elevated blood lead levels to the U.S. Occupational Safety and Health Administration (OSHA) for onsite inspection
- Delivered presentations at ten professional meetings
- Provided leadership and management support to IDPH Institutional Review Board (IRB), with three Division of Epidemiologic Studies staff serving as members, one as vice chair, one as the IRB's standing coordinator, and one as a regular member.
- On behalf of IDPH, reviewed, edited, and published the Illinois Morbidity and Mortality Bulletin (IMMB) which features scientific articles based on analyzing Illinois data

1.3 Illinois Health and Hazardous Substances Registry Coordinating Council

The IHHSR Act included that the Health and Hazardous Substances Coordinating Council should be comprised of 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. Due to time and budgetary constraints, the Council did not have a face-to-face meeting in fiscal year 2018. Instead, the Council reviewed and approved the annual report via written ballot.

1.4 Goals for Fiscal Year 2020

1. Continue to collect complete, timely, and high quality data to monitor disease distributions and trends among Illinois residents
2. Engage partners, stakeholders, and communities in data dissemination and utilization to support health research and programs
3. Respond to public concerns about disease clusters in Illinois with registry data and information
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 of Epidemiologic Studies' programs
6. Conduct epidemiologic studies with registry data to provide information to the public health community and to policy makers
7. Provide epidemiological data and information to federal, state, and local health education and intervention programs
8. Work through the Division of Epidemiologic Studies Program Review and IDPH's Institutional Review Board (IRB) to provide researchers with high-quality and timely registry data to support research advancing scientific knowledge and improving public health
9. Provide health regulatory 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 to maintain the registry's certification status and data utilization.

2. Program Data

Tables 2.1 and 2.2 summarize the registry's data collection and dissemination activities for last year compared with data from the previous years. In order to be consistent with the common reporting schedule, numbers in Table 2.1 are expressed in calendar years during which cases were diagnosed or defined. There is normally a two-year time delay for cases being reported to IHHSR. Due to the dynamic nature of the registry databases, the numbers in the table may not be the same as previously reported. These numbers represent cases processed or estimated by the registry and they do not reflect rate calculations that would require population denominators, nor case completeness that would require independent evaluations. Projections or forecasts for the future year also are included.

Table 2.1 Registry Data Collection

	Calendar 2013	Calendar 2014	Calendar 2015	Calendar 2016	Calendar 2017	Estimated 2018
ISCR Invasive Neoplasms (including bladder <i>in situ</i>)	66,436	67,952	69,198	68,954	63,135 ¹	72,790
Breast <i>in situ</i> female only	2,584	2,483	2,470	2,443	2,419 ¹	2,400
Brain – benign/borderline	2,391	2,549	2,496	2,383	2,153 ¹	2,000
APORS Cases – All	9,724 ²	10,377	11,402	12,144	12,388	12,000
NBDPN Children	2,141	2,113	2,355 ⁷	2,821 ⁷	2,792 ^{3,7}	2,400
# NBDPN Birth Defects	3,507	3,843	5,357 ⁷	5,595 ⁷	4,862 ^{3,7}	4,000
Occupational Disease Reports						
ABLR lead poisoning						
New reports	623 ⁴	1,060	1,704	852	770	908 ⁵
Total reports	2,161 ⁴	2,347	3,056	2,918	2,463	2,580 ⁵
Occupational Fatality Cases	176	164	172	171	163	166
Injuries	176	164	172	171	163	166
Occupational Safety and Health Survey⁶						
Estimated Cases based on						
Sampling	38,690	38,280	39,700	33,170	37,400	37,812
Sprains, strains	13,580	14,320	15,309	11,940	12,850	13,768
Bruises, contusions	3,110	2,880	3,255	2,580	2,790	2,994
Cuts, lacerations	3,170	2,600	3,613	2,810	4,590	3,382
Fractures	3,340	4,010	4,405	3,070	4,690	3,764
Multiple injuries	790	1,450	715	420	300	751
Carpal tunnel syndrome	380	270	238	290	240	335
Heat burns	380	310	596	530	560	494
Tendonitis	200	70	38	70	130	98
Amputations	260	160	199	300	190	217
Chemical burns	180	60	238	60	140	133
Hazardous Substances (GIS)						
Geocoding registry cases	All	All	All	All	All	

¹ Reporting is not complete for the calendar year indicated. The numbers are estimated based on the current projected incidence.

² The numbers for 2013 are lower because APORS case definition changed in 2013 and a new reporting mechanism was introduced. It took a while for hospital staffs to adjust to the changes.

³ To date 8/16/18 – data are not complete

⁴ IHHSR Rule change to lower threshold for reporting cases of elevated adult lead levels to mirror the federal requirements from $\geq 25\mu\text{g}/\text{dL}$ to $\geq 10\mu\text{g}/\text{dL}$.

⁵ Actual counts for 2018

⁶ Private industries only, cases with days away from work include those that result in days away from work with or without job transfer or restriction.

⁷ In 2015, 2016 and 2017, APORS collected information about additional diagnoses suspected of being associated with prenatal exposure to the Zika virus.

Table 2.2 Registry Data Dissemination, Reports and Publications

	FY15	FY16	FY17	FY18	FY19	Estimated FY20
Data Requests						
General information	27	23	39	15	20	20
Data and reports	77	59	32	33	30	30
Cluster inquiries	22	8	6	9	8	8
Confidential data released and research collaborations	23	17	22	19	18	15
Confidential data applications	4	1	0	0	1	5
Quality Assurance Studies						
<i>Casefinding visits</i>						
APORS	22 ¹	4	4	4	1	0
ISCR	74	31	51	69	42	50
<i>Cases added from casefinding visits</i>						
APORS ²	8,350	7,158	9,729 ³	13,703	11,095	10,000
ISCR ⁴	856	683	1,142	1,182	917	1,200
<i>External audits of facility data</i>						
ISCR	204	229	244	0	1	2
<i>Internal quality control reports issued</i>						
APORS	6	3	2	4	4	4
ISCR	3	3	3	2	2	2
ABLR	0	1	0	0	0	0
Public Use Microdata Files	5	5	5	5	5	5
Publications						
Epidemiologic report series	7	6	8	8	1	6
IMMB and other publications	0	3	2	1	1	1
Peer-reviewed publications	2	5	2	4	5	2
Publications by outside researchers	16	21	18	19	23	18
Oral/poster presentations	8	5	7	10	4	5
Grant Proposals Funded	5	5	7	5	5	5

¹ Fewer hospital casefinding visits have been conducted since FY14 because field staff access medical records remotely for almost all reporting hospitals.

² Represents additional birth defects identified and confirmed through the active case verification process where the medical records or previously submitted cases are reviewed.

³ The APORS program has been doing additional chart review on infants born in 2015, 2016, and 2017 with Zika-associated birth defects in collaboration with the U.S. Zika Birth Defects registry.

⁴ Represents cases missed by hospital reporting, but identified by ISCR during casefinding visits.

3. Illinois State Cancer Registry

As the only population-based source for cancer incidence information in Illinois, the Illinois State Cancer Registry (ISCR) collects cancer cases through mandated reporting by hospitals, ambulatory surgical treatment centers, non-hospital affiliated radiation therapy treatment centers, independent pathology labs, physicians, and through the voluntary exchange of cancer patient data with 11 other states. For the 2016 diagnosis year, ISCR received reports from three Veteran's Administration (VA) facilities in Illinois.

ISCR continues to require reporting facilities to submit cases in an electronic format. There are currently 187 reporting hospitals in Illinois and all are reporting electronically. Dermatologists and pathology labs have been set up with access to a web-based reporting system. Ambulatory centers and radiation therapy centers use either the free Abstract Plus reporting software or the Internet-based Web-Plus program.

