

# Annual Report Illinois Health and Hazardous Substances Registry

July 2022 through June 2023

December 2023



## Annual Report Illinois Health and Hazardous Substances Registry July 2022 through June 2023



A Report to Gov. JB Pritzker and the 103<sup>rd</sup> General Assembly from the Illinois Department of Public Health Sameer Vohra, MD, JD, MA Director

Prepared by the Division of Epidemiologic Studies December 2023

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## 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			
ATSDR	Agency for Toxic Substances and Disease Registry			
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			
FY	Fiscal Year			
IBCCP	Illinois Breast and Cervical Cancer Program			
ICCCP	Illinois Comprehensive Cancer Control Program			
IDCFS	Illinois Department of Children and Family Services			
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 Substances Registry			
IMMB	IDPH's Illinois Morbidity and Mortality Bulletin			
IOSP	Illinois Occupational Surveillance Program			
IRB	Institutional Review Board			
ISCR	Illinois State Cancer Registry			
NAACCR	North American Association of Central Cancer Registries			
NAD	North American Datum			
NAS	Neonatal Abstinence Syndrome			
NBDPN	National Birth Defects Prevention Network			
NCCR	National Childhood Cancer Registry			
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			
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)]. This is the registry's 37<sup>th</sup> annual report and it describes major registry activities and accomplishments from July 2022 through June 2023 (FY23).

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.
- 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 2023 Highlights

- Received \$3.5 million in federal funds and \$8,816 from other non-general state revenue sources, mostly through competitive processes, to support activities of the Division of Epidemiologic Studies.
- Collected detailed case reports on Illinois residents with 65,397 newly diagnosed cancer cases (2020), 15,087 children with adverse pregnancy outcomes (2019), 1,052 adult lead poisoning cases (2022), 9,179 representative non-fatal occupational disease and injury sample records (2021), and 176 fatal occupational injuries (2021).
- Dr. Jane Fornoff, Adverse Pregnancy Outcomes Reporting System manager, officially accepted the position of division chief in March 2023. She continued to contribute to the IDPH COVID-19 response through FY23 as the lead for the IDPH modeling and data teams and to assist with analyses.
- Working from home has continued beyond the end of the COVID-19 pandemic emergency declaration and is expected to continue for the foreseeable future. Dr. Fornoff and two other Division staff come into the office daily. Most registry staff work remotely, with weekly or monthly visits to the office for in-person meetings or to manage incoming reports on paper or electronic media.
- Responded to 27 requests for general information about the registry, 32 requests for epidemiologic reports and registry data, and three special data requests or collaborations from outside researchers.
- Responded to nine inquiries about perceived cancer excesses in local communities and neighborhoods.
- Prepared and submitted one grant proposal to support the registry's operations and research.
- Released seven reports in the Epidemiologic Report Series and prepared four 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 at least 28 published studies by outside researchers.
- Data collected by the IHHSR were submitted to federal and other collaborating agencies and organizations to add to various national and international health surveillance data systems.
- 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 followup services.
- Referred 27 employees from 27 employers with elevated blood lead levels to the U.S. Occupational Safety and Health Administration (OSHA) for onsite inspection.
- Delivered presentations at four professional meetings.
- Provided leadership and management support to the IDPH Institutional Review Board (IRB.) One Division of Epidemiologic Studies staff member serves as vice chair and one as the IRB's standing coordinator.
- Implemented IRB management software for improved handling of data requests and developed manuals for IDPH staff and external researchers.

#### 1.3 Illinois Health and Hazardous Substances Registry Coordinating Council

The IHHSR Act lists the composition of the Health and Hazardous Substances Coordinating Council as follows: 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), and Public Health; and director 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 2023. Instead, the council reviewed and approved the annual report via written ballot.

#### 1.4 Goals for Fiscal Year 2024

- 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 and contracts.
- 5. Pursue grants and other funding opportunities to sustain and to 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 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

Figures under section 2.1 summarize the registry's data collection and dissemination activities for 2022 and compare with data from the previous years. 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 up to the time of this report 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.

#### 2.1 ISCR Data Collection

As the only population-based source for cancer incidence information in Illinois, the Illinois State Cancer Registry (ISCR) collects cancer incidence information 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.



Incidence of Neoplasms Data as of November 2022

■ Neoplams, including bladder in situ ■ Breast in situ female only ■ Brain – benign/borderline

## 2.2 APORS Data Collection

The Adverse Pregnancy Outcomes Reporting System (APORS) collects information on Illinois infants and young children born with birth defects or other abnormal conditions. APORS staff review medical records assure the completeness and quality of records for newborns with neonatal abstinence diagnoses (NAS) and birth defects designated by the National Birth Defects Prevention Network (NBDPN) as core, recommended, or extended surveillance conditions. APORS started routinely reviewing medical records of infants with NAS in 2019.



APORS Cases, 2009-2020

## 2.3 ODR Data Collection

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). ABLR is a population-based surveillance program of laboratory-reported adult blood levels. ABLR collects data on cases of elevated blood lead levels of 10 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. CFOI documents all fatal work injuries in Illinois, collecting information on the circumstances of each fatality and on the characteristics of each decedent. SOII surveys a sample of about 6,000 employers about non-fatal workplace injuries and illnesses, and the total number of employees and hours worked.



Occupational Safety and Health Survey estimated cases based on sampling

ABLR Lead Poisoning and Occupational Fatality Cases



## 2.4 Registry Data Dissemination, Reports, and Publications

Division staff publish data in a variety of ways, and IHHSR data are also used by external researchers. The Division of Epidemiologic Studies receives a variety of data requests, for existing reports, non-confidential, and confidential data.





#### 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 incidence information 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 2020 diagnosis year, ISCR received reports from one Veteran's Administration (VA) facility in Illinois.

ISCR continues to require reporting facilities to submit data in an electronic format. There are currently 178 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, the Internet-based Web-Plus program, or purchase vendor software.

ISCR staff continue to work remotely, receiving, processing, and producing all data. COVID-19 did require in-person training workshops and casefinding audits of reporting facilities to be canceled. ISCR was able to highlight available on-demand webinar coding training already present on the ISCR website and provide additional phone support to meet the training needs of cancer reporters. ISCR staff continue to complete all registry tasks and are on track for submission of 2021 diagnosis year data to the National Cancer Institute's (NCI) Surveillance, Epidemiology, and End Results Program (SEER), the U.S. Centers for Disease Control and Prevention's (CDC) National Program of Cancer Registries (NPCR), and the North American Association of Central Cancer Registries (NAACCR) in November 2023.

