



## Message from Director Ezike

Welcome to the eighth issue of the Illinois Morbidity and Mortality Bulletin (IMMB), an IDPH publication created to present topics of interest to public health communities and professionals in Illinois through scientific analysis and interpretation of data.

In this issue, staff from the Division of Chronic Disease Prevention and Control and Southern Illinois University examine tobacco product use among middle and high school students with asthma utilizing data from the 2015 Illinois Youth Tobacco Survey.

In the second article, staff from the Division of Epidemiologic Studies explore the prevalence of major birth defects and other selected adverse outcomes in Illinois from 2008-2012.

We encourage manuscript contributions from public health professionals at the state and local levels, as well as those in hospitals and academic institutions. Please send your manuscripts to IMMB's editor, Tiefu Shen, M.D., Ph.D. at [Tiefu.Shen@illinois.gov](mailto:Tiefu.Shen@illinois.gov) (217.785.1873)

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## Tobacco Product Use Among Middle and High School Students with Asthma – Illinois Youth Tobacco Survey

Asthma is one of the most common chronic diseases among children. Many factors contribute to successful asthma management, including avoidance of environmental factors or triggers that worsen asthma symptoms. For those with asthma, tobacco smoke leads to poor asthma control, decreased lung function, and increased need for medications. As tobacco use is nearly always established in adolescence, the objective of this study was to determine tobacco use prevalence among Illinois students with or without current asthma, with a concurrent analysis of the likelihood of an asthma attack based on tobacco product usage. Data was analyzed ..... [read more](#)

## Birth Defects and Other Adverse Pregnancy Outcomes in Illinois, 2008-2012

Since 1989, the Illinois Department of Public Health's (IDPH) Adverse Pregnancy Outcomes Reporting System (APORS) has collected information on Illinois infants born with congenital anomalies (birth defects) and other serious neonatal conditions. APORS is the most complete source of data on adverse pregnancy outcomes that exists in Illinois and provides the foundation for surveillance of birth defects. Infants identified through APORS are referred to local health departments for follow-up services with the aim of addressing and preventing further developmental issues. Between 2008 and ..... [read more](#)

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Birth Defects and Other Adverse Pregnancy Outcomes in Illinois, 2008-2012 [Page 13](#)

## **Tobacco Product Use Among Middle and High School Students with Asthma – Illinois Youth Tobacco Survey**

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### **Abstract**

*Asthma is one of the most common chronic diseases among children. Many factors contribute to successful asthma management, including avoidance of environmental factors or triggers that worsen asthma symptoms. For those with asthma, tobacco smoke leads to poor asthma control, decreased lung function, and increased need for medications. As tobacco use is nearly always established in adolescence, the objective of this study was to determine tobacco use prevalence among Illinois students with or without current asthma, with a concurrent analysis of the likelihood of an asthma attack based on tobacco product usage. Data was analyzed from the 2015 Illinois Youth Tobacco Survey to assess patterns of current use of tobacco product types among Illinois middle school and high school students by self-reported asthma status. Among students with current asthma, significantly more students used any tobacco product, including electronic cigarettes, compared to students without current asthma. Students with current asthma who used tobacco products were significantly more likely to have had an asthma attack compared to students with current asthma who did not use tobacco products.*

### **Introduction**

Asthma is a chronic inflammatory disorder of the airways that leads to episodes of reversible breathing problems due to airway narrowing and blockage. These episodes can range in severity from mild to life threatening. Symptoms of asthma include wheezing, coughing, chest tightness, and shortness of breath.<sup>1</sup> Asthma is one of the most common chronic diseases among children.<sup>2</sup> Overall, among children ages 0 to 17 years, about 8 percent have asthma nationally (7.9%) and in Illinois (8.8%). According to a recent national survey, when parents were asked to rank the severity of asthma in their child, about 3 percent of parents rated the condition as moderate to severe.<sup>3</sup>

Many factors contribute to successful asthma management, including appropriate diagnosis, treatment initiation to achieve asthma control, identification and/or remediation of environmental factors or triggers that worsen symptoms, asthma self-management skills, and long term follow up care and communication between the patient and health care provider.<sup>4</sup> National Asthma Education and Prevention Program Asthma Management Guidelines state persons with asthma should not smoke or be exposed to secondhand smoke, as it may contribute to or exacerbate asthma symptoms.<sup>5</sup> Although unsafe for all adults and children, for persons with asthma, combustible tobacco products lead to impaired response to corticosteroids; worsening pulmonary function; increased symptoms; poor asthma control; increased need for medical management<sup>6</sup>; additional missed school days; and higher rates of hospitalizations and Emergency Department (ED) visits. Counterintuitively, some studies suggest adolescents with asthma are more likely to smoke than their peers.<sup>6</sup>

