

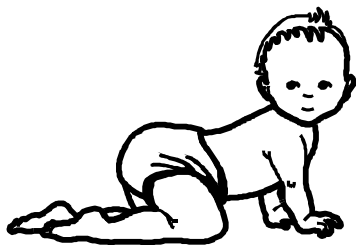
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## First Step Toward Services for High-risk Infants

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The Adverse Pregnancy Outcomes Reporting System (APORS) plays an important role in making sure high-risk infants receive the services needed to promote optimal growth and development. When hospitals complete APORS reports for infants born with birth defects or other adverse consequences, they are taking the first step to assure that these infants and their parents receive follow-up services. Services must be provided as quickly as possible (1) to minimize disability by identifying possible conditions requiring further evaluations, diagnosis and treatment, and (2) to assure home environments are safe and nurturing.

Hospitals complete the APORS's Infant Discharge Record within seven days of a newborn baby's discharge from the hospital. In addition to sending the report to the Illinois Department of Public Health (IDPH), a copy is sent to the local health department responsible for providing high-risk infant follow-up services. That action initiates a home visit to the family by a local health department nurse within seven days of notification.

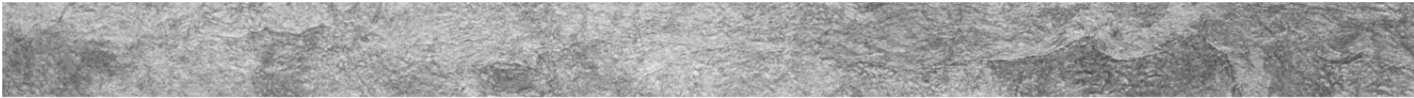


Public health nurses can provide services to high-risk infants and their families for up to two years. A nurse contacts the parents as soon as possible to arrange the first home visit. At that visit, the nurse gives the baby a simple physical examination and a Denver developmental screening, evaluates the home for infant safety, provides health and parent education, reinforces hospital discharge treatment instructions and makes referrals to other public health and community social services that can assist the family. If the parents agree to receive additional follow-up services, the local health nurse will visit the infant and family at least five additional times during the next two years – when the infant is 2, 6, 12, 18 and 24 months old. At each visit, the infant's physical, developmental, psychosocial, cognitive and emotional growth is assessed so that any need for further services can be identified quickly.

Based on need, some families may be referred to special programs. Some

### Hepatitis B Rules

The regulations for reporting adverse pregnancy outcomes will be modified in 1999 to require the identification of infants who were prenatally exposed to hepatitis B or who were diagnosed with hepatitis B infection during the newborn hospitalization. At its December 1998 meeting, the State Board of Health approved language for this rule change so that these infants can receive needed vaccines immediately. The Illinois Department of Public Health will proceed to promulgate the change to APOR's administrative rules (77 Il. Adm. Code 840.210). The rule making process will take three to four months. Until the change takes effect, hospitals are asked to report infants diagnosed with a prenatal exposure to hepatitis B (ICD-9-CM code V01.7) and those with a hepatitis B infection (ICD-9-CM code 774.4) in the same manner as they do other reportable conditions affecting newborn infants. Information about the proposed rule may be obtained by contacting Trish Egler, APORS manager, at 217-785-7133.



may be eligible for services such as the Special Supplemental Nutritional Program for Women, Infants and Children (WIC), early intervention programs for children birth to 3 years who have developmental delays, family planning and genetic counseling. During all of the contacts with parents of high-risk children, the local health department nurses offer support, education and assistance so that parents are better able to care for their children.

Each year approximately 15,000 infants are reported to the Adverse Pregnancy Outcomes Reporting System by Illinois hospitals. A very large percentage of those infants' families take advantage of the follow-up services provided by local health departments. The high-risk infant follow-up program is administered by the Illinois Department of Human Services. The partnership of the state departments, local health departments and hospitals benefits Illinois families.

## Jessie's Story

Jessie is an APORS baby. She was born in a central Illinois hospital two weeks early. Her parents, both in their early 20s, never expected a problem. Since they already had a healthy 4-year-old son. During Jessie's newborn hospital stay, the staff suspected that she might have a birth defect. However, it was not until after Jessie's parents took her home that they learned she had Down syndrome.

Within two days after the county health department was notified by the hospital, Jessie and her parents started receiving services. Mary Smith, a registered nurse, immediately made a visit to Jessie's home. Both has many questions and concerns. While they had occasionally seen a child with Down syndrome, neither knew how it could occur and what it meant to have a baby with a birth defect. First, Mary reassured Jessie's mother and explained that neither parent was at fault. She went on to explain that, besides Down syndrome, Jessie had a heart defect that would require surgery. Mary gave Jessie a physical examination and a developmental screening. It was reassuring that Jessie was feeding well and did not have any immediate health concerns.