ISCR became part of the NCI's SEER Program in March 2021 and was awarded a contract totaling \$22,752,223, over seven years. As part of this contract, ISCR had the opportunity to migrate the Illinois cancer database to a new software system known as SEER\*DMS. ISCR began preparation activities in March 2022 and completed the successful migration of almost 2.8 million records to the new data system in June 2022.

#### 3.1 Review and Evaluation of Fiscal Year 2023 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 25<sup>th</sup> consecutive year.
- In-person casefinding visits for the 2021 diagnosis year were suspended due to the COVID-19 pandemic. However, case reporting was maintained as reporting facilities continued to submit cases for processing by ISCR staff.
- Completed interstate data exchange by transmitting 4,559 de-duplicated, edited state-specific cases to 11 states and received and processed 8,690 cases from 11 states.

- Completed death clearance for the 2020 death year and maintained a death certificate only rate of 1.2%. In total, 3,983 cancer diagnoses were followed with 370 letters or lists mailed to hospitals, physicians, nursing homes, and hospice centers.
- Added 91.5% of cases for the 2021 diagnosis year to the ISCR database by December 2022.
- Added 100% of cases for the 2020 diagnosis year to the ISCR database by December 2022.

# 3.1.2 Maintain and Enhance Activities Related to Physician and Pathology Reporting

• Maintained reporting by physicians and pathology labs.

## 3.1.3 Provide Training for Reporting Facilities and for Central Registry Staff

- In-person training was canceled due to the COVID-19 pandemic.
- Provided on-demand access to 30 training webinars on a variety of topics through the ISCR training website, including access to cancer site-specific coding training from NAACCR.
- Provided on-demand access to a nine-part "Introduction to Cancer Reporting" webinar training series available to cancer reporters across the state.
- Provided on-demand access to a melanoma coding webinar designed specifically for dermatology clinics.
- Provided individual phone or email support for 1,711 requests related to technical support and reporting issues.
- Attended the national educational conferences of the National Cancer Registrars Association and the NAACCR, along with the SEER Advanced Workshops, which were held virtually due to the COVID-19 pandemic.
- Provided limited individual training conducted by the quality control field staff via phone, as necessary.
- 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 1 per 1,000 primary cases.
- Met NPCR/NAACCR standards for data quality.
- Matched vital records death data to the ISCR database to update unknown values in the latter.



Percent of Cancer Records Updated via Linkage with Vital Records Death Master

- Applied GenEDITS metafiles to the ISCR database, ran all standard setterrequired edits, and performed reconciliation for identified errors.
- Added census tract information to the cancer database. All records were geocoded using MapMarker<sup>®</sup> Version 31; 93.9% 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. 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 public use data files, annual state cancer incidence and mortality reports, annual county cancer incidence report, and updated the cancer query system.
- Provided general cancer information for cancer inquiries and conducted cancer incidence investigations when a known environmental carcinogenic exposure has been documented.
- Provided data for the Illinois Comprehensive Cancer Control Program (ICCCP).
- Provided data for the Illinois Breast and Cervical Cancer Program (IBCCP).
- Updated incidence projections.
- Submitted 1,825,761 cases to NPCR and NAACCR for the 1995-2020 diagnosis years call for data in November 2022.
- Submitted 1,604,790 cases to SEER for the 2000-2021 diagnosis years call for data in November 2022.

- Submitted 73,722 cases to NPCR and NAACCR for the 2021 diagnosis year call for data in November 2022.
- Submitted 107,443 cases to SEER for the National Childhood Cancer Registry 1995-2020 diagnosis years call for data in November 2022.
- Submitted 1,645,130 cases to SEER for the 2000-2021 diagnosis years call for data in February 2023.

#### 3.1.6 Provide Adequate Program Management

- Kept registry staff informed of grant progress, standards change, and reporting issues through monthly staff meetings.
- Monitored registry operations activities to meet grant objectives and contract deliverables via electronic tracking and an internal database dashboard.

## 3.2 Fiscal Year 2023 Major Accomplishments

# 3.2.1 North American Association of Central Cancer Registries Gold Certification

For the 25<sup>th</sup> 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% or better completeness of case ascertainment; 98% validity of information recorded for selected data variables (age, sex, race, and state/county); death-certificate only cases less than 3%; duplicate primary cases fewer than 1 per 1,000; 100% 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

The Registry of Excellence recognition was again suspended by NPCR for the 2022 NPCR data submission due to the Covid-19 pandemic. Nevertheless, ISCR met all standards associated with the Registry of Distinction quality standard indicating complete, timely, and high-quality data available for cancer control activities.

## 3.2.3 Collaboration with State and National Organizations

## **3.2.3.1** 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.

## 3.2.3.2 Division of Vital Records (IDPH)

Death certificate data from the Division of Vital Records (VR) is 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 hospitalbased 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.

#### 3.2.3.3 North American Association of Central Cancer Registries

ISCR provided comprehensive data from 1995-2020 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.

#### 3.2.3.4 National Program of Cancer Registries (NPCR)

ISCR submitted comprehensive data from 1995-2020 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.

#### 3.2.3.5 NCI's Surveillance, Epidemiology, and End Results (SEER) Program

ISCR submitted comprehensive data from 2000-2020 to the SEER call for data in November 2022 and again for diagnosis years 2000-2021 in February 2023 in accordance with the NCI/SEER contract. These biannual data submissions contribute Illinois data to the national cancer surveillance effort and include Illinois in all SEER data products.

#### 3.2.3.6 NCI's National Childhood Cancer Registry (NCCR)

The NCCR is a public health surveillance data resource with the primary goal to better understand the causes, outcomes, effective treatments, and the later effects of cancer among children, adolescents, and young adults in the U.S. ISCR submitted data from 1995-2020 to this effort for the November 2022 call for data.

#### 3.2.3.7 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.

## **3.2.3.8 CDC Agency for Toxic Substances and Disease Registry (ATSDR)** ISCR is participating in the pilot of a multi-site investigation into cancer incidence in people living near ethylene oxide emitters. This is in conjunction with CDC and ATSDR.

## 3.2.4 Quality Control Reports

- **3.2.4.1** Redeford B. Assessment of Duplicate Records for 1995-2021 Diagnosis Years. Quality Control Report Series 22:03. Springfield, Ill.: Illinois Department of Public Health, October 2022.
- **3.2.4.2** Squires, K. *Linking Illinois State Cancer Registry Records with Vital Records Death Master File to Enhance Data Completeness.* Quality Control Report Series 22:04. Springfield, Ill.: Illinois Department of Public Health, August 2022.