3.1 Review and Evaluation of Fiscal Year 2019 Goals

3.1.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry

- Met NAACCR gold certification standard for complete, accurate, and timely data for the 21st consecutive year
- Maintained case reporting at all non-federal facilities by conducting 42 facility case finding visits for the 2017 diagnosis year; 917 missed cases were identified
- Completed interstate data exchange by transmitting 1,430 de-duplicated, edited state-specific cases to 11 states and received and processed 5,012 cases from 11 states
- Completed death clearance for the 2016 death year and maintained a death certificate only rate of 2.1 percent. In total, 3,558 cancer diagnoses were followed with 341 letters or lists mailed to hospitals, physicians, nursing homes, and hospice centers
- Added 90 percent of cases for the 2017 diagnosis year to the ISCR database by December 2018
- Added 100 percent of cases for the 2016 diagnosis year to the ISCR database by December 2018

3.1.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintained reporting by physicians and pathology labs

- Expanded reporting by physicians in Illinois by 5 percent through focused targeting and training

3.1.3 Provide Training for Reporting Facilities and for Central Registry Staff

- Provided basic training by entering into a limited, six-month personal services contract with the North American Association of Central Cancer Registries (NAACCR) to provide four basic training sessions and seven advanced training sessions; these onsite training sessions were presented in the spring of 2019 in central, southern, and northern Illinois; the trainer position (required by the National Program of Cancer Registries (NPCR)) has not been filled
- Provided six in-person reporting workshops across the state designed solely for dermatologists reporting melanoma
- Provided on demand access to a SEER Summary Staging training webinar available to all cancer reporters across the state
- Provided on demand access to a nine-part "Introduction to Cancer Reporting" webinar training series available to all cancer reporters across the state
- Provided individual phone or e-mail support for 1,813 requests related to technical support and reporting issues
- Attended the national educational conferences of the National Cancer Registrar's Association and the NAACCR
- Attended the annual educational conference sponsored by the Cancer Registrars of Illinois in September 2018
- Provided access to 32 advanced training workshops for 531 reporters via WebEx® utilizing nationally developed advanced training materials
- Provided limited individual training by the quality control field staff at 16 facilities
- Provided ongoing educational opportunities for central registry staff through participation in 12 nationally broadcast education webinars

3.1.4 Ensure Data Quality

- Maintained a duplicate rate of fewer than one per 1,000 primary cases
- Met NPCR/NAACCR standards for data quality
- Applied GenEDITS metafiles to the ISCR database and ran all standard-setter required edits and performed reconciliation for identified errors

- Matched vital records death data to the ISCR database to update unknown values in the latter; Race codes: of 20,497 cases with an unknown or missing race, 448 (2.2 percent) cases were matched and updated with a valid race; Maiden name: 19,584 cases (4.4 percent) were matched and updated with valid maiden names; Hispanic origin: 388 cases, or 4.2 percent, were matched and updated with valid data element codes for Hispanic origin; Birthplace: of 549,264 cases with unknown or missing birthplace, 38,195 cases (7.0 percent) were matched and updated with a valid birthplace; Death variable information also was updated
- Added census tract information to the cancer database; all records were geocoded using MapMarker® Version 30; 92.8 percent of the addresses were geocoded to an address specific level
- Ensured override flags were within the NPCR average by reviewing the NPCR Data Evaluation Reports revealing that the percentage of override flags in the ISCR submission file were lower for all associated edits than the NPCR median

3.1.5 Maintain Data Use Activities

- Produced annual cancer statistics, including the public use data file, annual state cancer report, annual county cancer report, and updated the cancer query system
- Provided general cancer information for cancer inquiries and conducted cancer assessments when there is evidence of long environmental contaminations by carcinogens.
- Provided data for the Illinois Comprehensive Cancer Control Program (ICCCP)
- Provided data for the Illinois Breast and Cervical Cancer Program (IBCCP)
- Formed the Illinois Cancer Coalition in conjunction with the ICCCP and IBCCP to foster collaboration, cooperation, and data-driven practices among programs within the Illinois Department of Public Health that impact cancer prevention and control
- Performed data linkage with the IBCCP file and provided the required information back to the IBCCP program
- Produced one epidemiologic report
- Produced two quality control reports
- Updated incidence projections
- Submitted 1,504,596 cases to NPCR and NAACCR for the 1995-2016 call for data
- Submitted 63,135 cases to NPCR for the 2017 diagnosis year call for data

3.1.6 Provide Adequate Program Management

- Kept registry staff informed of grant progress, standards changes and reporting issues through monthly staff meetings
- Monitored registry operations activities to meet grant objectives via an electronic tracker, and streamlined registry operations through more efficient use of staff and resources

3.2 Fiscal Year 2019 Major Accomplishments

3.2.1 North American Association of Central Cancer Registries Gold Certification

For the 21st consecutive year, ISCR has been recognized as having met the **gold standard** – the highest standard for registry certification. To be awarded this honor, a registry must have 95 percent or better completeness of case ascertainment; 98 percent validity of information recorded for selected data variables (age, sex, race and state/county); death-certificate only cases less than three percent; duplicate primary cases fewer than one per 1,000; 100 percent of the records passing the NAACCR EDITS without error; and data submissions within 24 months of the close of the accession year.

3.2.2 National Program of Cancer Registries (NPCR) Registry of Excellence

For the 6th consecutive year, ISCR has been recognized as a Registry of Excellence by the U.S. Centers for Disease Control's National Program of Cancer Registries – their highest standard for registry certification. To be awarded this honor, a registry must have met all CDC NPCR standards for data completeness and quality. ISCR is one of 18 states to receive this designation.

3.2.3 Initiation and Completion of a High-Profile Cancer Assessment in Willowbrook, Illinois

In response to community concerns and CDC/ATSDR recommendations, ISCR initiated and completed a comprehensive assessment of cancer incidence in populations surrounding a Sterigenics facility which has been emitting for years a known cancer-causing chemical, ethylene oxide (EtO), into the air. The study was the first of its kind in the nation and is currently being modeled by other states as they tackle the same concern about EtO in their communities. Throughout the study, the registry staff kept the local leadership and local community informed of every major step they took in data gathering, data analysis and report preparation. When the study was completed, the draft report was sent out for peer review and input, and as soon as the final report was released, staff went to townhall meetings to report, explain and answer questions from residents about the study's findings. The staff also briefed state and local leaders, and legislators right before the report was released. The careful execution and rollout of the study's report has won praises from local leaders and other agencies. The study generated a lot of interest and attention from media and the public that the Department issued a news release, and a designated email box was created to answer questions.

3.2.4 Collaboration with State and National Organizations

3.2.4.1 Illinois Comprehensive Cancer Control Program - Illinois Department of Public Health (IDPH)

IDPH has implemented the Comprehensive Cancer Control State Plan, which identified cancer prevention and control priorities for Illinois. Several Division of Epidemiologic Studies staff provided technical and operational support for the program through committee participation.

3.2.4.2 Vital Records – Illinois Department of Public Health

Death certificate data from the IDPH 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 matched cases. Death information available from the VR death file also is 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 seen at their facilities.

The VR death file also contributes to the data quality and item-specific completeness of the ISCR database through a matching protocol. Known information from the VR death file is imported into the ISCR database (when unknown on the ISCR database) for the following variables: race, birthplace, Hispanic origin, and maiden name.

3.2.4.3 North American Association of Central Cancer Registries (NAACCR)

ISCR provided comprehensive data from 1995-2016 to NAACCR in response to the call for data and registry certification process. The data were used to support research and generate cancer descriptions in North America publications. Staff also participated in various NAACCR committees and workgroups, contributing knowledge and expertise to this volunteer organization.

3.2.4.4 U.S. Centers for Disease Control (CDC) National Program of Cancer Registries (NPCR)

ISCR submitted comprehensive data from 1995-2016 to the CDC NPCR 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.

3.2.4.5 Illinois Breast and Cervical Cancer Program (IBCCP)

ISCR provided data support for this state and federally-funded program, which focuses on developing comprehensive education, outreach, and screening for breast and cervical cancer.

3.2.4.6 American Cancer Society (ACS)

Illinois statewide cancer incidence and mortality data were provided to ACS for its production of Illinois Cancer Facts and Figures. Registry staff regularly attend ACS activities in the area of data and epidemiology. The collaboration is ongoing.

3.2.5 Quality Control Reports

3.2.5.1 Parrish P. *Assessment of Duplicate Records for 1995-2016 Diagnosis Years*. Quality Control Report Series 18:05. Springfield, Ill.: Illinois Department of Public Health, November 2018.