Among U.S. and Illinois high school students in 2017, almost 28 percent reported having ever tried cigarette smoking; 8 percent reported currently smoking cigarettes (at least one time during the last 30 days); 42 percent reported having ever used an electronic vapor product (including e-cigarettes, e-cigars, e-pipes, vape pipes, vaping pens, e-hookahs, and hookah pens); and 13 percent reported currently using an electronic vapor product.<sup>7</sup> Despite current tobacco use, cigarette smoking has declined dramatically among Illinois high school students. Since 2008, cigarette smoking among Illinois high school seniors has decreased from 21 percent to five percent in 2018.<sup>8</sup>

Alarming, e-cigarette use by high school seniors is higher than cigarette use was 10 years ago. Between 2016 to 2018, e-cigarette use in Illinois increased from 18.4 percent to 26.7 percent among high school seniors, a 45 percent increase; a 15 percent increase was seen among 8<sup>th</sup> grade students; and a 65 percent increase among 10<sup>th</sup> grade students.<sup>8</sup> E-cigarettes put youth at risk for addiction and possibly worse asthma outcomes<sup>9</sup>, yet almost 40 percent of 10<sup>th</sup> and 12<sup>th</sup> grade youth believe there is low or no risk of negative health effects.<sup>8</sup>

As tobacco use is nearly always established in adolescence, the objective of this study was to determine tobacco use prevalence among students with or without current asthma, with a concurrent analysis of the likelihood of an asthma attack based on tobacco product usage.

## **Methods**

Data was analyzed from the 2015 Illinois Youth Tobacco Survey (IYTS)<sup>10</sup> to assess patterns of current use (at least one time during the last 30 days) of six tobacco product types among Illinois middle school (grades 6-8) and high school (grades 9-12) students by self-reported asthma status.

## **Data Source**

Data were obtained from the 2015 IYTS, the most current year available. The IYTS is a cross-sectional, voluntary, school-based, self-administered, pencil-and-paper questionnaire survey of Illinois middle and high school students. A two-stage cluster sample design was used to produce a representative sample of high school students in grades nine through 12 and middle school students in grades six through eight.

## **Study Sample**

The sample size for the 2015 data contained 4,622 records, representing 2,344 middle school students and 2,278 high school students. Students were classified as “having current asthma” if they provided a positive response to the survey question “Has a doctor, nurse, or other health professional ever told you that you have asthma” and “Do you still have asthma?”

## **Independent Variables**

Participants were asked about current (past 30-day) use of cigarettes<sup>1</sup>, clove cigarettes<sup>2</sup>, cigars<sup>3</sup>, smokeless tobacco<sup>4</sup>, e-cigarettes<sup>5</sup>, pipe tobacco<sup>6</sup>, and bidis<sup>7</sup> (small imported cigarettes wrapped in a leaf). Current use for each product was defined as use on  $\geq 1$  day during the past 30 days. “Any tobacco product use” was defined as use of one or more of the above tobacco products in the past 30 days, and “ $\geq 2$  tobacco product use” was defined as use of two or more of the above tobacco products in the past 30 days. “Any combustible tobacco product use” was defined as the use of cigarettes, cigars, pipe tobacco, and/or bidis in the past 30 days. E-cigarette use was excluded from the “any combustible tobacco product use” as tobacco is not burned, but rather heated.

## **Dependent Variable**

Asthma attack was identified by a positive response to the question, “During the past 12 months, have you had an episode of asthma or asthma attack?”

## **Statistical Analysis**

SAS version 9.4 (SAS Institute, Inc., Cary, North Carolina) was used. Data were weighted to account for the complex survey design and adjusted for nonresponse<sup>11</sup>. Descriptive analyses were performed using Rao-Scott chi-square tests to examine how tobacco use differed by current asthma status and asthma attack in the past year. A p-value of  $< 0.05$  was considered statistically significant. Weighted prevalence estimates with 95% confidence intervals (CIs) were calculated. Current use estimates for 2015 were determined for no tobacco use, cigarettes, e-cigarettes, any combustible tobacco product, any tobacco product, and  $\geq 2$  tobacco products, overall and by high school level.

To examine the association between asthma attacks and use of tobacco products, weighted adjusted prevalence ratios (APRs) and corresponding 95% CIs were examined using Cox’s proportional hazards regression analysis (assuming a constant time variable)<sup>12</sup> with adjustment on the following categorical variables: gender, race, and ethnicity. Multi-collinearity was assessed using variance inflation factor (VIF) in the model. A value of five or greater was used as the cutoff to determine collinearity. Eight variables were examined as predictors of an asthma attack in the last 12 months. Collinearity was not found among any of these variables as VIF scores for all variables were  $\leq 1.1$ .

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<sup>1</sup> Past 30-day use of cigarettes was determined by asking, “During the past 30 days, on how many days did you smoke cigarettes?”

<sup>2</sup> Past 30-day use of clove cigarettes was determined by asking, “During the past 30 days, on how many days did you smoke clove cigarettes?”

<sup>3</sup> Past 30-day use of cigars was determined by asking, “During the past 30 days, on how many days did you smoke cigars, cigarillos, or little cigars?”

<sup>4</sup> Past 30-day use of smokeless was determined by asking, “During the past 30 days, on how many days did you use chewing tobacco, snuff, or dip?”