## 3.3 Goals for Fiscal Year 2024

- 3.3.1 Maintain Completeness and Timeliness of Reporting of Cancer Incidence Cases to the Illinois State Cancer Registry
  - Perform limited facility case finding for the 2021 diagnosis year at selected reporting facilities in Illinois and track identified missed cases to ensure reporting when circumstances permit (COVID-19).
  - Maintain interstate data exchange and complete exchanges by October 2023.
  - Continue death certificate clearance and maintain a death certificate only rate of less than 1.5%.
  - Achieve 98% case reporting for the 2022 diagnosis year by February 2024.
  - Achieve 100% case reporting for the 2021 diagnosis year by October 2023.

## 3.3.2 Provide Training for Reporting Facilities and for Central Registry Staff

- Develop, update, and maintain a cancer reporting training website for 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.

## 3.3.3 Ensure Data Quality

- Maintain duplicate rate of less than 0.01% using MatchPro to review submissions for duplicate tumor reports and apply NAACCR duplicate protocol.
- Meet SEER/NPCR/NAACCR standards for data quality and override flags.
- Perform sex verification using established ISCR procedure.
- Apply SEER, 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.

## 3.3.4 Maintain Data Use Activities

- Produce public use data set files, annual state and county incidence reports, annual state mortality report, and update cancer query system.
- Respond to cluster inquiries.
- Provide data and support for IBCCP and ICCCP.
- Perform linkage with IBCCP and update data files.
- Produce two epidemiologic reports.
- 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.
- Provide data to the National Childhood Cancer Registry and participate in associated linkage and research activities.
- Submit the 1995-2021 SEER/NPCR/NAACCR/NCCR data files and the preliminary NPCR 2022 data file for the annual call for data in October/November 2023. Submit the preliminary 2022data file for SEER call for data in February 2024.

## 3.3.5 Provide Adequate Program Management

- Hold monthly staff meetings.
- Monitor grant and contract activities.
- Update advisory committee and funding agencies on grant and contract 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 to refer children who require special services to correct and to prevent developmental problems and other disabling conditions.

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, or cannabis use, during the pregnancy.
- The infant was born at less than 31 completed weeks of gestation.
- A neonatal or fetal death has occurred.
- The infant or young child (less than 2 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.

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.

The Division Chief, Dr. Fornoff is currently acting as APORS Manager. The vacant position was posted in April 2023; a new manager will be hired as soon as possible.

#### 4.1 Review and Evaluation of Fiscal Year 2023 Goals

Improve Casefinding

- While webinars were suspended during the COVID-19 pandemic emergency declaration, training in APORS reporting continued through formal on-line trainings, use of the SharePoint<sup>®</sup> site for hospital staff, computer-based trainings, conversations with hospital staffs, and responses to emailed questions.
- Provided 10 trainings by phone or WebEx call and held 1,567 consultations via telephone or email with Illinois hospitals to improve APORS reporting.
- Updated the SharePoint<sup>®</sup> site with revised manuals and appendices and the most recent of the quality control reports; reminders were posted when patterns of problems are identified.
- In FY23, four genetic clinics reported 65 mothers carrying babies with prenatally suspected significant birth defects.



## Genetic Clinic Reports of Pregnancies Affected by a Suspected Birth Defect

- Reviewed the medical records of 608 infants identified from hospital discharge data; 98.4% of these cases were found to have conditions that meet the APORS review criteria.
- Reviewed charts of 1,410 mothers who experienced a fetal death to determine whether any birth defects were associated with the fetus. Of the reviewed charts, 4.8% were confirmed to be cases meeting the APORS case criteria.

#### Improve Quality of APORS Data

• APORS aims to complete active case verification for a birth cohort during the following two years. However, case verification for the 2020 birth cohort was completed late because abstractors were asked to focus on COVID in pregnancy during FY21 and FY22. Data collection for the 2020 birth cohort was completed in March 2023.

• Evaluated the timeliness of hospital reporting for cases reported in 2022; provided hospital-specific feedback and used results to identify hospital training needs. In 2022, 83.5% 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.



- Abstractors reviewed 239 charts of infants suspected to have neonatal abstinence syndrome (NAS), following the Council of State and Territorial Epidemiologists' recommendations. Of these, 99.6% were confirmed to have NAS. Another 10 cases were identified during chart review for other conditions.
- 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.
- Evaluated the rates of hospital reporting in 2021. Two-thirds of cases are reported by Level 3 hospitals that provide the highest level of care. The changes in proportions of cases reported by level may have been influenced in part by the COVID-19 pandemic in which transfer protocols were altered to accommodate the influx of patients in hospitals.



Case Reporting Rates by Hospital Level

#### Improve Program Effectiveness

- The APORS SharePoint<sup>®</sup> sites have been updated with revised manuals, appendices, and quality control reports. Hospitals and local health departments can also 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 and other adverse pregnancy outcomes was published to the Division of Epidemiologic Studies website.

## 4.2 Fiscal Year 2023 Major Accomplishments

## 4.2.1 Enhancement of the APORS Database

#### COVID-19 in Pregnancy

The APORS program collaborated with the IDPH Office of Health Protection's Division of Infectious Diseases, and the IDPH Office of Women's Health and Family Services, to better understand the impact of COVID-19 on pregnancy. APORS staff and contractual abstractors reviewed a total of 3,499 medical records (843 in FY23) from mothers who had COVID-19 during their pregnancy and the medical records for their babies. They have collected data about the mothers' health, pregnancies, and COVID-19 experiences; the infants' health at delivery and newborn stays; and COVID-19 testing for both. The data have been submitted to CDC for national level analysis and are also being analyzed by the IDPH Office of Women's Health and Family Services at the Illinois level.

## 4.2.2 Improved Birth Defects Surveillance

Hospital-reported cases are a starting point for birth defect surveillance. Potential birth defect cases were provided electronically to abstractor staff members, who then reviewed the infants' medical charts, verified the presence of birth defects, eliminated false positives, and collected additional diagnoses. In FY23, the abstractors reviewed reports of 4,799 birth defects submitted by hospitals. The charts show, for FY23, the disposition of the conditions reviewed or identified by the APORS staff, and the reasons reported defects were deleted.