During the initial visit, Mary



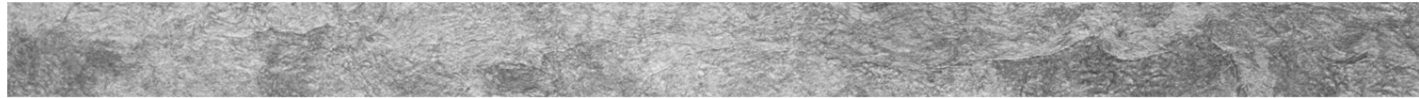
learned that both parents were employed, and Jessie's mom had health insurance. However, the family was concerned about its portion of costs for the needed heart surgery. Mary referred the family to Social Security for financial aid, but the family was ineligible for benefits. Then, Mary referred them to the University of Illinois' Division of Specialized Care for Children (DSCC). Jessie was accepted into a DSCC program that could provide some help with Jessie's medical costs and associated expenses.

Jessie's parents also needed assistance in finding a primary care physician with experience in caring for a child with Down syndrome

since not every doctor has such expertise. Mary identified an area physician who was knowledgeable, and the family was referred to that person.

Mary also linked the family with the Child and Family Connection, an early intervention agency that serves families of children, aged 0 to 3. The Child and Family Connection involved Mary in developing a care plan with Jessie's parents. This planning process asked the parents to assess Jessie's and their strengths and needs and to set goals. Jessie's parents wanted to learn more about Down syndrome and how they could meet their baby's needs. Mary worked with the parents to educate them on developmental milestones and what they could do to help Jessie achieve them. For example, a baby with Down syndrome often has weak muscle tone and suffers delays in rolling over. Jessie's parents were taught to do exercises with her to strengthen her muscles. For additional information, the county health department purchased a book on Down syndrome for Jessie's parents.

Jessie's parents were not the only ones who needed to be educated about Down syndrome. A relatively rare occurrence, the annual number of babies born in



Illinois with Down syndrome has averaged 163 since 1989. Mary, who had never provided services to a baby like Jessie, discovered there was much she needed to learn. She researched the syndrome and learned what nursing physical assessments should be done. For example, Down babies may have problems such as hearing loss or thyroid dysfunction. Mary used this information as she assessed Jessie during visits. In addition, Mary worked with Jessie's parents so that they understood the importance of hearing examinations and of keeping the doctor aware of Jessie's development.

Within a few months, Jessie began having problems while

feeding. She began sweating profusely and became cyanotic. Jessie had been seeing a heart specialist in Peoria, who recommended surgery. The operation was successful, but she was hospitalized for three weeks afterward due to respiratory complications. DSCC assisted the family by paying for their transportation and lodging while Jessie was hospitalized. Once released, Jessie recovered quickly, had no feeding problems and gained weight.

Jessie is now 9 months old. The family is enrolled in the county health department's WIC program. Mary continues to provide assistance to the family. Since Jessie was

born, Mary has met with the family eight times and spoken frequently with them between visits. Mary will continue to monitor Jessie's progress, to reinforce the child's medical treatment, to provide health information and parent education, and to make necessary referrals. Every child with Down syndrome is unique with different potential for growth and development. Early actions taken by the family can positively influence how the child develops. It is good to know that hospitals can bring in local health departments to assist and support families for better outcomes for APORS babies.

## Illinois Counties With Need for Cancer Screening

### Purpose

The Illinois State Cancer Registry is the only population based source for cancer incidence data in Illinois. This study originally was conducted by research staff of the Division of Epidemiologic Studies in February of 1998. The assessment was a direct response to the Illinois breast and Cervical Cancer Program. Later the purpose of the needs assessment was to provide local providers with information regarding the degree of need in a particular county for breast and cervical cancer screening services.