3.2.5.2 Hebert L. *Linking Illinois State Cancer Registry Records with Vital Records Death Master File to Enhance Data Completeness*. Quality Control Report Series 18:04. Springfield, Ill.: Illinois Department of Public Health, October 2018.

3.3 Goals for Fiscal Year 2020

3.3.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry

- Perform facility casefinding for the 2018 diagnosis year at selected reporting facilities in Illinois and track identified missed cases to ensure reporting
- Maintain interstate data exchange and complete exchanges by November 2019
- Continue death certificate clearance and maintain death certificate only rate of less than three percent
- Achieve 90 percent case reporting for the 2018 diagnosis year by December 2019
- Achieve 95 percent case reporting for the 2017 diagnosis year by December 2019

3.3.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

- Maintain contact with existing physician offices for reporting and training (n=152)
- Maintain contact with existing pathology labs for reporting and training (n=14)
- Expand reporting of physician offices in Illinois by identifying offices, training personnel, and implementing reporting for those not currently submitting cases to ISCR
- Perform facility case finding and implement any additional training needed at newly reporting physician offices in Illinois

3.3.3 Provide Training for Reporting Facilities and for Central Registry Staff

- Contract with NAACCR education staff to provide five training workshops across the state
- Develop, update, and maintain new cancer reporting training website for all Illinois Cancer reporters
- Provide individual phone support for technical and operational issues from cancer incidence reporters and reporting facilities
- Provide monthly advanced training workshops via the Web, utilizing established seminars
- Provide on-demand basic training webinars for cancer reporting
- Provide on-demand staging training webinars for cancer reporting
- Provide ongoing educational opportunities for central registry staff through webinars and attendance at relevant regional and national association and grant meetings
- Update membership status in national associations

3.3.4 Ensure Data Quality

- Maintain duplicate rate of less than 0.01 percent using Link Plus to review submissions for duplicate tumor reports and apply NAACCR duplicate protocol
- Meet NPCR/NAACCR standards for data quality and override flags
- Perform gender verification using established ISCR procedure
- Apply NPCR, NAACCR and Illinois-specific GenEDITS metafiles to ISCR database for reconciliation of inter- and intra-record inconsistencies
- Update ISCR unknown variables by linking to the IDPH's death file
- Geocode all records on the ISCR database
- Update case vital status via linkage with the National Death Index

3.3.5 Maintain Data Use Activities

- Produce public use data set file, annual state and county report file, update cancer query system, and produce annual report of incidence rates by local community. Provide data visualization tools on ISCR website to facilitate understanding and access to state and local cancer data.

- Respond to cluster inquiries
- Provide data and support for IBCCP and ICCCP
- Perform linkage with IBCCP and update data files
- Produce one epidemiologic report
- Produce a publication for the layperson on cancer in Illinois
- Perform linkage with Indian Health Services and update code for Native American race
- Process applications for confidential data
- Update incidence and mortality projections
- Submit the 1995-2017 NPCR/NAACCR file for combined call for data and submit the 2018 data file for NPCR call for data

3.3.6 Provide Adequate Program Management

- Hold monthly staff meetings
- Monitor grant activities
- Update advisory committee on grant progress and activities

4. Adverse Pregnancy Outcomes Reporting System

The Adverse Pregnancy Outcomes Reporting System (APORS) collects information on Illinois infants and young children 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 in order to correct and prevent developmental problems and other disabling conditions.

Mandated statewide data collection began in August 1988. Licensed Illinois hospitals are required to report adverse pregnancy outcomes to APORS. In addition, APORS receives reports from four hospitals in St. Louis that are part of the southern Illinois perinatal network.

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; shows signs and symptoms of drug toxicity or withdrawal; or the mother admits to illegal drug use (except cannabis) during the pregnancy;
- the infant or young child (younger than two years of age) is diagnosed with a congenital anomaly; a congenital infection; an endocrine, metabolic, or immune disorder; a blood disorder; or another high-risk medical condition;
- the infant was born at 31 completed weeks of gestation; or
- a neonatal or fetal death has occurred.

4.1 Review and Evaluation of Fiscal Year 2019 Goals

Improve Casefinding

- Ninety-six (80.7%) of the 119 birth facilities that are part of the Illinois Perinatal Network have been trained on and are using the APORS database introduced in FY14; more than 87% of cases are reported to APORS electronically. The database automatically generates APORS case reports for newborns who are premature (≤ 30 completed weeks); are part of triplet or higher order births; who have a serious infection, birth defect, or seizures marked on the birth certificate; or who die before the birth certificate is filed.
- Training in APORS reporting continued through formal trainings, webinars, use of the SharePoint® site for hospital staff, computer-based trainings, conversations with hospital staffs, and responses to questions

- Provided 9 trainings in person, by phone, or webinar and held 1,329 consultations via telephone or e-mail with Illinois hospitals to improve APORS reporting.
- Updated SharePoint® site with revised manuals and appendices, and the most recent of the quality control reports; reminders are posted when patterns of problems are identified.
- Received three hospital discharge data files covering all hospitals containing data for children as old as two years of age—these data have been imported into the IDPH chart review database. An additional 112 children born in 2016, 585 born in 2017, 972 born in 2018 and 4 born in 2019 were identified as possible APORS birth defect cases.
- Reviewed the medical records of 1,928 infants identified from hospital discharge data; on average, 63.7% of the cases were found to have conditions that meet the APORS review criteria
- Reviewed charts of 74 mothers who experienced a fetal death associated with a congenital anomaly on the fetal death certificate, to verify the information on the certificate. Of the reviewed charts, 71.6% were confirmed to be cases meeting the APORS case criteria.
- Rapid case ascertainment of birth defects associated with the Zika virus is almost complete, with 7 cases (of 1,333) still needing initial chart review. An additional 18 cases need supplementary data collection.
- Four genetic clinics have reported 504 mothers carrying babies with prenatally suspected significant birth defects. Of the reports that meet the APORS criteria, most were eventually matched to an APORS report obtained from a fetal death or live delivery. About 5% (28 reports) identified APORS cases that were not reported by hospital nurseries. Neither birth nor fetal death certificates could be found for another 10 cases, indicating that the mother terminated the pregnancy.

Improve Quality of APORS Data

- Evaluated the timeliness of hospital reporting for cases reported in January through December 2018; provided hospital-specific feedback and used results to identify hospital training needs. In 2018, 74.0% of hospitals met the APORS timeliness standard of reporting cases within seven days of infants' hospital discharge. Hospitals are notified twice yearly of their timeliness status and provide more intensive education to facilities that are non-compliant.
- Evaluated the rates of hospital reporting in 2017. The case reporting rates ranged from 0.0 to 22.6% with the average being 6.8%. This degree of variation is not unexpected, since hospitals providing the highest level of care have the most cases to report.
- APORS aims to complete active case verification for a birth cohort during the following year. Rapid case verification for Zika associated birth defects slowed this process for the

2015 and 2016 birth cohorts. The 2017 birth cohort should be completed on time. The reabstraction study for 2016, demonstrates most fields are accurate more than 97% of the time. The exceptions are delivery weight, street address, date and method of diagnoses, and diagnoses that are not among the selected conditions for which chart review is done. A training quiz is also used to monitor staff performance and individual feedback is provided.

- Evaluated Illinois surveillance of neonatal abstinence syndrome (NAS) in 2015 and 2016, by comparing hospital reporting with chart review data. More than a fourth (28.4%) of babies with NAS in these years were not reported to APORS. Distributed the results of the study to hospitals, and, in collaboration with the Illinois Perinatal Quality Collaborative, provided improved guidelines on reporting NAS and prenatal drug exposure to APORS.
- Hospitals are contacted if a report is incomplete or is internally contradictory. These contacts are used as training opportunities when appropriate. If hospital staffs are unaware that reports have been automatically generated by the APORS database, APORS staff notifies them and asks for the reports to be completed.