<sup>5</sup> Past 30-day use of e-cigarettes was determined by asking, “During the past 30 days, on how many days did you use electronic smoking devices, also known electronic cigarettes, e-cigarettes, e-cigars, e-cigarillos, e-pipes, e-hookahs, personal vaporizers (PV), vaping pens, vape pens, or hookah pens?”

<sup>6</sup> Past 30-day use of pipe tobacco was determined by asking, “During the past 30 days, on how many days did you smoke tobacco in a pipe?”

<sup>7</sup> Past 30-day use of bidis was determined by asking, “During the past 30 days, on how many days did you smoke bidis?”

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## Results

In 2015, 12.9 percent (95% CI: 11.1%-14.6%) of middle and high school students had current asthma. During the past 12 months, 22.3 percent (95% CI: 19.9%-24.6%) of students with current asthma had an asthma attack. Of all middle and high school students, 18.5 percent (95% CI: 15.1%-21.8%) had used any tobacco product. E-cigarettes were the tobacco product used most (13.6%, 95% CI: 11.2-16.1%), followed by cigarettes (8.3%, 95% CI: 6.8%-9.8%). Any combustible tobacco product was used by 12.2 percent (95% CI: 9.6%-14.7%) of students (Table 1).

**TABLE 1. Prevalence of tobacco product\* usage among Illinois middle and high school students in the past 30 days, by school level — Illinois Youth Tobacco Survey, 2015**

Tobacco Product	Middle School		High School		Combined	
	% (95% CI)	Estimated users (n)	% (95% CI)	Estimated users (n)	% (95% CI)	Estimated users (n)
Cigarettes	2.6% (1.5-3.7)	9,437 (65)	11.8% (9.6-13.9)	69,893 (243)	8.3% (6.8-9.8)	79,330 (308)
E- cigarettes	5.9% (4.2-7.6)	21,292 (145)	18.3% (14.9-21.8)	109,503 (392)	13.6% (11.2-16.1)	130,795 (537)
Any combustible tobacco product	4.4% (12.7-34.3)	16,336 (117)	16.9% (13.1-20.6)	102,434 (364)	12.2% (9.6-14.7)	118,770 (481)
Any tobacco product	7.7% (5.5-9.9)	28,440 (195)	25.0% (20.3-29.8)	152,035 (550)	18.5% (15.1-21.8)	180,475 (745)
≥2 tobacco products	2.3% (1.3-3.4)	8,142 (57)	11.4% (8.5-14.3)	63,819 (205)	7.9% (6.0-10.0)	71,961 (262)
No tobacco use	92.3% (90.1-94.5)	340,666 (2,149)	75.0% (70.2-79.7)	455,664 (1,728)	81.5% (78.2-84.9)	796,330 (3,877)

**Abbreviation:** CI = confidence interval; E-cigarettes = electronic cigarettes; n= unweighted count

**\*Product type:** Cigarette- Past 30-day use of cigarettes was determined by asking, “During the past 30 days, on how many days did you smoke cigarettes?” and/or “During the past 30 days, on how many days did you smoke cigars, cigarillos, or little cigars?” and/or a response of pipe tobacco (not hookah) and bidis to the question, “In the past 30 days, which of the following products have you used on at least one day?”; E-cigarette-Past 30-day use of e-cigarettes was determined by asking, “During the past 30 days, on how many days did you use electronic smoking devices, also known electronic cigarettes, e-cigarettes, e-cigars, e-cigarillos, e-pipes, e-hookahs, personal vaporizers (PV), vaping pens, vape pens, or hookah pens?”; Any combustible tobacco product-defined as use of cigarettes, cloves, cigars, pipe tobacco, and/or bidis on at least one day in the past 30 days; Any tobacco product use - defined as use of any tobacco product (e-cigarettes, cigarettes, cloves cigarettes, cigars, smokeless tobacco, pipe tobacco, and/or bidis) on at least one day in the past 30 days; ≥2 tobacco products -defined as use of two or more tobacco products (e-cigarettes, cigarettes, cigars, smokeless tobacco, pipe tobacco, and/or bidis) on at least one day in the past 30 days.

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Among students with current asthma (Table 2), significantly more students with current asthma used any tobacco product compared to students without current asthma (26.5%, 95% CI: 20.6%-32.3% vs. 17.3%, 95% CI: 14.2%-20.4%), this was also true for e-cigarette use (20.0%, 95% CI: 15.9%-24.1% vs. 12.7%, 95% CI: 10.2%-15.1%) and any combustible tobacco product (17.3%, 95% CI: 12.8%-21.7% vs. 11.4%, 95% CI: 9.0%-13.8%).