## Primary Sources of Diagnoses and Review Outcome



## Reasons for Deleting a Reported Defect

## 4.2.3 Evaluation of Case Management Services Provided to APORS Cases

Home nursing visits were suspended during the COVID-19 pandemic. Services have been offered by telephone where community health agencies had the resources to do so. A survey to evaluate case management services was not undertaken this year.

#### 4.2.4 Linkages with Other Programs and Activities

- **4.2.4.1** 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. Most (12,394) infants were referred for contacts by local health department nurses. Counseling for parents is provided through the nurse visits, and referrals to necessary services were offered where possible. Included are 38 children with neural tube defects, whose families were referred for prevention counseling.
- **4.2.4.2 IDPH Office of Disease Control.** APORS identified infants for this Office's sexually transmitted disease (112 newborns), HIV program (73 newborns), and perinatal hepatitis B and C programs (329 newborns), which ensure infants with prenatally exposed to syphilis, HIV or hepatitis B or C infection are offered services.
- **4.2.4.3 IDPH Craniofacial Anomaly Program.** Data on infants born with cleft lip and/or palate (158 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.

- **4.2.4.4** 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 FY23, APORS referred 3,968 cases.
- **4.2.4.5** 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 FY23, APORS referred 1,715 cases.
- **4.2.4.6 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. A number of children with hypothyroidism, previously unknown to the NMS program, have been identified. In FY23, APORS referred 101 cases.
- **4.2.4.7 Illinois Department of Children and Family Services (DCFS).** Data are provided to DCFS monthly 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.
- **4.2.4.8** Illinois Department of Healthcare and Family Services (IDHFS). APORS data are provided monthly to IDHFS 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 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.
- **4.2.4.9** National Birth Defects Prevention Network (NBDPN.) APORS staff contributed data to and participated in a number of analyses. The APORS manager, Jane Fornoff, and data manager, Theresa Sandidge, served on the NBDPN Data Committee. Dr. Fornoff and the abstractor liaison, Jodi Snow, served on the NBDPN Surveillance Guidelines and Standards and the Surveillance Guidelines committees.
- **4.2.4.10 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.

**4.2.4.11 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, added, or dropped from the PRAMS questionnaire.

## 4.2.5 Quality Control Reports

- **4.2.6.1** Lingleo L, Sandidge T. *Timeliness Study Hospital Reports of Adverse Pregnancy Outcomes Received in 2022.* Quality Control Report Series 23:01. Springfield, Ill.: Illinois Department of Public Health, January 2023.
- **4.2.6.2** Sandidge T. *Rates of Hospital Reporting of Adverse Pregnancy Outcomes in 2021.* Quality Control Report Series 23:02. Springfield, Ill.: Illinois Department of Public Health, June 2023.

## 4.3 Goals for Fiscal Year 2024

#### Improve Casefinding

- Train and support hospitals in the use of the APORS database to ensure 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.
- Enhance the SharePoint<sup>®</sup> site for hospital staff to include materials that supplement face-to-face and telephone consultation and training offered by APORS staff.
- Match information from bi-annual hospital discharge information reports to the APORS newborn cases and identify potential birth defect cases and NAS cases.
- Review medical reports of infants identified in hospital discharge matching to ascertain and collect new birth defect cases.
- Explore the use of hospital discharge data to ascertain infants with prenatal birth defect diagnoses, and women with early induction of labor or excessive vaginal bleeding to ascertain new birth defect cases. (Postponed from FY21 due to both the APORS manger and the data steward providing the hospital discharge data being extensively involved in the IDPH COVID-19 response).
- Review maternal medical records where the pregnancy ended with a fetal death to ascertain and collect new birth defect and NAS cases.
- Recruit additional genetic clinics to increase prenatal case findings.

#### 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.
- Obtain hospital discharge data for infants with NAS to identify additional cases for chart review for infants suspected of having NAS to improve surveillance (Postponed from FY21 due to both the APORS manger and the data steward providing the hospital discharge data being extensively involved in the IDPH COVID-19 response).
- Implement an annual training plan for APORS abstractors.

#### Improve Program Effectiveness

- Enhance SharePoint<sup>®</sup> 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 and the National Birth Defects Prevention Network.
- Collaborate with IDPH, state, and local health department programs to assure the provision of perinatal services for high-risk infants.
- Continue the collaboration with CDC to provide data to the U.S. COVID-19 mother and infant registry.
- Produce statewide and county surveillance reports.

## 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).

The ODR staff continue to work remotely, though several staff return to the central office to maintain the ODR hotline. ODR staff have been provided cell phones, laptops, and additional monitors (if needed) to perform all duties from a home office. The Bureau of Labor Statistics (BLS) have moved all activities to a web-based platform, so all activities relating to SOII and CFOI can be completed remotely. The ABLR program is currently maintained by the University of Illinois at Chicago, School of Public Health, Environmental and Occupational Health Sciences. UIC began maintaining the ABLR program in November 2022.

## 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. The Illinois Administrative Code 77 Ill Adm Code 840 defines elevated blood levels as 10 ug/dL or higher. Laboratories are mandated to report results at or above this level. This program does not have federal or dedicated state funding. ABLR staff maintain a database of blood lead levels of 10 ug/dL and higher and refer employers with an employee with a blood lead level of at least 40  $\mu$ g/dL to OSHA in accordance with the memorandum of understanding. In calendar year 2021, 1,852 new lab reports were added to the ABLR database.



## Elevated Lead Level (ELL) Reports

## 5.1.1 Fiscal Year 2023 Accomplishments

- Notified OSHA quarterly of 27 companies that had, between them, 27 employees with elevated blood lead levels of  $\geq$ 40 µg/dL.
- Notified OSHA within 24 hours of zero cases with an elevated blood lead level of  $\geq$ 60 µg/dL.

# of Employees and Companies ABLR notified OSHA with an elevated blood lead level of ≥40 µg/dL



## 5.1.2 Interventions Resulting from ABLR Notifications of Elevated Lead Results

In calendar year 2022, the quarterly ABLR reports to OSHA led to no safety inspections in Illinois.

## 5.1.3 Goals for Fiscal Year 2024

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



Occupational Illness and Injuries Estimated from SOII

Source: U.S. Bureau of Labor Statistics, 2021.

## **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 2022, Illinois CFOI recorded 176 work related deaths. 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. CFOI staff currently use several methods of capturing data for the annual reporting of injuries. They currently use a news reporting service that scours local news agencies for potential workplace death; the Illinois Vital Records tags and reports any death certificate that are marked workplace injury; quarterly OSHA reports provided by BLS; National Highway Transportation and Safety Administration annual spreadsheet; and coroner and medical examiner case fatality form.