Improve Program Effectiveness

- In addition to the SharePoint® site updates of revised manuals, appendices, and quality control reports, hospitals and local health departments can access the forms to request additional materials.
- Maintained linkages with key organizations, such as the Illinois perinatal networks and the National Birth Defects Prevention Network and provided data to these organizations for use in their efforts to promote birth defect prevention.
- The APORS program worked with IDPH, state, and local programs to assure the ongoing provision of perinatal services for high risk infants.
- A surveillance report examining the prevalence of birth defects in Illinois was published.
- Was awarded a renewed CDC cooperative agreement to do birth defect surveillance; and completed the data collection for the one-year award through March of Dimes to undertake improved surveillance of neonatal abstinence syndrome (NAS) in collaboration with Dr. Amanda Bennett from the Office of Women's Health and Ashley Horne, CSTE Fellow.
- Continued to provide Zika-associated birth-defect data to CDC. APORS will continue collecting this information until the 2016 and 2017 birth cohorts are completed.

4.2 Fiscal Year 2019 Major Accomplishments

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

APORS was approved for the final year of a four-year cooperative agreement with the CDC to enhance Illinois birth defects surveillance, prevention and service referral. Funding for 2018 is \$210,000.

4.2.2 Cooperative Agreement with the March of Dimes (MOD)

APORS closed out the March of Dimes award for NAS surveillance and is currently analyzing the data from the study.

4.2.3 Enhancement of the APORS Database

APORS staff completed modifications to the APORS database to accommodate the fields needed to document the rapid Zika ascertainment. In addition, changes were initiated to contain information collected by the abstractors during chart review. The modifications have not yet been implemented since previous modifications for another program are still awaiting approval from the database owners. However, the development database has been used to enter the rapid Zika ascertainment data, and it has been extracted and submitted to CDC.

All local health departments are using the APORS database introduced in FY14; and 96 hospitals are registered. These hospitals report more than 87 percent of the cases received by APORS.

4.2.4 Improved Birth Defects Surveillance

Hospital-reported cases are a starting point for birth defect surveillance. Potential birth defect cases were sent electronically to regional field staff members, who then reviewed the infants' medical charts, verified the presence of birth defects, eliminated false positives, and collected additional diagnoses. In FY19, the abstractors reviewed 9,268 birth defects reported by hospitals. The table shows the disposition of the conditions reviewed by the APORS staff.

Source	Reported	Confirmed	Deleted
Hospital Nursery Reporting	6,188	3,525	2,472
Hospital Discharge Data	3,080	1,655	1,340
Chart Review	0	11,427	0
Other ¹	31	22	9
Any Source	9,299	16,629	3,821

¹ Vital record certificates, genetic clinics, Newborn Metabolic Screening Program

Abstractors deleted 913 reported birth defects that could not be found in the charts, or that had been ruled out by the facility. Another 2,299 were not collected because the infant did not have a collected birth defect or because the birth defect did not meet specific criteria (often conditions that are considered normal in a premature infant). Some conditions were deleted because they

were included as parts of confirmed complex conditions (552). The remaining 57 conditions were deleted for other reasons.

Case abstraction for 2016 birth cohort was completed in January 2018. The goal is to be complete within two years of the birth year. This year was slower as a new staff member was trained and the Zika surveillance continued.

Abstractors continued to prioritize chart review for infants reported with microcephaly in response to Zika virus concerns. They have almost completed collection of additional information, such as head circumference, length, and weight measurements for infants with Zika virus-related birth defects.

4.2.5 Evaluation of Case Management Services Provided to APORS Cases

APORS collaborated with community health agencies (CHA's) in surveying APORS families offered or receiving case-management services through the High-risk Infant Follow-up Program. CHA's have documented outcomes in 79.8 percent of the cases referred in FY19. Some families (24.2 percent) could not be contacted or live in an area where services are not available. Among the families with surviving newborns and documented outcomes who were offered services, 34.0 percent accepted.

4.2.6 Linkages with Other Programs and Activities

4.2.6.1 Perinatal Programs

4.2.6.1.1 Illinois Department of Human Services High-risk Infant Follow-up. APORS continued to identify infants for the Illinois Department of Human Services (IDHS) perinatal management and high-risk infant tracking program. More than 10,000 (10,212) infants were referred for local health department nurse visits. Physical and psychological development monitoring and counseling for parents are provided through the nurse visits. Included are 49 children with neural tube defects, whose families were referred for prevention counseling.

4.2.6.1.2 IDPH Division of Infectious Diseases. APORS identified infants for the IDPH Division of Infectious Diseases' sexually transmitted disease (94 newborns) and perinatal hepatitis B programs (262 newborns), which ensure infants with congenital syphilis and infants prenatally exposed to or diagnosed with a hepatitis B infection are offered services.

APORS continued working with the Division of Infectious Diseases to monitor Zika virus-exposed pregnant women and their babies. APORS collaborates with local departments to report de-identified information on neonates and infants at two, six, 12, and

24 months of age to the U.S. Zika Virus Pregnancy Registry. The reports are linked to the maternal reports submitted by the Division of Infectious Diseases.

- 4.2.6.1.3 IDPH Craniofacial Anomaly Program.** Data on all infants born with cleft lip and/or palate (178 newborns) were supplied to the IDPH Division of Oral Health Craniofacial Anomaly Program to ensure these infants receive appropriate services at multidisciplinary clinics throughout the state.
- 4.2.6.1.4 University of Illinois at Chicago Division of Specialized Care for Children (DSCC).** APORS refers newborns to the DSCC for free diagnostic services and assistance with medical treatment. The infants have, or are suspected of having, a treatable chronic medical condition. The conditions include orthopedic, visual, auditory, craniofacial, heart, and urinary defects. In FY19, APORS referred 4,253 cases.
- 4.2.6.1.5 Illinois Department of Human Services Early Intervention Program (EI).** APORS refers newborns to the EI for free developmental services. The infants have, or are suspected of having, a condition that will impact their intellectual or physical development. The conditions include brain, spinal, visual, auditory, craniofacial, and chromosomal defects. In FY19, APORS referred 1,865 cases.
- 4.2.6.1.6 IDPH's Newborn Metabolic Screening (NMS) Program.** APORS refers newborns reported to the program with possible metabolic conditions to IDPH's NMS Program. This program assures children receive timely follow-up for these severe conditions. Several children with hypothyroidism previously unknown to the NMS program have been identified.
- 4.2.6.1.7 Illinois Department of Children and Family Services (DCFS).** Data are being provided to DCFS on a monthly basis through the IHFS data warehouse. The data are pulled into individual eHealth Passports that travel with children in DCFS custody as they move between placements. This helps assure children receive the services they need in a timely manner.
- 4.2.6.1.8 Illinois Department of Healthcare and Family Services.** APORS data are provided monthly to DHFS for inclusion in the Enterprise Data Warehouse. This links APORS

surveillance data to case management and public aid data. Before confidential APORS data can be accessed by anyone outside the program, requests are reviewed through the IDPH Division of Epidemiologic Studies' centralized review process. Any concerns about the application are then referred back to the researcher; once these are addressed, the application is submitted for IRB approval.

4.2.6.2 National Birth Defects Prevention Network (NBDPN)

APORS submitted data for the NBDPN's annual report. The APORS manager, Jane Fornoff, and data manager, Theresa Sandidge, served on the NBCPN data committee. The abstractor liaison, Jodi Snow, served on the NBDPN data standards committee and in two working groups.

4.2.6.3 Perinatal Networks

APORS maintained communications with the perinatal network administrators to facilitate hospital reporting of APORS cases. Timeliness for APORS reporting is used as one quality measure for hospitals' annual perinatal assessment. Administrators also were kept notified about the need to provide remote access to electronic medical records and the new APORS data system.

4.2.6.4 Pregnancy Risk Assessment Monitoring System (PRAMS)

The APORS manager served on the PRAMS Steering Committee. The committee provided recommendations about the questions that should be retained or dropped from the PRAMS questionnaire.

4.2.7 Quality Control Reports

4.2.7.1 Sandidge T. *Family Survey of Services Provided Through the High Risk Infant Follow-up (HRIF) Program*. Quality Control Report Series 18:03. Springfield, Ill.: Illinois Department of Public Health, August 2018.

4.2.7.2 Fornoff, J. *Evaluation of Illinois Surveillance of Neonatal Abstinence Syndrome in 2015 and 2016*. Quality Control Report Series 18:06. Springfield, Ill.: Illinois Department of Public Health, November 2018.