**TABLE 2. Prevalence of tobacco use among middle and high school students in the past 30 days with current asthma<sup>^</sup>, by product\* and school level— Illinois Youth Tobacco Survey, 2015**

Tobacco Product	With Current Asthma		Without Current Asthma	
	% <sup>¶</sup> (95% CI)	Estimated users <sup>¶</sup> (n)	% <sup>¶</sup> (95% CI)	Estimated users <sup>¶</sup> (n)
<b>High school students</b>				
Cigarettes	-	11,903(43)	11.3% (8.7-13.8)	57,990(200)
E- cigarettes <sup>§</sup>	28.6% (23.3-33.8)	22,569(78)	16.8% (13.2-20.3)	86,934(314)
Any combustible tobacco product <sup>§</sup>	24.0% (18.4-29.6)	19,197(71)	15.8% (12.1-19.5)	83,236(293)
Any tobacco product <sup>§</sup>	36.8% (30.2-43.5)	29,426 (103)	23.2% (18.7-27.8)	122,609(447)
≥2 tobacco products	-	11,231(41)	10.7% (7.6-13.8)	52,587(164)
No tobacco product use	63.2% (56.5-69.8)	50,464(191)	76.8% (72.2-81.3)	405,200(1,537)
<b>Combined Middle and High School</b>				
Cigarettes	10.9% (8.1-13.6)	13,392(57)	7.9% (6.2-9.6)	65,938(251)
E- cigarettes <sup>§</sup>	20.0% (15.9-24.1)	24,772(96)	12.7% (10.2-15.1)	106,022(441)
Any combustible tobacco product <sup>§</sup>	17.3% (12.8-21.7)	21,686(92)	11.4% (9.0-13.8)	97,083(389)
Any tobacco product use <sup>§</sup>	26.5% (20.6-32.3)	33,221(133)	17.3% (14.2-20.4)	147,254(612)
≥2 tobacco products	10.9% (7.0-14.7)	12,403(50)	7.5% (5.5-9.5)	59,558(212)
No tobacco use	73.5% (67.7-79.4)	92,326(440)	82.7% (79.6-85.8)	704,004(3,437)

¶Weighted to yield representative estimates of Illinois middle and high school students attending public schools.

§ Use of tobacco product type significantly differed by asthma status: Rao-Scott chi-square test; p value <0.05.

†Data are statistically unreliable because samples size was <50 or relative standard error was >0.3.

**Abbreviation:** CI = confidence interval; E-cigarettes = electronic cigarettes; n= unweighted count

<sup>^</sup>Current asthma determined by positive response to “Has a doctor, nurse, or other health professional ever told you that you have asthma?” and to “Do you still have asthma?”

**\*Product types:** Cigarette- Past 30-day use of cigarettes was determined by asking, “During the past 30 days, on how many days did you smoke cigarettes?” and/or “During the past 30 days, on how many days did you smoke cigars, cigarillos, or little cigars?” and/or a response of pipe tobacco (not hookah) and bidis to the question, “In the past 30 days, which of the following products have you used on at least one day?”; E-cigarette-Past 30-day use of e-cigarettes was determined by asking, “During the past 30 days, on how many days did you use electronic smoking devices, also known electronic cigarettes, e-cigarettes, e-cigars, e-cigarillos, e-pipes, e-hookahs, personal vaporizers (PV), vaping pens, vape pens, or hookah pens?”; Any combustible tobacco product-defined as use of cigarettes, cloves, cigars, pipe tobacco, and/or bidis on at least one day in the past 30 days; Any tobacco product use - defined as use of any tobacco product (e-cigarettes, cigarettes, cloves cigarettes, cigars, smokeless tobacco, pipe tobacco, and/or bidis) on at least one day in the past 30 days; ≥2 tobacco products -defined as use of two or more tobacco products (e-cigarettes, cigarettes, cigars, smokeless tobacco, pipe tobacco, and/or bidis) on at least one day in the past 30 days.

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Among students with current asthma who had an asthma attack in the past 12 months (Table 3), significantly more students with current asthma used any tobacco product compared to students without current asthma (26.5%, 95% CI: 20.6%-32.3% vs. 17.3%, 95% CI: 14.2%-20.4%), this was also true for e-cigarette use (15.9%, 95% CI: 15.9%-24.1% vs. 12.7%, 95% CI: 10.2%-15.1%) and any combustible tobacco product (17.3%, 95% CI: 12.8%-21.7% vs. 11.4%, 95% CI: 9.0%-13.8%).

**TABLE 3. Prevalence of tobacco use among middle and high school students in the past 30 days who have had an asthma attack<sup>^^</sup> in the past 12 months, by product\* and school level— Illinois Youth Tobacco Survey, 2015**