Fatal Occupational Injuries by Employee Status

Source: U.S. Bureau of Labor Statistics, 2021.

#### 5.2.1 Review and Evaluation of Fiscal Year 2023 Goals

- Completed the summary report of the 2022 fatal occupational injury data. The report is currently under IDPH review.
- 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 2024

- Publish an enhanced summary report of the 2022 fatal occupational injury data.
- Meet the deadlines for data completion required by BLS.

## 5.3 Survey of Occupational Injuries and Illnesses (SOII)

SOII (formerly the Occupational Safety and Health Survey) focuses on surveillance of non-fatal workplace injuries and illnesses. The Illinois SOII is supported through a cooperative agreement between the state and the BLS. The Illinois data are pooled with data collected by 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 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 2023 Goals

- Submitted data files on all reported occupational injuries and illnesses of the surveyed companies to the BLS.
- Collected, coded, and entered all 2022 data prior to BLS deadlines.

## 5.3.2 Survey Process and Achievements for Fiscal Year 2023

In January 2023, BLS and ODR sent survey forms to a sample of 5,155 private and 359 public employers for 2022 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 and email to solicit data. The final, overall survey response rate was 85%, which met the cooperative agreement minimum requirement for data publication at the time of this report.

## 5.3.3 Goals for Fiscal Year 2024

- Continue all data collection activities in FY24 and maintain the high standards achieved by the program.
- Complete the descriptive report of 2023 Survey of Occupational Injuries and Illnesses.
- Meet the deadlines assigned by BLS.

## 5.4 Illinois Occupational Surveillance Program (IOSP)

The Illinois Occupational Surveillance Program (IOSP; illinoisinjuryprevention.org) is a NIOSH-funded worker surveillance program housed at UIC School of Public Health that operates in collaboration with IDPH and other state agencies. IOSP serves as the bona fide agent of IDPH in this grant program. IOSP is ending the first year of funding of a five-year cycle and will continue to collaborate with the Occupational Surveillance Program, as well as the Illinois Partnership for Safety, managed by IDPH under the CDC's Injury and Violence Prevention program.

## 5.4.1 Occupational Health Indicators

The number of employees forming the baseline for the occupational health indicators does change from year to year. The COVID pandemic had a particularly large impact, substantially reducing the number of employees in 2020 and 2021.



Number of employees, >16 years



## Number of workers in high morbidity risk occupations

Almost all cases of pneumoconiosis can be attributed to occupational exposures. Asbestosis, coal workers pneumoconiosis, and silicosis are the major types of pneumoconiosis. These types of pneumoconiosis are associated with many serious respiratory complications including respiratory infections, chronic bronchitis, emphysema, lung cancer, pleuritis, progressive systemic sclerosis, renal disease, and respiratory failure. Controlling occupational dust exposure is the best way to prevent pneumoconiosis. U.S. regulators are developing more protective standards to protect workers from occupational dust exposure and there is an international effort to ban on asbestos which is mined across the globe.



Hospitalizations for Pneumoconiosis, Abestosis, and Silicosis

Almost no pesticide poisonings are work-related (based on the case definition of acute pesticide related illness by NIOSH). Young children (<5 years) are disproportionately exposed to pesticides. These poisonings are preventable and usually result from failure to secure pesticides in child-proof containers and store them in child-proof cabinets above ground level. Many exposures in those 25-34 years of age involve self-harm or suicide attempts. Most work-related exposures involve people between the ages of 25 and 64.



## Hospitalizations and Emergency Department Visits for Pesticide Related Illness, by Age Group

## 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 other 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 capacity within the IHHSR system.

## 6.1 Geocoding Process and Accomplishments

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.31<sup>®</sup>.

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 process includes address standardization, verification of ZIP code based on city, and 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 varies little by year of. A detailed quality assessment of the geocoding results for cancer data has been completed and serves as a reference document for researchers using geocoded registry data.



## 6.2 Goals for Fiscal Year 2024

Continue to geocode new records submitted to ISCR and APORS.

## 7. Cluster Inquiries and Assessments

## 7.1 Review and Evaluation of Fiscal Year 2023 Goals

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

#### 7.2 Fiscal Year 2023 Accomplishments

In FY23, IDPH received nine requests for assistance 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 caller concerns.

## 7.3 Fiscal Year 2024 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.

The Division Chief led the IDPH Modeling and Data Intelligence teams contributing to the IDPH COVID-19 response. Registry staff have examined patterns and trends in cases, testing, positivity, hospital resource use, and deaths trends. They also have forecast future trends and resource needs.

#### 8.1 Fiscal Year 2023 Major Accomplishments

## 8.1.1 Provision of Epidemiologic Support to IDPH Committees and Workgroups

Division of Epidemiologic Studies staff continued to co-chair and participate in IDPH's IRB, opioids projects/databases, IDPH Academic Partnership, IVRS Steering Committee, and Internal Data Sharing Workgroup. Six staff serve on different committees in various capacities. Division staff also supported data activities related to the response to the COVID-19 pandemic.

#### 8.1.2 Provision of Peer-Review Service to Scientific Publication

Division of Epidemiologic Studies staff provided professional reviews to journals.

#### 8.1.3 Provision of Epidemiologic Supervision and Tutoring

Division of Epidemiologic Studies staff provided supervisor roles and other assistance to a Graduate Public Service Intern in FY23.

## 8.1.4 Publication of the IDPH Illinois Morbidity and Mortality Bulletin (IMMB)

Publication of the IMMB has been postponed indefinitely while research staff assist with the COVID-19 pandemic.

#### 8.1.5 Technical Assistance

Technical assistance has been provided by staff to various IDPH offices and divisions in the areas of statistics/epidemiology, research methods, data confidentiality review, Freedom of Information Act (FOIA) and media requests, data linkage, SAS<sup>®</sup> programming, data analysis and interpretation, data deduplication, surveillance system evaluation, quality control, and research data requests. Division of Epidemiologic Studies 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, and de-identification of individual data records. Division staff also provided interviews and responses to medical requests on various disease issues.

## 8.1.6 IDPH Institutional Review Board

The Division of Epidemiologic Studies continued to staff the IDPH IRB, with one staff member serving as the IRB manager, one as vice-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 IDPH responsible individuals (RIs) in various programs.