4.2.7.3 Sandidge T, Fornoff J. *Timeliness Study – Hospital Reports of Adverse Pregnancy Outcomes Received in 2018*. Quality Control Report Series 19:01. Springfield, Ill.: Illinois Department of Public Health, January 2019.

4.2.7.4 Sandidge T. *Rates of Hospital Reporting of Adverse Pregnancy Outcomes in 2017*. Quality Control Report Series 19:02. Springfield, Ill.: Illinois Department of Public Health, May 2019.

4.3 Goals for Fiscal Year 2020

Improve Casefinding

- Train and support hospitals in the use of the APORS database to ensure that cases automatically generated by the database (premature infants, triplet, or higher order births and those with birth defects marked on the birth certificate) are completed in a timely manner
- Provide consultation and training to supplement the self-directed training for hospital nursing staff when indicated or requested
- Enhance the SharePoint® site for hospital staff to include materials that supplement face-to-face and telephone consultation and training offered by APORS staff
- Match information from periodic hospital discharge information reports to the APORS newborn cases and identify potential birth defect cases
- Review medical reports of infants identified in hospital discharge matching to ascertain and collect new birth defect cases
- Complete rapid case ascertainment of birth defects associated with Zika virus in the 2015, 2016, and 2017 birth cohorts
- Recruit additional genetic clinics to increase prenatal case finding

Improve Quality of APORS Data

- Evaluate the accuracy of hospital reporting in terms of timeliness, completeness, 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
- Provide consultations and supplemental training to hospitals identified as problem reporters in terms of timeliness, accuracy, or case completeness
- Add chart review for infants suspected of having neonatal abstinence syndrome to improve NAS surveillance

Improve Program Effectiveness

- Enhance SharePoint® sites for hospitals and community health agencies that contain relevant reference and training materials for the different groups

- Maintain linkages with key organizations, such as the Illinois perinatal networks, the Greater Illinois Chapter of the March of Dimes, and the National Birth Defects Prevention Network
- Collaborate with IDPH, state, and local health programs to assure the provision of perinatal services for high-risk infants
- Collaborate with CDC to provide data to the U.S. Zika Pregnancy Registry
- Produce statewide and county surveillance reports
- Monitor activities and accomplishments associated with meeting the goals and objectives set forth in the CDC cooperative agreement

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 Survey of Occupational Injuries and Illnesses (SOII), formerly referred to as the Occupational Safety and Health Survey (OSH).

5.1 Adult Blood Lead Registry (ABLR)

ABLR collects data on all cases of elevated blood lead levels for adults 16 years of age and older and notifies federal enforcement agencies to trigger site inspections and/or interventions. In 2012, the Illinois Administrative Code related to elevated blood lead definition and collection was changed to reflect the new guidelines defining elevated blood levels. Laboratories are mandated to report levels ≥ 10 $\mu\text{g}/\text{dL}$. This program was funded through a purchase order for data with the CDC's National Institute for Occupational Safety and Health (NIOSH). In 2013, however, NIOSH canceled all contracts to fund state programs that use fiscal year 2013 funds in accordance with the federal Budget Control Act of 2011. Starting in 2014, due to lack of funding, ABLR staff only recorded cases of ≥ 40 $\mu\text{g}/\text{dL}$ to refer employers who have employees with elevated blood lead levels ≥ 40 $\mu\text{g}/\text{dL}$ to OSHA per the memorandum of understanding. Reports for cases less than 40 $\mu\text{g}/\text{dL}$ were archived. In 2015, Division staff developed a new Access database that automated the entry of electronic reports and streamlined the manual data entry of paper reports. As a result, the backlog of 2014 electronic lab reports and all of 2015's electronic lab reports were entered in FY15. Data collection continues and in calendar year 2018, 2,581 new lab reports were added to the ABLR database.

5.1.1 Fiscal Year 2019 Accomplishments

- Notified OSHA quarterly of any company that had employees with elevated blood lead levels ≥ 40 $\mu\text{g}/\text{dL}$ of blood
- Notified OSHA within 24 hours of any case with an elevated blood lead level ≥ 60 $\mu\text{g}/\text{dL}$

5.1.2 Interventions Resulting from ABLR Notifications of Elevated Lead Results

In calendar year 2018, ABLR made six referrals (employees) to OSHA for six companies with employees who had blood lead levels greater than or equal to 40 $\mu\text{g}/\text{dL}$ of blood. These quarterly ABLR reports to OSHA led to no safety inspections in Illinois.

5.1.3 Goals for Fiscal Year 2020

- Notify OSHA quarterly of any company that has employees with elevated blood lead levels equal to or greater than 40 $\mu\text{g}/\text{dL}$
- Notify OSHA within 24 hours of any case with an elevated blood lead level equal to or greater than 60 $\mu\text{g}/\text{dL}$

5.2 **Census of Fatal Occupational Injuries and Illnesses (CFOI)**

The U.S. Bureau of Labor Statistics (BLS) developed CFOI as a cooperative venture between the states and the federal government to gather data about these events. IDPH has participated in CFOI since 1993. The data compiled by CFOI are published each year and contain information on the workers involved and the events surrounding each fatality.

In 2017, Illinois CFOI recorded 163 work related deaths. From January - June 2008, fatal occupational illnesses were collected by manually reviewing death certificates to collect information where the decedent's occupation, known occupational exposures, and cause of death were linked in scientific publications. In mid-2008, electronic death certificates were implemented in the Division of VR and the manual review was no longer possible. This operational change affected the number of fatal occupational illnesses collected in Illinois. Beginning in 2012 and moving forward, BLS ceased collecting work related illness fatalities. BLS has determined that because the capture of illnesses cannot be comprehensive, they would prefer staff spend time collecting and verifying injuries only.

5.2.1 **Review and Evaluation of Fiscal Year 2019 Goals**

- Completed the summary report of the 2016 fatal occupational injury data
- Provided information on fatal occupational injuries to the BLS, the funding source, in accordance with the required schedule

5.2.2 **Goals for Fiscal Year 2020**

- Publish a summary report of the 2018 fatal occupational injury data by January 2020
- Meet the deadlines for data completion required by BLS

5.3 **Survey of Occupational Injuries and Illnesses (SOII) (formerly Occupational Safety and Health Survey)**

SOII focuses on surveillance of non-fatal workplace injuries and illnesses. The Illinois SOII is supported through a cooperative agreement between the states and the BLS. 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 also are published annually and specifically for Illinois 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 2019 Goals**

- Submitted data files on all reported occupational injuries and illnesses of the surveyed companies to the BLS
- Collected, coded, and entered all 2017 data prior to BLS deadlines

5.3.2 Survey Process and Achievements for Fiscal Year 2019

In January 2019, BLS and ODR sent survey forms to 5,384 private employers and 356 public employers for 2018 data. A second request for data was sent in February, a third request was sent in April, and a fourth request was sent in May. Non-responding companies were then contacted by telephone to solicit data. The final, overall survey response rate was 87 percent, which exceeded the cooperative agreement minimum requirement for data publication.

5.3.3 Goals for Fiscal Year 2020

- Continue all data collection activities in FY20 and maintain the high standards achieved by the program
- Complete the descriptive report of 2018 Survey of Occupational Injuries and Illnesses (SOII)
- Meet the deadlines assigned by BLS

6. Hazardous Substances Registry

The Hazardous Substances Registry component of the IHHSR is not funded. As a result, only geocoding activities are performed through support from funded components to create value-added registry data. The geocodes assigned to cancer and birth defect incident reports form the basis for development of a comprehensive geographic information system (GIS) capacity within the IHHSR system.

6.1 Geocoding Process and Accomplishments

6.1.1 Geocoding Cancer and Birth Defects Data

Population-based data for the Illinois State Cancer Registry and the Adverse Pregnancy Outcomes Reporting System were geocoded in-house using software program, Map Marker USA v.30®.