### Method

Each Illinois county was ranked on six indicators:

- cervical cancer mortality:** five-year average age-adjusted rates (AAR) for 1992-1996, Illinois females of all races
- breast cancer mortality:** five-year average age-adjusted rates (AAR) for 1992-1996, Illinois females of all races
- poverty level:** percentage of women older than age 40 who are under the 200 percent poverty level
- breast cancer *in situ* incidence:** five-year average age-adjusted rates (AAR) for 1990-1994, Illinois females of all races
- invasive breast cancer incidence:** five-year average age-

adjusted rates (AAR) for 1990-1994, for Illinois females of all races

**cervical cancer incidence:** five-year average age-adjusted rates (AAR) for 1990-1994, Illinois females of all races

The rates for each indicator were grouped into seven categories with one seventh of the counties falling into each. The counties with the highest incidence and mortality rates were given the highest value of seven, with the exception of breast cancer *in situ*, where the order was reversed and counties with the highest incidence and mortality rates received the lowest value of one. A county given the value of one is considered to have the least need for service and therefore the lowest incidence and mortality rates, while a county with the value of seven has the greatest need for service on that particular indicator. Finally, all the values for each of the six indicators were added (shown in Table 1) and then ranked in descending order. The counties with the highest rank has the greatest need for breast and cervical cancer screening.

### Results

Table 1 shows the descending scores by county. The scores ranged from 14 to 38 (possible 7 to 42). The counties in italics are currently served by the Illinois Breast and

Cervical Cancer Program (IBCCP)

**Table 1 Illinois Counties Ranked by Need of Breast and Cervical Screening Services**

Counties not served are in **bold type**. Counties served are *italicized*.

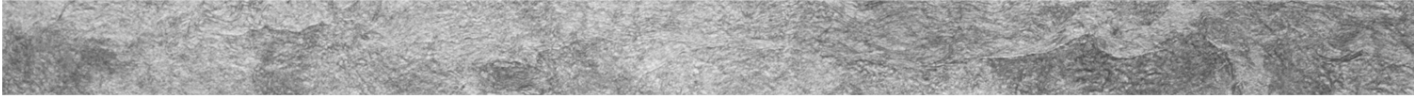
County	Rank	County	Rank	County	Rank	County	Rank	County	Rank
<i>Mason</i>	38	<b>Tazewell</b>	28	<i>Calhoun</i>	25	<i>Warren</i>	23	<b>Lee</b>	20
<i>Greene</i>	36	<i>St. Clair</i>	28	<b>Randolph</b>	25	<b>Hardin</b>	23	<i>Ogle</i>	20
<i>Fulton</i>	36	<i>Peoria</i>	28	<b>Edgar</b>	25	<b>Livingston</b>	23	<i>Jo Daviess</i>	20
<b>Gallatin</b>	36	<b>Pulaski</b>	27	<i>Knox</i>	25	<i>Wayne</i>	23	<b>Woodford</b>	19
<b>Cumberland</b>	33	<b>Morgan</b>	27	<i>Winnebago</i>	25	<b>Shelby</b>	23	<b>Pope</b>	19
<b>Clay</b>	33	<i>Adams</i>	27	<b>Kane</b>	25	<b>Douglas</b>	22	<i>Hancock</i>	19
<b>Cass</b>	33	<i>Carroll</i>	27	<i>De Witt</i>	25	<b>Clark</b>	22	<i>Lake</i>	19
<i>Williamson</i>	32	<i>Rock Island</i>	27	<b>Edwards</b>	24	<b>Alexander</b>	22	<b>Kendall</b>	18
<i>Marion</i>	32	<b>Whiteside</b>	26	<i>Jefferson</i>	24	<b>Jersey</b>	22	<b>Monroe</b>	18
<i>Schuyler</i>	32	<b>Jackson</b>	26	<b>Sangamon</b>	24	<b>McLean</b>	22	<i>Henry</i>	18
<b>Lawrence</b>	32	<b>De Kalb</b>	26	<b>McHenry</b>	24	<i>Champaign</i>	22	<i>Bond</i>	18
<i>Perry</i>	31	<i>McDonough</i>	26	<b>Bureau</b>	24	<b>Will</b>	22	<b>Scott</b>	18
<b>Massac</b>	30	<b>Iroquois</b>	26	<i>Macoupin</i>	24	<i>Du Page</i>	21	<i>Marshall</i>	16
<i>Cook</i>	30	<b>Coles</b>	26	<i>Stephenson</i>	24	<b>Madison</b>	21	<b>Ford</b>	16
<b>Christian</b>	29	<i>LaSalle</i>	26	<i>Menard</i>	24	<b>Wabash</b>	21	<i>Mercer</i>	16
<i>Franklin</i>	29	<b>Vermilion</b>	26	<b>Saline</b>	24	<i>Clinton</i>	21	<b>Grundy</b>	15
<b>Johnson</b>	29	<i>Kankakee</i>	26	<i>Stark</i>	24	<b>Union</b>	21	<b>Moultrie</b>	14
<b>White</b>	29	<i>Brown</i>	26	<b>Putnam</b>	23	<b>Fayette</b>	20	<i>Piatt</i>	14
<i>Hamilton</i>	29	<i>Logan</i>	26	<b>Jasper</b>	23	<b>Macon</b>	20		
<b>Effingham</b>	29	<b>Crawford</b>	26	<i>Washington</i>	23	<b>Henderson</b>	20		
<i>Pike</i>	29	<i>Montgomery</i>	25	<b>Richland</b>	23	<b>Boone</b>	20		