In FY23, the IRB procured, customized, and implemented IRB software to streamline the management of IRB applications. Manuals were developed for IDPH staff responsible for data release and for researchers requesting data for human subject research.

## 8.2 Scientific Publications in Fiscal Year 2023

The following articles have been submitted, accepted, or published.

- 8.2.1 Outcomes up to age 36 months after congenital Zika virus infection U.S. States Neelam V, Woodworth KR, Chang DJ, Roth NM, Reynolds MR, Akosa A, Carr CP, Anderson KN, Mulkey SB, DeBiasi RL, Biddle C, Lee EH, Elmore AL, Scotland SJ, Sowunmi S, Longcore ND, Ahmed M, Langlois PH, Khuwaja S, Browne SE, Lind L, Shim K, Gosciminski M, Blumenfeld R, Khuntia S, Halai UA, Locklear A, Chan M, Willabus T, Tonzel J, Marzec NS, Barreto NA, Sanchez C, Fornoff J, Hale S, Nance A, Iguchi L, Adibhatla SN, Potts E, Schiffman E, Raman D, McDonald MF, Stricklin B, Ludwig E, Denson L, Contreras D, Romitti PA, Ferrell E, Marx M, Signs K, Cook A, Leedom VO, Beauregard S, Orantes LC, Cronquist L, Roush L, Godfred-Cato S, Gilboa SM, Meaney-Delman D, Honein MA, Moore CA, Tong VT. Pediatrics Research. 2023 Sep 1;. doi: 10.1038/s41390-023-02787-9. Epub ahead of print. PMID: 37658124.
- 8.2.2 Prevalence and descriptive epidemiology of Turner Syndrome in the United States, 2000-2017: a report from the National Birth Defects Prevention Network Martin-Giacalone BA, Lin AE, Rasmussen SA, Kirby RS, Nestoridi E, Liberman RF, Agopian AJ, Carey JC, Cragan JD, Forestieri N, Leedom V, Boyce A, Nembhard WN, Piccardi M, Sandidge T, Shan X, Shumate CJ, Stallings EB, Stevenson S, Lupo PJ. American Journal of Medical Genetics Part A 2023; 191(5) 1339-1349.
- 8.2.3 Prevalence of individual brain and eye defects potentially related to Zika virus in pregnancy in 22 U.S. states and territories, January 2016 June 2017 Delaney A, Olson SM, Roth NM, Cragan JD, Godfred-Cato S, Smoots AN, Fornoff J, Nestoridi E, Eckert V, Forkner A, Stolz A, Crawford K, Cho SJ, Elmore A, Langlois P, Nance A, Denson L, Forestieri N, Leedom VO, Tran T, Valencia-Prado M, Romitti P, Barton JE, St John K, Mann S, Orantes L, DeWilde L, Tong VT, Gilboa SM, Moore CA, Honein MA. 2022; Birth Defects Research Aug 15;114(14):805-811. doi:

10.1002/bdr2.2067. Epub 2022 Jul 30. PMID: 35906998; PMCID: PMC10391873. http://doi.org/10.1002/bdr2.2067

8.2.4 Zika-associated birth defects reported in pregnancies with laboratory evidence of confirmed or possible Zika Virus infection, U.S. Zika pregnancy and infant registry, December 1, 2015 to March 31, 2018. Roth NM, Reynolds MR, Lewis EL, Woodworth KR, Godfred-Cato S, Delaney A, Akosa A, Valencia-Prado M, Lash M, Elmore A, Langlois P, Khuwaja S, Tufa A, Ellis EM, Nestoridi E, Lyu C, Longcore ND, Piccardi M, Lind L, Starr S, Johnson L, Browne SE, Gosciminski M, Velasco PE, Johnson-Clarke F, Locklear A, Chan M, Fornoff J, Toews KE, Tonzel J, Marzec NS, Hale S, Nance AE, Willabus T, Contreras D, Adibhatla SN, Iguchi L, Potts E, Schiffman E, Lolley K, Stricklin B, Ludwig E, Garstang H, Marx M, Ferrell E, Moreno-Gorrin C, Signs K, Romitti P, Leedom V, Martin B, Castrodale L, Cook A, Fredette C, Denson L, Cronquist L, Nahabedian JF 3rd, Shinde N, Polen K, Gilboa SM, Martin SW, Cragan JD, Meaney-Delman D, Honein MA, Tong VT, Moore CA. Morbidity and Mortality Weekly Report 2022 Jan 21; 71(3):73-79. doihttp://doi.org/10.15585/mmwr.mm7103a1. PMID: 35051132; PMCID: PMC8774158.

## 8.3 Peer-Reviewed Articles That Used Registry Data

- 8.3.1 Bertrand KA, Zirpoli G, Pillalamarri BN, Szalat R, Palmer JR, Kataria Y. Prevalence of monoclonal gammopathy of undetermined significance (MGUS) in US Black women. Am J Hematol 2022. doi: 10.1002/ajh.26638. PMCID: PMC9476624.
- 8.3.2 Bethea TN, Dash C, Adams-Campbell LL. A prospective cohort study of physical activity in relation to lung cancer incidence among Black women. Cancer Epidemiol 2022;78:102146. doi: 10.1016/j.canep.2022.102146. PMCID: PMC9133140.
- 8.3.3 Bigham Z, Robles Y, Freund KM, Palmer JR, Bertrand KA. Hypertensive diseases of pregnancy and risk of breast cancer in the Black Women's Health Study. Breast Cancer Res Treat 2022;194(1):127-35. doi: 10.1007/s10549-022-06606-3. PMCID: PMC9190198.
- 8.3.4 Chantaprasopsuk S, Rees-Punia E, Patel AV. Physical activity, obesity, and bladder cancer incidence. Cancer Causes Control. 2023. doi: 10.1007/s10552-023-01711-0
- 8.3.5 Cronin, KA, Scott, S, Firth, AU, et al. Annual Report to the Nation on the Status of Cancer, part 1: National Cancer Statistics. *Cancer*. 2022; 128(24): 4251-4284. doi:10.1002/cncr.34479
- 8.3.6 Erhunmwunsee L, Wing SE, Zou X, Coogan PF, Palmer JR, Wong FL. Neighborhood disadvantage and lung cancer risk in a national cohort of never smoking Black women. Clin Lung Cancer 2022;173:21-27. doi: 10.1016/j.lungcan.2022.08.022. PMCID: PMC9588723.
- 8.3.7 Gao G, Lunetta KL, Bertrand K, Zirpoli G, Palmer JR, et al. Polygenic risk scores for prediction of breast cancer risk in women of African ancestry: a cross-

ancestry approach. Hum Mol Genet 2022. doi: 10.1093/hmg/ddac102. PMCID: PMC9476624.