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

The level of completeness for each geocode element varied little by year of diagnosis (see range in Table 6.1.1.1). 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 6.1.1.1 Percentage of IHHSR Reports with Complete Geocoding as of November 2018

Range of Percentage Complete by Diagnosis Year			
	Average all years	Lowest	Highest
Cancer Reports (n=1,874,828 cases for diagnosis years 1986-2016)			
ZIP code	100.0	100.0	100.0
ZIP +4 code	96.2	92.0	99.0
Lat/Lon code ¹	100.0	100.0	100.0
address specific	92.8	87.1	96.7
centroid ZIP +4	0.5	0.2	0.8
centroid ZIP +2	0.6	0.4	1.2
centroid ZIP	6.2	2.3	11.7
APORS Reports (n= 429,578) cases for birth years 1989-2018)			
ZIP code	98.6	97.5	100.0
ZIP +4 code	94.8	92.4	99.3
Lat/Lon code ¹	98.6	97.5	100.0
address specific	93.7	91.6	98.8
centroid ZIP +4	1.1	0.5	1.8
centroid ZIP +2	1.6	0.2	3.7
centroid ZIP	2.2	0.2	5.3
¹ Latitude and longitude			

6.2 Goals for Fiscal Year 2019

- Continue to geocode new records submitted to ISCR and APORS

7. Cluster Inquiries and Assessments

7.1 Review and Evaluation of Fiscal Year 2019 Goals

- Responded to all inquiries with information and educational materials regarding cancer diseases

7.2 Fiscal Year 2019 Accomplishments

In FY19, IDPH received nine 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. Staff used published cancer rates by county, epidemiologic reports, and data from the public data files or general information about the frequency of cancer or causes of cancer to help address the callers' concerns. A comprehensive review and assessment of cancer incidence was conducted in Willowbrook, IL to respond to community concerns about ethylene oxide, a known carcinogen. The study process included multiple conference calls, analysis of observed

and expected cancer cases for specific geographic areas, and additional explanation of cancer registry collection methods and quality control measures. The investigation revealed higher than expected cancer cases in adult women largely driven by Hodgkin's lymphoma in two study areas. Females also had higher than expected numbers of cases of breast cancer cases. Pediatric cancers were also examined; pediatric lymphoma was observed to be elevated in the study area. While increases in cancer cases were observed in specific areas of the study many inconsistencies and differences existed between genders, across study areas, and among cancer sites. These results were presented and discussed directly with requestors that included community members, medical professionals, and state legislators. This particular investigation was published in March of 2019, nine months from the original request, and is publicly available.

7.3 Fiscal Year 2020 Objectives

- Respond to all inquiries with information and educational materials regarding cancer diseases
- Complete cluster assessments within 12 months of the written request if there is a known carcinogenic exposure and a cancer assessment is launched

8. Research Program

The research section of the IHHSR provides a crucial link between data collection and data dissemination and between raw data and information. Through various formats, registry data were summarized, tabulated, analyzed, presented, and disseminated to policy makers, health professionals, and the public.

8.1 Fiscal Year 2019 Major Accomplishments

8.1.1 Provision of Epidemiologic Support to IDPH Committees and Workgroups

IDPH Division of Epidemiologic Studies staff continued to co-chair and participate in IDPH's IRB, the Open Data Forum, Public Use Data Group (PUDG), Opioids projects/databases, IDPH Academic Partnership, IVRS Steering Committee, and Internal Data Sharing Workgroup. Six staff serve on different committees in various capacities.

8.1.2 Provision of Peer-Review Service to Scientific Publication

Division staff provided professional reviews to the Journal; Health Security, on articles about climate changes and data security.

8.1.3 Provision of Epidemiologic Supervision and Tutoring

Division staff provided supervisor roles and other assistance to various interns, CDC assignees and CSTE fellows during FY19.

8.1.4 Publication of the Department-wide Illinois Morbidity and Mortality Bulletin (IMMB)

The Division continued to publish this bulletin on behalf of IDPH. IMMB targets statewide public health professionals, researchers, and policy makers. The inauguration issue contained three articles. Subsequent issues contained two reports each. A total of six issues have been published as of the end of FY19.

8.1.5 Technical Assistance

Technical assistance has been provided by staff in the areas of statistics/epidemiology, research methods, data confidentiality review, Freedom of Information Act (FOIA) and media requests, data linkage, SAS® programming, data analysis and interpretation, data de-duplication, surveillance system evaluation, quality control, and research data requests continued to be provided by researchers to various IDPH offices and divisions. IDPH Division of Epidemiologic Studies (Division) researchers were frequently called upon by the IDPH Office of the Director, the Institutional Review Board (IRB), and other IDPH programs for expertise on different technical and research issues, such as program evaluation, de-identification of individual data records, and updating State Health Improvement Plan (SHIP) documents and statistics. The Division researchers also continued to provide guidance and technical assistance to

IDHFS in its effort to establish new policy and practices for public data release. Division staff also provided interviews and responses to medical requests on various disease issues.

8.1.6 IDPH Institutional Review Board

The Division continued to staff the IDPH IRB, with one staff serving as the IRB manager and one as acting chair, and one serving on the board. A number of data requests from outside researchers and organizations were processed and fulfilled. The IRB also serves as a link between outside researchers and Department Responsible Individuals (RIs) in various programs.

8.2 Scientific Publications in Fiscal Year 2019

The following articles have been submitted, accepted or published:

- 8.2.1** Leveraging Existing Birth Defects Surveillance Infrastructure to Build Neonatal Abstinence Syndrome Surveillance Systems — Illinois, New Mexico, and Vermont, 2015–2016. Lind JN, Ailes EC, Alter CC, Fornoff JE, Brozicevic P, Garcia Saavedra LF, Tomedi LE, Gambatese M, Carroll B; Orantes L, Martin B, Horne AA, Reefhuis J. *Morbidity and Mortality Weekly Report* 2019;68:177–180. DOI: <http://dx.doi.org/10.15585/mmwr.mm6807a3>.
- 8.2.2** Gastroschisis Trends and Ecologic Link to Opioid Prescription Rates — United States, 2006–2015. Short, TD, Stallings EB, Isenburg J, O’Leary LA, Yazdy MM, Bohm MK, Ethen M, Chen X, Tran T, Fox DJ, Fornoff J, Forestieri N, Ferrell E, Ramirez GM, Kim J, Shi J, Cho SJ, Duckett K, Nelson N, Zielke K, St. John K, Martin B, Clark C, Huynh M, Benusa C, Reefhuis J. *Morbidity and Mortality Weekly Report* 2019; 68:31–36. DOI: <http://dx.doi.org/10.15585/mmwr.mm6802a2>.
- 8.2.3** D’Arcy M, Coghil A, Lynch C, Koch L, Li J, Pawlish K, Morris C, Rao C, Engels E. Survival after cancer diagnosis among solid organ transplant recipients in the United States. *Cancer* 2019; 0:1-10. DOI: 10.1002/cncr.31782.
- 8.2.4** Spector L, Brown M, Wantman E, Letterie G, Toner J, Doody K, Ginsburg E, Williams M, Koch L, Schymura M, Luke B. Association of In Vitro Fertilization with Childhood Cancer in the United States. *JAMA Pediatrics* 2019 Apr 1:e190392. DOI: 10.1001/jamapediatrics.2019.0392.
- 8.2.5** Garner K. Ecological Association Between Smoking Prevalence and Lung Cancer Incidence across Illinois Counties. *Illinois Morbidity and Mortality Bulletin*, March 2019.
- 8.2.6** Division of Epidemiological Studies, Illinois Department of Public Health. Cancer Assessment near Sterigenics in Willowbrook, Illinois, 1995-2015, Available at <http://www.dph.illinois.gov/data-statistics/epidemiology/cancer-registry>, March, 2019.