Tobacco product	Asthma attack		No asthma attack		¶Weighted to yield representative estimates of Illinois middle and high school students attending public schools. § Use of tobacco product type significantly differed by asthma status: Rao-Scott chi-square test; p value <0.05. †Data are statistically unreliable because samples size was <50 or relative standard error was >0.3.
	% <sup>¶</sup> (95% CI)	Estimated users <sup>¶</sup> (n)	% <sup>¶</sup> (95% CI)	Estimated users <sup>¶</sup> (n)	
<b>High school students</b>					
Cigarettes	-	10,090(39)	15% (11.4-18.6)	26,897(91)	
E- cigarettes§	33.6% (26.8-40.3)	17,532(63)	20.2% (14.8-25.6)	36,771(130)	
Any combustible tobacco product§	28.9% (20.9-36.9)	15,443(61)	20.2% (15.1-25.4)	36,968(129)	
Any tobacco product§	40.0% (33.9-46.2)	21,379(78)	28.9% (22.7-35.2)	52,886(189)	
≥2 tobacco products	-	9,961(37)	13.0% (8.0-18.0)	21,822(66)	
No tobacco use	60.0% (53.8-66.1)	32,011(126)	71.1% (64.8-77.3)	129,829(486)	
<b>Combined Middle and High School</b>					
Cigarettes	15.1% (9.9-20.4)	12,038(51)	10.8% (8.2-13.4)	29,727(113)	
E- cigarettes§	24.7% (20.0-29.3)	19,568(79)	16.1% (12.4-20.0)	44,835(187)	
Any combustible tobacco product§	22.5% (16.3-28.7)	18,146(80)	15.0% (11.5-18.5)	42,234(172)	
Any tobacco product §	31.3% (25.4-37.2)	25,203(104)	22.4% (17.8-26.9)	62,812(260)	
≥2 tobacco products	-	10,478(41)	9.5% (6.2-12.9)	24,678(88)	
No tobacco use	68.7% (62.8-74.6)	55,312(274)	77.6% (73.2-82.2)	218,108(1,043)	

error was >0.3.

<sup>^^</sup>Asthma attack determined by positive response to “During the past 12 months, have you had an episode of asthma or asthma attack?”

**Abbreviation:** CI = confidence interval; E-cigarettes = electronic cigarettes; n= unweighted count

**\*Product types:** Cigarette- Past 30-day use of cigarettes was determined by asking, “During the past 30 days, on how many days did you smoke cigarettes?” and/or “During the past 30 days, on how many days did you smoke cigars, cigarillos, or little cigars?” and/or a response of pipe tobacco (not hookah) and bidis to the question, “In the past 30 days, which of the following products have you used on at least one day?”; E-cigarette-Past 30-day use of e-cigarettes was determined by asking, “During the past 30 days, on how many days did you use electronic smoking devices, also known electronic cigarettes, e-cigarettes, e-cigars, e-cigarillos, e-pipes, e-hookahs, personal vaporizers (PV), vaping pens, vape pens, or hookah pens?”; Any combustible tobacco product-defined as use of cigarettes, cloves, cigars, pipe tobacco, and/or bidis on at least one day in the past 30 days; Any tobacco product use - defined as use of any tobacco product (e-cigarettes, cigarettes, cloves cigarettes, cigars, smokeless tobacco, pipe tobacco, and/or bidis) on at least one day in the past 30 days; ≥2 tobacco products -defined as use of two or more tobacco products (e-cigarettes, cigarettes, cigars, smokeless tobacco, pipe tobacco, and/or bidis) on at least one day in the past 30 days.

Students with current asthma were significantly more likely to have had an asthma attack (Table 4) with the following tobacco product use: any combustible tobacco product (APR=1.39; 95% CI: 1.00-1.93, p value= <.05); any tobacco product (APR=1.35; 95% CI: 1.03-1.76, p value =<.05); and e-cigarettes (APR=1.21; 95% CI: 1.17-1.26; p-value=<.01). No tobacco use was a protective factor for self-report of an asthma attack (APR=0.90; 95% CI: 0.82-0.99, p value=<.05).

**Table 4. Adjusted Prevalence Ratio of Asthma Attacks Associated with Tobacco Product Use among Middle and High School Students in Illinois— Illinois Youth Tobacco Survey, 2015**

	Adjusted Prevalence Ratio <sup>1</sup>	95% CI <sup>2</sup>	P-value <sup>1</sup>
Cigarettes	1.31	0.88-1.93	0.18
E- cigarettes	1.53	1.18-2.00	<.01
Any combustible tobacco product	1.39	1.00-1.93	<.05
Any tobacco product	1.35	1.03-1.76	<.05
≥2 tobacco products	1.44	0.89-2.36	0.14
No tobacco use	0.90	0.82-0.99	<.05

<sup>1</sup>Cox Proportional Hazard Ratio used to calculate adjusted prevalence ratio and corresponding p-value (p-value <0.05 was considered significant)  
<sup>2</sup> 95% confidence interval (CI) was calculated using sampling weights  
<sup>4</sup>Adjusted based on sex, race, and ethnicity

## Discussion

Despite tobacco use being one of the most common asthma triggers and its role in increasing asthma-related symptoms and disease severity, significantly more Illinois students with current asthma use tobacco more often than students without asthma. Although there is ample evidence that tobacco use is associated with poor asthma management and can lead to detrimental health effects, these data show students with current asthma are engaging in compromising tobacco use behaviors that may lead to a lifetime of addiction.