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- 8.3.9 Koutros S, Kiemeney LA, Pal CHOUDHURY, et al. Genome-wide association study of bladder cancer reveals new biological and translational insights. Eur Urol. 2023. doi: 10.1016/j.eururo.2023.04.020
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  - 8.4.1 American Cancer Society. *Cancer Facts & Figures 2023*. Atlanta, GA.: American Cancer Society; 2022.
  - 8.4.2 CiNA Explorer: An interactive tool for quick access to key NAACCR cancer statistics based on the Cancer in North American (CiNA) dataset from the North American Association of Central Cancer Registries. Available from (https://apps.naaccr.org/explorer) 2023.
  - 8.4.3 National Program of Cancer Registries and Surveillance, Epidemiology, and End Results Program SEER\*Stat Database: NPCR and SEER Incidence U.S. Cancer Statistics 2001–2020 Public Use Research Database, 2022 submission (2001–2020), United States Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute. Released June 2023. Available at www.cdc.gov/cancer/uscs/public-use.
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  - 8.4.7 U.S. Cancer Statistics Working Group. U.S. Cancer Statistics Data Visualizations Tool, based on 2022 submission data (1999-2020): U.S. Department of Health and Human Services, Centers for Disease Control and Prevention and National Cancer Institute; <u>https://www.cdc.gov/cancer/dataviz</u>, released June 2023.
  - 8.4.8 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.

#### 8.5 Epidemiologic Report Series

The following reports were released in IDPH's Epidemiologic Report Series; all reports are available to the public on the Division of Epidemiologic Studies' website:

8.5.1 Reyes B, Garner K, Fornoff J. Disparities in breast and cervical cancer incidence and mortality rates for females in Illinois, 1996 – 2019. Epidemiologic Report

Series 23:01. Springfield, Ill.: Illinois Department of Public Health, September 2022.

- 8.5.2 Garner K, Fornoff J. Pediatric cancer incidence and mortality in the vicinity of nuclear power plants in Illinois, 1996 2019. Epidemiologic Report Series 23:02. Springfield, Ill.: Illinois Department of Public Health, October 2022.
- 8.5.3 Sandidge T, Fornoff JE, Shen T. *Birth defects and other adverse pregnancy outcomes in Illinois 2015-2019.* Epidemiologic Report Series 23:03, Springfield, Ill.: Illinois Department of Public Health, September 2022.
- 8.5.4 Garner K, Fornoff J. Illinois county cancer statistics review incidence, 2016-2020.
   Epidemiologic Report Series 23:05. Springfield, Ill.: Illinois Department of Public Health, April 2023.
- 8.5.5 Garner K, Fornoff J. Illinois state cancer incidence review and update, 1986-2020. Epidemiologic Report Series 23:06. Springfield, Ill.: Illinois Department of Public Health, April 2023.
- 8.5.6 Garner K, Fornoff J. Illinois cancer mortality review and update, 1986-2020. Epidemiologic Report Series 23:07. Springfield, Ill.: Illinois Department of Public Health, April 2023.
- 8.5.7 Swenny M, Wamack, J. Census of fatal occupational injuries, Illinois 2021. Epidemiologic Report Series 23:08. Illinois Department of Public Health, April 2023.

Title	Event	Date	
APORS database	Roseland Hospital High Risk	August 2022	
APORS database	Pike County Health Department, Pittsfield, virtual	August 2022	
APORS database	Randolph County Health Department, Chester, virtual	September 2022	
APORS database	Perry County Health Department, Pinckneyville, virtual	September 2022	
Cancer Surveillance: Information Source for Cancer Prevention, Control, and Research	Univ. of Illinois Chicago, School of Public Health, virtual	September 2022	
Certified Tumor Registrars and the U.S. Cancer Surveillance System	Central Illinois Health Information Management Association, virtual	September 2022	

#### 8.6 FY 2023 Presentations by IDPH Division of Epidemiologic Studies Staff

Title	Event	Date
ISCR Town Hall	Training for all reporting facilities, virtual	September 2022
APORS database	University of Chicago Hospitals, Chicago, virtual	October 2022
Introduction to APORS/HRIF	University of Chicago Hospitals, Chicago, virtual	October 2022
ISCR Town Hall	Training for all reporting facilities, virtual	October 2022
APORS database	Oak Park Health Department, Oak Park, virtual	November 2022
ISCR Town Hall – Extent of Disease training	Training for all reporting facilities, virtual	November 2022
What's New for Diagnosis Year 2023 Reporting	Training for all reporting facilities, Mount Vernon, IL	November 2022
What's New for Diagnosis Year 2023 Reporting	Training for all reporting facilities, Arlington Heights, IL	December 2022
What's New for Diagnosis Year 2023 Reporting	Training for all reporting facilities, Joliet, IL	December 2022
What's New for Diagnosis Year 2023 Reporting	Training for all reporting facilities, Springfield, IL	December 2022
APORS database	DuPage County Health Department, Wheaton, virtual	February 2023
APORS refresher	MacNeal Hospital, Berwyn, virtual	April 2023
Colorectal Cancer in Illinois	Illinois Cancer Partnership Colorectal Roundtable, virtual	May 2023
APORS database	HRDI, Chicago, virtual	June 2023
Cancer Burden in Illinois	Illinois Cancer Partnership Annual Meeting, virtual	June 2023
Illinois Cancer Statistics	Illinois Breast and Cervical Cancer Lead Agencies Meeting, virtual	June 2023

## 8.7 Research Data Release and Collaborations

Principal Investigator (Affiliation)	Title	Date	Funding Source
Alpa V. Patel, Ph.D. American Cancer Society	Cancer Prevention Study II	1995, ongoing	ACS
Mardge Cohen, M.D. Women's Interagency HIV Study	Women's Interagency HIV Study	2000, ongoing	NIH