As shown in Table 2, the largest percentage of counties not served by the IBCCP falls into the second lowest quintile group, while the smallest percentage (16 percent) and number (nine) of counties served fall into the highest and second highest quintile group. The counties with the highest scores have the greatest need for breast and cervical cancer screening services. Further, the counties in the three top quintiles also have the greatest unmet need for screening.

**Table 2 Illinois County Quintiles and the Number and Percentage of Counties not served by IBCCP**

Screening Need	Counties not served by IBCCP	
	No.	%
38 to 29	10	18
29 to 26	9	16
26 to 23	10	18
23 to 21	14	26
21 to 14	13	24



# Illinois State Cancer Registry

## Continuing Education

- In September 1998, ISCR provided technical support for the North American Association of Central Cancer Registries' program, *Data Confidentiality: from Rumor to Court Order*.
- In October 1998, ISCR presented a two-hour, land-based conference on staging, comparing the three staging schemes required by ISCR and answering questions submitted by participants.

If you are interested in viewing the video of either of these presentations contact Teri Gorsek at 217-557-0184.

## Data Acquisition Manual

The revised copy of the ISCR Data Acquisition Manual has been distributed to all reporting facilities, with an effective date of January 1, 1999, for those facilities not currently submitting in the NAACCR 6.0 data exchange format. The most important changes in the new manual are the addition of both clinical and pathological Tumor, Node, Metastasis (TNM) staging, changes to the EOD staging scheme, addition of treatment information variables and coding of site and morphology by non-registry facilities.

# Occupational Safety and Health Survey

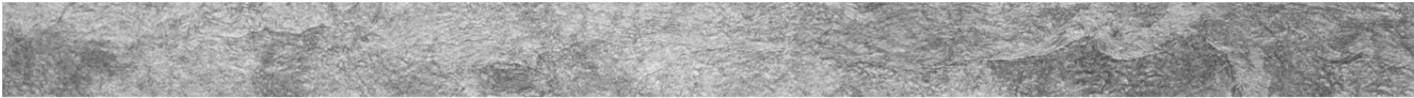
In October 1998, the Occupational Disease Registry began collaborating with the federal Bureau of Labor Statistics (BLS) on an occupational safety and health survey for Illinois. BLS has conducted this survey since 1992, but could not provide data for Illinois specific companies. This survey will identify the types of job related injuries and illnesses that befell individuals employed by Illinois companies. Companies are required to

provide injury and occupational illness data to the BLS. Survey results for 1998 will be available at the end of 1999.

Definitions of nonfatal occupational injuries and illnesses used in the annual survey are the same as those used by employers to keep logs of incidents throughout the survey (calendar) year. The survey identifies the nature of injury or illness, the part of

the body affected, the source of the injury or illness, and the event or exposure. The survey also identifies the occupation of the affected employee.

In addition to injury and illness counts, the survey data will be used to calculate incidence rates. Incidence rates permit comparison among industries and establishments of varying sizes, thus allowing a common statistical base across industries.



Most companies with 10 or more employees are subject to survey participation. In addition, some companies with less than 10 employees will be required to participate in order to get a good sampling of both large and small companies. To insure comparability and reliability, BLS designs and identifies the survey sample for each state.

Each employer completes a single report form for national and state estimates of occupational injuries and illnesses. This procedure insures maximum comparability of estimates. Summary information on the number of injuries and illnesses is copied directly from employer logs and entered onto the form. State agency and BLS personnel edit the summary data and code case characteristics.. Initial estimates of data are issued. The estimating procedure generates occupational injury and illness

estimates for approximately 900 Standard Industrial Classification codes. Each year, BLS will publish a comprehensive bulletin covering national results, while Illinois will prepare a report covering state results.

National and state policy makers can use the survey results as an indicator of occupational safety and health problems. Both labor and management use the estimates in

evaluating safety programs. Other users include insurance carriers involved in workers' compensation, industrial hygienists, manufacturers of safety equipment, researchers and others concerned with job safety and health.

Many factors can influence counts and rates of injuries and illnesses in a given year. These include not only the year's injury and illness experience, and the employer's understanding of work related injuries, but also the level of economic activity in a particular industry group.



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