Students with asthma who choose to use tobacco products may encounter the same social risk factors associated with tobacco use as those who do not have asthma, including parental or caregiver smoking, having friends who use tobacco products, or may be influenced to avoid stigmatization of having a chronic disease.<sup>13</sup> Additional influences may include lower socioeconomic status (SES), lack of parental involvement, lower self-image, or as a method to cope with stress.<sup>14</sup>

Parents and caregivers play crucial roles in counteracting social influences and the effects of the \$1 million per hour the tobacco industry spends on advertising and promotion.<sup>15</sup> Nearly all adult smokers first use cigarettes before 21 years of age (95%),<sup>16</sup> underscoring the importance of youth tobacco use prevention and sustained exposure to prevention messages from multiple caregivers, including parents and other family members, as well as school staff and coaches. In Illinois, 32 percent of 8<sup>th</sup> grade students and 49 percent of 12<sup>th</sup> grade students reported their parents or guardians did not talk to them about using tobacco.<sup>8</sup>



Health care providers have the opportunity to educate youth and families on the dangers of tobacco use and negative impact on asthma management. The American Academy of Pediatrics issued a policy statement in 2015 recommending health professionals screen all teenagers for tobacco and offer counseling and cessation services for adolescents and parents and caregivers,<sup>17</sup> yet 39 percent of Illinois high school youth did not recall health care providers asking about tobacco use, and only 35 percent reported their health care provider advising not to use tobacco products.<sup>18</sup> Parental smoking has been strongly associated with adolescent smoking,<sup>19</sup> therefore it is imperative health care providers connect both youth and their caregivers to smoking cessation resources.

Illinois is not alone in the e-cigarette epidemic among students with and without asthma. The United States Food and Drug Administration (FDA) is taking steps to address the use of e-cigarettes in adolescents, as a staggering 3.62 million U.S. middle and high school students were current users in 2018. E-cigarette use increased 78 percent among high school students and 48 percent among middle school students from 2017-2018.<sup>20</sup> Such an increase may be attributed to friends or family using e-cigarettes; the belief of perceived safety; the availability of appealing flavors such as chocolate, mint, or fruit<sup>20</sup>; the ability to be used discreetly; high nicotine content<sup>21</sup>; and increased exposure to tobacco advertising.<sup>22</sup> More research is needed with regard to the use of electronic nicotine delivery devices (ENDS), including the effects of secondhand exposure to ENDS aerosols.<sup>23</sup>

Significant disparities in tobacco use exist as people of lower SES have higher rates of smoking and increased exposure to secondhand smoke.<sup>24</sup> In Illinois, asthma prevalence among adults in lower income brackets is nearly two times higher than those with higher income.<sup>25</sup> Additionally, adults of lower SES may be more likely to be uninsured, underinsured, or on Medicaid and less likely to receive assistance for cessation. Medicaid programs are less likely to provide comprehensive cessation coverage.<sup>26</sup>

Comprehensive, sustained, and multi-component strategies can help prevent and reduce the use of all forms of tobacco products among U.S. youth. Such strategies include evidence-based school programs, smoke-free policies, and sustained community efforts. Tobacco 21, a growing youth tobacco prevention strategy which raises the minimum legal sales of tobacco products, including e-cigarettes, from age 18 to 21, is another step to address tobacco use in adolescents. Chicago, Illinois enacted Tobacco 21 in 2016, and in the year after implementation, a 36% decrease in 18-20 year olds using cigarettes was reported.<sup>16</sup> Statewide implementation of Tobacco 21 took effect July 1, 2019.

Asthma itself is a complex disease, and both asthma and tobacco use have genetic and environmental influences.<sup>27,28</sup> Emphasis is placed on asthma control, yet more youth with asthma use tobacco products. Preventing tobacco use of all types is critical for youth, and in particular those with asthma. Determining which tobacco control strategies are most effective and assessing how youth perceive safety of tobacco products<sup>29</sup> and the impact on asthma management is essential.

## **Limitations**

Limitations to this study include the use of self-reported data which is subject to recall and social desirability bias. The findings may not be generalizable to all youths because the sample did not include students who are home schooled, students that drop out of school, or students in private schools. Additionally, the survey did not clearly capture past 30 day use of hookah in the same manner as other tobacco products. As such, hookah was excluded from the definition of tobacco.

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## **Birth Defects and Other Adverse Pregnancy Outcomes in Illinois, 2008-2012**

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### **Abstract**

*Since 1989, the Illinois Department of Public Health's (IDPH) Adverse Pregnancy Outcomes Reporting System (APORS) has collected information on Illinois infants born with congenital anomalies (birth defects) and other serious neonatal conditions. APORS is the most complete source of data on adverse pregnancy outcomes that exists in Illinois and provides the foundation for surveillance of birth defects. Infants identified through APORS are referred to local health departments for follow-up services with the aim of addressing and preventing further developmental issues. Between 2008 and 2012 APORS collected information on 62,122 infants and identified 40,798 birth defects in addition to thousands of other adverse outcomes. This article explores the prevalence of major birth defects and other selected adverse outcomes in Illinois for the five-year period spanning 2008-2012.*

### **Introduction**

Birth defects have long been a leading cause of infant mortality in the United States, and they contribute substantially to childhood morbidity and long-term disability. In 2012, birth defects were responsible for 20.9% of infant deaths in the U.S.<sup>1</sup> and 15.8% of infant deaths in Illinois, ranking birth defects as the second leading cause of these deaths in Illinois<sup>2</sup>.