8.3 Other Recent Reports or Publications That Used Registry Data

- 8.3.1** March of Dimes. *Peristats*. Available at <https://www.marchofdimes.org/Peristats/ViewSection1.aspx?reg=17&slev=4&sec=5>
- 8.3.2** Grosse S, Berry R, Tilford J, Kucik J, Waitzman N. Retrospective Assessment of Cost Savings from Prevention. *American Journal of Preventive Medicine* 2016 May volume 50, issue 5, Supplement 1, Pages S74-S80.
- 8.3.3** Birth Defects Research Part A: Clinical and Molecular Teratology Volume 110, Issue 19, November 2018, Pages: S23-S25.
- 8.3.4** Ostrom QT, Gittleman H, Truitt G, Boscia A, Kruchko C, Barnholtz-Sloan JS; CBTRUS Statistical Report: Primary brain and central nervous system tumors diagnosed in the United States in 2011–2015, *Neuro-Oncology*, Volume 20, Issue suppl_4, October 2018, Pages iv1–iv86, doi: 10.1093/neuonc/noy131.
- 8.3.5** U.S. Centers for Disease Control and Prevention. *State Cancer Profiles*. Interactive query available at <http://statecancerprofiles.cancer.gov/>; U.S. Department of Health and Human Services, U.S. Centers for Disease Control and Prevention.
- 8.3.6** U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on November 2018 submission data: U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; www.cdc.gov/cancer/dataviz, (<https://www.cdc.gov/cancer/dataviz>) June 2019.
- 8.3.7** 2001–2016 Database: National Program of Cancer Registries and Surveillance, Epidemiology, and End Results SEER*Stat Database: NPCR and SEER Incidence – USCS 2001–2016 Public Use Research Database, United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Released June 2019, based on the November 2018 submission. Available at www.cdc.gov/cancer/npcr/public-use. (<https://www.cdc.gov/cancer/npcr/public-use>)
- 8.3.8** 2005–2016 Database: National Program of Cancer Registries and Surveillance, Epidemiology, and End Results SEER*Stat Database: NPCR and SEER Incidence – USCS 2005–2016 Public Use Research Database, United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Released June 2019, based on the November 2018 submission. Available at www.cdc.gov/cancer/npcr/public-use. (<https://www.cdc.gov/cancer/npcr/public-use>)
- 8.3.9** Sherman R, Firth R, De P, Green D, Hofferkamp J, Johnson C, Kohler B, Charlton M, Hofer B, Hsieh M, Nash S, Qiao B (eds). *Cancer in North America: 2012-*

2016. *Volume One: Combined Cancer Incidence for the United States, Canada and North America*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. May 2019.

- 8.3.10** Alshahrani SM, Fraser GE, Sabate J, Knutsen R, Shavlik D, Mashchak A, Lloren JI, Orlich MJ. Red and Processed Meat and Mortality in a Low Meat Intake Population. *Nutrients*. 2019 Mar 14;11(3). pii: E622. doi: 10.3390/nu11030622. PMID: 30875776
- 8.3.11** Sherman R, Firth R, De P, Green D, Hofferkamp J, Johnson C, Kohler B, Charlton M, Hofer B, Hsieh M, Nash S, Qiao B (eds). *Cancer in North America: 2012-2016. Volume Two: Registry-specific Cancer Incidence in the United States and Canada*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. May 2019.
- 8.3.12** Sherman R, Firth R, De P, Green D, Hofferkamp J, Johnson C, Kohler B, Charlton M, Hofer B, Hsieh M, Nash S, Qiao B (eds). *Cancer in North America, 2012-2016. Volume Three: Registry-specific Cancer Mortality in the United States and Canada*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. May 2019.
- 8.3.13** Elizabeth Ward, Recinda L Sherman, S Jane Henley, Ahmedin Jemal, David A Siegel, Eric J Feuer, Albert U Firth, Betsy A Kohler, Susan Scott, Jiemin Ma, Robert N Anderson, Vicki Benard, Kathleen Cronin, Annual Report to the Nation on the Status of Cancer, 1999–2015, Featuring Cancer in Men and Women ages 20–49, *JNCI: Journal of the National Cancer Institute*, Online May 30, 2019, djz106, <https://doi.org/10.1093/jnci/djz106>
- 8.3.14** American Cancer Society. *Cancer Facts & Figures 2019*. Atlanta, GA.: American Cancer Society; 2019.
- 8.3.15** Altekruse SF, Shiels MS, Modur SP, Land SR, Crothers KA, Kitahata MM, Thorne JE, Mathews WC, Fernández-Santos DM, Mayor AM, Gill JM, Horberg MA, Brooks JT, Moore RD, Silverberg MJ, Althoff KN, Engels EA. Cancer burden attributable to cigarette smoking among HIV-infected people in North America. *AIDS* 2018 Feb 20;32(4):513-521. **PMCS797998**
- 8.3.16** Miles FL, Lloren JIC, Haddad E, Jaceldo-Siegl K, Knutsen S, Sabate J, Fraser GE. Plasma, Urine, and Adipose Tissue Biomarkers of Dietary Intake Differ Between Vegetarian and Non-Vegetarian Diet Groups in the Adventist Health Study-2. *J Nutr*. 2019 Apr 1; 149(4):667-675. doi: 10.1093/jn/nxy292. PMID: 30770530.
- 8.3.17** Jaceldo-Siegl K, Haddad E, Knutsen S, Fan J, Lloren J, Bellinger D, Fraser GE. Lower C-reactive protein and IL-6 associated with vegetarian diets are mediated by BMI. *Nutr Metab Cardiovasc Dis*. 2018 Mar 13. pii: S0939-4753(18)30093-0. doi: 10.1016/j.numecd.2018.03.003. [epub ahead of print] PMID: 29704951.

- 8.3.18** Johnson C, Wilson R, Sherman R, Firth R, De P, Green D, Hofferkamp J, Kohler B, Charlton M, Hofer B, Hsieh M, Nash S, Qiao B (eds). *Cancer in North America, 2012-2016. Volume Four: Cancer Survival in the United States and Canada 2008-2014*. Springfield, Ill.: North American Association of Central Cancer Registries, Inc. May 2019.
- 8.3.19** Prevalence of selected birth defects by maternal nativity status, United States, 1999–2007. Kirby RS, Mai CT, Wingate MS, Janevic T, Copeland GE, Flood TJ, Isenburg J, Canfield MA for the National Birth Defects Prevention Network. Birth Defects Research. 2019; 1–10. <https://doi.org/10.1002/bdr2.1489>.
- 8.3.20** Status of population-based birth defects surveillance programs before and after the Zika public health response in the United States. Anderka M, Mai CT, Judson EM, Langlois PH, Lupo PJ, Hauser K, Salemi JL, Correia H, Canfield MA, Kirby RS for the National Birth Defects Prevention Network. Birth Defects Research, Part A: Clinical and Molecular Teratology. 2018; 110: 1388-1394.
- 8.3.21** Study of selected birth defects among American Indian/Alaska Native population: A multi-state population-based retrospective study, 1999-2007. Marengo LK, Flood TJ, Ethen MK, Kirby RS, Fisher S, Copeland G, Meyer RE, Dunn J, Canfield MA, Anderson T, Yazzie D, Mai CT; National Birth Defects Prevention Network. Birth Defects Research. 2018; 110(19):1412-1418.
- 8.3.22** Population-based birth defects data in the United States, 2011–2015: A focus on eye and ear defects. Stallings EB, Isenburg JL, Mai CT, Liberman RF, Moore CA, Canfield MA, Salemi JL, Kirby RS, Short TD, Nembhard WN, Forestieri NE, Heinke D, Alverson CJ, Romitti PA, Huynh M, Denson LE, Judson EM, Lupo PJ for the National Birth Defects Prevention Network Birth Defects Research. 2018; 110(19):1478-1486
- 8.3.23** Substance-exposed newborn infants and public health law: Differences in addressing the legal mandate to report. Hoerr JJ, Heard AM, Baker MM, Fogel J, Glassgow AE, Kling WC, Clark MD, Ronayne JP. Child Abuse and Neglect, 2018 81(206-213)

8.4 Epidemiologic Report Series

The following report was released in IDPH's Epidemiologic Report Series; all reports are available to the public upon request:

Sandidge T, Fornoff JE, Shen T. **Birth Defects and Other Adverse Pregnancy Outcomes in Illinois 2008-2012.** Epidemiologic Report Series 19:03. Springfield, Ill.: Illinois Department of Public Health, June 2019.