Principal Investigator (Affiliation)	Title	Date	Funding Source
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
Lynn Rosenberg, Sc.D., M.S. Sloan Epidemiology Center Boston University	Black Women's Health Study	February 2007, ongoing	NIH/NCI
Mark Canfield Texas Department of State Health Services	Study of Selected Birth Defects Among Minorities 1999-2007	July 2012, ongoing	
Brinton, Trabert, Ph.D. National Cancer Institute	Infertility Follow-up Study	2012, ongoing	NCI
Garth Rasuscher, Ph.D. University of Illinois at Chicago	Comparative Effectiveness of Breast Imaging Modalities: A Natural Experiment	2013, ongoing	Agency for Health Research and Quality
Herbert Chen, M.D.	Medullary Thyroid Carcinoma Surveillance Study – A Case- Series Registry	2014, ongoing	The MTC Registry Consortium
Alpa V. Patel, Ph.D.	Cancer Prevention Study III	2015, ongoing	ACS
Gary Fraser, M.D., Ph.D.	Adventist Health Study II	2015, ongoing	NCI
Eric Engels, Ph.D. National Cancer Institute	Transplant Cancer Match Study	2016, ongoing	NCI
Dr. Frank Bove, Sc.D.	Cancer Incidence Study of Marines/Navy Personnel and Civilian Employees Exposed to Contaminated Drinking Water at USMC Base Camp Lejeune	2020, ongoing	Agency for Toxic Substances and Disease Registry
Dr. Mayris Webber, DrPH	Maintenance and Extension of a Cohort of Career Firefighters as a Non-WTC Exposed Comparison for the FDNY Firefighter Cohort	2020, ongoing	National Institute for Occupational Safety and Health
Humberto Parada, Jr., PhD, MPH San Diego State University	Characterizing the Burden of Cancer among Adults from the	2022, ongoing	San Diego State University HealthLINK

Principal Investigator (Affiliation)	Title	Date	Funding Source		
	Hispanic Community Health Study/Study of Latinos		Center for Transdisciplinary		
			Research		
Joyce Woo Ann and Robert H. Lurie Children's Hospital of Chicago	Effects of Illinois perinatal regionalization policy for infants born with congenital heart disease	2022, ongoing	Stanley Manne Children's Research Institute		
Wendy Nembhard University of Arkansas for Medical Sciences	Mortality and Causes of Death among Children with and without Birth Defects in the United States	2022, ongoing			
NOTE: Following are definitions of acronyms used in the above table: American Cancer Society (ACS), National Cancer Institute (NCI), National Institutes of Health (NIH)					

## 9. Grants and Contracts

The table below summarizes the IDPH Division of Epidemiologic Studies grant awards for FY23.

Grant or Contract	Agency	Status	Amount	Grant Period	
Occupational and Health Survey in Illinois (continuation)	BLS	Funded September 2022	\$125,600	10/1/22 – 9/30/23	
Census of Fatal Occupational Injuries in Illinois (continuation)	BLS	Funded September 2022	\$106,000	10/1/22 – 9/30/23	
National Cancer Prevention and Control Program-National Program of Cancer Care (continuation)	CDC	Funded June 2022	\$950,000	7/1/22 – 6/29/23	
Surveillance, Epidemiology, and End Results	NCI	Funded March 2021	\$1,523,537	3/3/21 – 4/30/21 5/1/22 – 4/30/23	
Perinatal Hepatitis B Program (submitted by IDPH Division of Infectious Diseases) (continuation)	CDC	Funded 2018	\$50,000	7/1/22 – 6/30/23	
Illinois Occupational Surveillance Program (IOSP)	NIOSH	Funded July 2020	\$2,709,308	7/1/20 – 6/30/25	
NOTE: Full titles of acronyms used in the above table are U.S. Centers for Disease Control and Prevention (CDC), U.S. Bureau of Labor Statistics (BLS), National Institute of Occupational Safety and Health (NIOSH), and Illinois Department of Public Health (IDPH).					

## 9.1 Funded Grants and Contracts

The IDPH Division of Epidemiologic Studies received \$3.8 million and IOSP received \$2.7 million in grant awards in Fiscal Year 2023.



## **Division Funding Through Grants and Contracts**

## 9.1.1 National Cancer Prevention and Control Program

In June 2022, CDC awarded IDPH \$7.45 million in funding for the first year of a five-year project period of the National Cancer Prevention and Control Program. This grant combined two previous grants: the National Comprehensive Cancer Control Program and the National Program of Cancer Registries (NPCR). The Division of Epidemiologic Studies received \$950,000 for the NPCR component, which is in its 29<sup>th</sup> year. The progress for this project is described in Section 3.

## 9.1.2 Surveillance, Epidemiology, and End Results

In March of 2021, NCI announced Illinois had been chosen for the SEER program and awarded the state a contract totaling \$22,752,223 including state matching funds, over seven years. Becoming a SEER registry has been an objective of the Illinois State Cancer Registry for many years, although funding opportunities for new states to become SEER registries occur infrequently. This achievement is significant and places Illinois in the top echelon of population-based cancer registries. Illinois' participation in the SEER program will significantly expand ISCR's cancer surveillance activities in Illinois to include patient follow-up, enhanced data collection, rigorous quality control of cancer data, and increased opportunities to participate in research projects and collaborations.

## 9.1.3 Perinatal Hepatitis B Program

The Division of Epidemiologic Studies received \$50,000 in January 2022 to continue expansion of APORS surveillance and data collection (23<sup>rd</sup> year) to include perinatal hepatitis B and to enhance a tracking system that identifies newborn infants requiring follow-up immunization services. The progress for this project is described in Section 4.

## 9.1.4 Survey of Occupational Injuries and Illnesses in Illinois

IDPH received \$125,600 in September 2022 from BLS to support the 25<sup>th</sup> year of the Survey of Occupational Injuries and Illnesses, (formerly the Occupational Safety and Health Survey) in Illinois. This project is described in Section 5.

## 9.1.5 Census of Fatal Occupational Injuries in Illinois

IDPH received \$106,000 in September 2022 from BLS to support the 31<sup>st</sup> year of the Census of Fatal Occupational Injuries (CFOI) in Illinois. This project is described in Section 5.

## 9.1.6 Illinois Occupational Surveillance Program

IOSP received \$ 2,709,308 from NIOSH to submit the 29 Occupational Health Indicators for 2020-2025 by calendar year and to aid with the Adult Blood Lead Registry. In addition to the basic program (providing indicators, four separate programs were funded: Linking Occupational Surveillance Data, Work Practices, and OSHA Enforcement Activities; Pesticide Related Illness Surveillance Program; COVID-19 Supplemental Project to Address Vaccine Hesitancy among Essential Workers (one year only); COVID-19 Cases in the Illinois Workers' Compensation Claims (one year only).

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