Children born weighing less than 1,500 grams (about 3 pounds 5 ounces) are considered to have very low birth weights. In 2012, 1.4% of Illinois infants had very low birth weights<sup>3</sup>, mirroring that of the U.S.<sup>4</sup>. While medical advances over the years have increased the survival of these infants, disorders relating to short gestation and low birth weight remain the second leading cause of infant death in the U.S. and the leading cause of infant death in Illinois (17.8 and 26.3% respectively)<sup>1,2</sup>.

Each year IDPH's Adverse Pregnancy Outcomes Reporting System (APORS), Division of Epidemiologic Studies, obtains information on infants with birth defects, and many other conditions and diseases that significantly

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impact the lives of children and families in Illinois. Table 1 illustrates the number of cases and rates of different selected neonatal conditions included in APORS case definition between 2008 and 2012.

**Table 1. Frequency of Reported Infants Meeting APORS Case Criteria, 2008-2012<sup>1</sup>**

Infants	5-Year Total	Annual Average	Rate <sup>2</sup>	% APORS Cases
Total APORS Cases	62,122	12,424.4	745.7	100.0
Birth Defects	40,798	8,159.6	477.1	65.7
Very Low Birth Weight	16,256	3,251.2	195.1	26.2
Positive for Controlled Substances	9,549	1,909.8	114.6	15.4
Fetal Deaths	4,875	975.0	58.5	7.8
Died During Newborn Hospitalization	3,492	698.4	41.9	5.6
Intrauterine Growth Restriction	4,424	884.8	53.1	7.1
Congenital Infections	3,259	651.8	39.1	5.2
Retinopathy of Prematurity	2,473	494.6	29.7	4.0
Endocrine, Metabolic or Immune Disorder	921	184.2	11.1	1.5
Blood Disorder	652	130.4	7.8	1.0
Infant Exposed to Alcohol	128	25.6	1.5	0.2

<sup>1</sup>Infants may be counted in more than one category as multiples adverse outcomes may coexist.

<sup>2</sup> Rate per 10,000 live births

Source: Illinois Department of Public Health, Adverse Pregnancy Outcomes Reporting System, January 2019

Information collected by APORS is used to track trends, describe disease patterns and inform public health policy and program development. Also, because infants with congenital anomalies or other problems often need special services to reach their full potential, babies identified through APORS are referred to their local health departments for follow-up services.

APORS encompasses the most complete source of information in Illinois on adverse outcomes for several reasons. All Illinois hospitals are required to report infants meeting the APORS case definition born to Illinois women. Additionally, perinatal centers in St. Louis that belong to the Illinois perinatal network also participate. Birth certificates (maintained by the IDPH's Division of Vital Records) are an additional data source, allowing APORS to identify infants with very low birth weights or with certain birth defects who were unreported by the hospitals. The Division of Vital Records also provides information about fetal deaths from the death certificates. APORS works closely with the Newborn Metabolic Screening program at IDPH to identify infants with endocrine, metabolic and immune disorders as well.

APORS strives to continuously improve case identification and quality as well. In 2002, APORS began systematic active case verification whereby APORS staff review charts for infants reported with certain conditions that are likely to be associated with one or more birth defects. As a result, as the charts are reviewed, APORS staff are able to correct and add to information reported by hospitals.

Results for this article are depicted in two sections. The first contains prevalence rates for specific major defects within six groupings defined by body system affected. The second section provides prevalence for other specific adverse pregnancy outcomes, including most of those listed in Table 1. Definitions of birth defects and other conditions are provided in the Appendix.

## Methods

### ***Calculation and Interpretation of Rates and Confidence Intervals***

Annual prevalence rates (per 10,000 live births) for selected adverse pregnancy outcomes identified during the newborn hospital stay or associated with a fetal death were calculated as

$$10,000x \frac{\text{number of infants with selected anomaly}}{\text{number of live births}}$$

The numbers of live births were obtained from the IDPH's master birth files. Occurrence of a specific adverse outcome is assumed to be a rare event, therefore following a Poisson distribution. Exact confidence intervals were calculated for each rate<sup>5</sup> as

$$\mu_L = \frac{1}{2} \chi^2_{2x, 0.025}$$

$$\mu_U = \frac{1}{2} \chi^2_{2x+2, 0.975}$$

Where  $\mu_L$  and  $\mu_U$  are lower and upper confidence limits for X, the number of birth defects, and  $\chi^2$  is Chi-square deviate at  $p=0.05$  with degrees of freedom specified (either  $2X$  or  $2X+2$ ). Where there are many birth defect cases, the confidence interval is narrow, indicating that the rate is stable. Where there are few birth defect cases, the confidence interval becomes very wide, indicating that the rate is not very stable. A small change in the number of infants born with the specific birth defect could result in a large change in the rate.