8.5 Fiscal Year 2019 Presentations by IDPH Division of Epidemiologic Studies Staff

Title	Event	Date
APORS-Data System Training	Clinton County Health Department by phone	July 2018
APORS-Data System Training	Swedish American Hospital (Rockford) by phone	August 2018
APORS-Data System Training	Advocate Condell Medical Center (Libertyville) by phone	August 2018
RESEARCH-briefing on carcinogen issues in Willowbrook	Advisory committee meeting with city officials in Willowbrook	September 2018
RESEARCH-lecture on cancer surveillance to graduate students	UIC School of Public Health in Chicago	September 2018
APORS-Data System Training	St. Elizabeth's Hospital (Belleville) by phone	October 2018
APORS-Perinatal Hepatitis B	Various hospitals and local health departments via webinar	October 2018
APORS-Confidential Data Release	University of Chicago Urban Labs via webinar	October 2018
RESEARCH-Assessing Identifiability in Public Use Data – talk about the algorithm developed by the Division	CSTE Data Workgroup via webinar	November 2018
APORS-Data System Training	St. Mary's Hospital (Decatur) by phone	January 2019
APORS-Data System Training	Pekin Hospital (Pekin) by phone	February 2019
ISCR-Basic Training Workshops	Mt. Vernon & Springfield	March 2019
APORS-Reporting NAS and Drug Exposure to APORS	Various hospitals & health departments via webinar	March 2019
APORS-HRIF Family Survey Review	Various hospitals & health departments via webinar	March 2019
APORS-Data System Training	DeKalb County Health Department (DeKalb) by phone	April 2019
ISCR-Co-presentation on how state registries can better collaborate with NPCR, provide input and better plan for changes	NPCR Program Review Meeting in Atlanta, GA	April 2019

Title	Event	Date
ISCR-Basic Training Workshops	Downers Grove & Arlington Heights	April 2019
ISCR-Advanced Coding Training Workshops	Arlington Heights, Mt. Vernon & Springfield	April 2019
ISCR-Advanced Coding Training Workshops	New Lenox, Chicago, Carterville & Springfield	May 2019
ISCR-Dermatology Coding Training Workshops	Chicago, Elmhurst, Springfield & Joliet	May 2019
APORS-Database Training & Program Overview	Barnes-Jewish Hospital (St. Louis) via webinar	June 2019
ISCR-Dermatology Coding Training Workshops	Carterville & Peoria	June 2019

8.6 Research Data Release and Collaborations

Principal Investigator (Affiliation)	Title	Date	Funding Source
Mark Canfield Texas Department of State Health Services	Study of Selected Birth Defects Among Minorities 1999-2007	July 2012, ongoing*	
Ying Wang New York State Department of Health	Survival of Infants and Children With Selected Major Birth Defects	January 2012, closed 9/7/18	
U.S. Centers for Disease Control and Prevention	Prevalence Data by Race for Selected Birth Defects for Publication in <i>Birth Defects Research</i>	May 2019	CDC
Lynn Rosenberg, Sc.D., M.S. Sloan Epidemiology Center Boston University	Black Women's Health Study	February 2007, ongoing	NIH/NCI
Rosalind Ramsey-Goldman, M.D., Dr.PH. Northwestern University	Exposure to Immunosuppressive Drugs and Cancer Risk in Systemic Lupus Erythematosus	August 2004, ongoing	NIH/NCI
Meir Stampfer, M.D. Channing Laboratory Brigham and Women's Hospital	Health Professionals Follow- up Study/Nurses' Health Study I and II	January 2004, ongoing	NIH
Eugenia Calle, Ph.D. American Cancer Society	Cancer Prevention Study II	1995, ongoing	ACS
Brinton, Trabert, Ph.D. National Cancer Institute	Infertility Follow-up Study	2012, ongoing	NCI
Alicia Gilseman, Ph.D. RTI International	Forteo Patient Registry	February 2010, ongoing	Eli Lilly and Company
Mardge Cohen, M.D. Women's Interagency HIV Study (WIHS)	Women's Interagency HIV Study (WIHS)	2000, ongoing	NIH
Garth Rauscher, Ph.D. University of Illinois at Chicago	Comparative Effectiveness of Breast Imaging Modalities: A Natural Experiment	April 2013, ongoing	Agency for Health Research and Quality
Barbara Luke, Ph.D. Michigan State University Logan Spector, Ph.D. University of Minnesota	Assisted Reproductive Technology and Risk of Cancer in Women	January 2014*	NCI

Principal Investigator (Affiliation)	Title	Date	Funding Source
Barbara Luke, Ph.D. Michigan State University Logan Spector, Ph.D. University of Minnesota	Assisted Reproductive Technology and Risk of Childhood Cancer	July 2016*	NCI
Diana Miglioretti, Ph.D.	Risk-Based Cancer Screening in Community Settings	July 2014*	NCI
Gary Fraser, M.D., Ph.D.	Adventist Health Study II	March 2015, ongoing	NCI
Herbert Chen, M.D.	Medullary Thyroid Carcinoma Surveillance Study – A Case- Series Registry	September 2014, ongoing	The MTC Registry Consortium
Alicia Gilseman, Ph.D. RTI International	Osteosarcoma Surveillance Study	September 2014, ongoing	Eli Lilly & Company
Alpa V. Patel, Ph.D.	Cancer Prevention Study III	September 2015, ongoing	ACS
NOTE: Following are definitions of acronyms used in the above table: American Cancer Society (ACS), U.S. Centers for Disease Control and Prevention (CDC), Cancer in North America (CINA), Illinois Department of Children and Family Services (DCFS), Illinois Department of Human Services (DHS), Geographic Information System (GIS), International Agency for Research on Cancer (IARC), National Cancer Institute (NCI), National Institutes of Health (NIH), Women’s Interagency HIV Study (WIHS)			
*Data set released; study remains open			

9. Grants

The table below summarizes the IDPH Division of Epidemiologic Studies grant awards for FY2019.

Grant	Agency	Status	Amount	Grant Period
Occupational and Health Survey in Illinois (continuation)	BLS	Funded September 2018	\$122,900	10/1/18 – 9/30/19
Census of Fatal Occupational Injuries in Illinois (continuation)	BLS	Funded September 2018	\$103,800	10/1/18 – 9/30/19
Improvement of Birth Defects Surveillance Program (continuation)	CDC	January 2019	\$210,000	2/1/19 – 1/31/20
National Cancer Prevention and Control Program-National Program of Cancer Care (continuation)	CDC	Funded June 2018	\$1,100,000	7/1/18 – 6/30/19
Perinatal Hepatitis B Program (submitted by IDPH, Division of Infectious Disease) (continuation)	CDC	Funded 2018	\$100,000	1/1/19 – 6/30/19
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 Funded Grants

The Division of Epidemiologic Studies received \$1.64 million in grant awards in fiscal year 2019.

9.1.1 Survey of Occupational Injuries and Illnesses in Illinois (formerly Occupational Safety and Health Survey)

IDPH received \$122,900 in September 2018 from BLS to support the 21st year of the Survey of Occupational Injuries and Illnesses (SOII) in Illinois. This project is described in Section 5.

9.1.2 Census of Fatal Occupational Injuries in Illinois

IDPH received \$103,800 in September 2018 from BLS to support the 27th year of the Census of Fatal Occupational Injuries (CFOI) in Illinois. This project is described in Section 5.

9.1.3 Improvement of Birth Defects Surveillance Program

In January 2019, IDPH received \$210,000 for year four of the fourth round of surveillance grants. The progress for this project is described in Section 4.

9.1.4 National Cancer Prevention and Control Program

In June 2018, CDC awarded IDPH \$8.4 million in funding for the second year of a fourth five-year project period year of the National Cancer Prevention and Control Program. This grant combines two previous separate grants: the National Comprehensive Cancer Control Program and the National Program of Cancer Registries (NPCR). The IDPH Division of Epidemiologic Studies received \$1.1 million for the NPCR component, which is in its 24th year. The progress for this project is described in Section 3.

9.1.5 Perinatal Hepatitis B Program

The IDPH Division of Epidemiologic Studies received \$100,000 in January 2019 to continue expansion of APORS surveillance and data collection (19th year) to include perinatal hepatitis B and to enhance a tracking system that identifies newborn infants requiring follow-up immunization services. This funding ended in June 2018. The progress for this project is described in Section 4.