To compare two rates, it is important to look at their confidence intervals as well as their values. As a conservative approximation, if two confidence intervals overlap, then there is no evidence that the two rates are different. If two confidence intervals do not overlap, then the rates are said to be statistically different. In this report, 95% confidence intervals are used; where the confidence intervals do not overlap the rates are statistically different at the 5% level ( $p < 0.05$ ).

## ***Multiple Comparisons***

Since this report examines many adverse outcomes, the corresponding statistical tests are subject to the “multiple comparison problem.” For a given birth defect, the observed rate is an estimate of the true birth defect rate in the population. When two rates from different times or groups are compared, statisticians will assert that the observed rates are evidence of the groups having differing birth defect rates, if the observed rates are so different that the chance of them coming from the same underlying population is less than 5%. The 5% type I error rate, however, suggests that when 100 comparisons are made, on average, five will be “significantly different,” when, in fact, there is no difference between the two groups. Therefore, as more comparisons are made, more may be statistically significant, just by chance. In this report, no explicit corrections of the multiple comparison problem were made; instead, exact probabilities are reported. The smaller the reported probability, the more likely it is that the difference is not simply the result of chance.

Because a baby may be born with more than one birth defect, he or she may be counted in more than one birth defect group. A baby may even have more than one birth defect from the same birth defect group. Therefore, the data in this report cannot be used to determine the number of children with a particular group of birth defects.

## **Results**

### ***Birth Defects***

Table 2 contains five-year prevalence rates for the state for major birth defects for six groupings according to body system affected. Cardiovascular system defects were by far the most commonly identified group of major defects in Illinois at a rate of 87.2 per 10,000 live births, with ventricular and atrial septal defects the most common type of cardiovascular defects reported (40.3 and 24.7 per 10,000 live births respectively). Genitourinary defects were the second most frequent group of defects found (32.9 per 10,000 live births) with hypospadias accounting for a majority of those cases at a rate of 26.6 per 10,000 live births. Alimentary tract defects, at a rate of 21.2 per 10,000 live births, were the third most frequent group of defects identified with cleft lip (with or without cleft palate) and cleft palate alone the top two most reported defects in that group (7.9 and 5.0 per 10,000 live births respectively). Central nervous system defects were reported at a rate of 17.4 per 10,000 live births, with hydrocephalus and microcephalus accounting for the majority of these defects. Down syndrome was the most common of the three chromosomal trisomies studied at 12.3 per 10,000 live births. Limb reduction defects and gastroschisis were the most common musculoskeletal defects identified at 4.6 and 3.8 per 10,000 live births respectively.



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**Table 2. Total Number and Prevalence Rates of Major Birth Defects in Newborn Infants, Illinois, 2008-2012**

Defect	ICD-9-CM Codes	Number	Rate <sup>1</sup>	95% CI <sup>2</sup>
<b>Central nervous system (CNS) defects involving the brain, spinal cord and associated tissues</b>				
Anencephalus	740.0-740.1	115	1.4	(1.1, 1.7)
Spina bifida <sup>3</sup>	741.00-741.93	240	2.9	(2.5, 3.3)
Encephalocele	742.0	56	0.7	(0.5, 0.9)
Microcephalus	742.1	440	5.3	(4.8, 5.8)
Hydrocephalus <sup>4</sup>	742.3	597	7.2	(6.6, 7.8)
<i>Total CNS Defects</i>		<i>1,448</i>	<i>17.4</i>	<i>(16.5, 18.3)</i>
<b>Cardiovascular system defects involving the heart and circulatory system</b>				
Common truncus	745.0	47	0.6	(0.4, 0.8)
Transposition of great arteries	745.1x	197	2.4	(2.0, 2.7)
Tetralogy of fallot	745.2	264	3.2	(2.8, 3.6)
Ventricular septal defect	745.4	3,359	40.3	(39.0, 41.7)
Atrial septal defect	745.5	2,056	24.7	(23.6, 25.8)
Endocardial cushion defect	745.6x	405	4.9	(4.4, 5.4)
Pulmonary valve atresia/stenosis	746.01, 746.02	226	2.7	(2.4, 3.1)
Tricuspid valve atresia/stenosis	746.0	70	0.8	(0.7, 1.1)
Ebstein anomaly	746.2	46	0.6	(0.4, 0.7)
Aortic valve stenosis	746.3	100	1.2	(1.0, 1.5)
Hypoplastic left heart syndrome	746.7	167	2.0	(1.7, 2.3)
Coarctation of aorta	747.10	264	3.2	(2.8, 3.6)
Total anomalous pulmonary venous return (TAPVR)	747.41	60	0.7	(0.5, 0.9)
<i>Total Cardiovascular System Defects</i>		<i>7,261</i>	<i>87.2</i>	<i>(85.2, 89.2)</i>
<b>Alimentary tract defects involving orofacial area and gastrointestinal system</b>				
Cleft palate alone	749.0x	417	5.0	(4.5, 5.5)
Cleft lip (with or without cleft palate)	749.10-749.25	656	7.9	(7.3, 8.5)
Choanal atresia	748.0	85	1.0	(0.8, 1.3)
Esophageal atresia/ tracheoesophageal fistula	750.3	183	2.2	(1.9, 2.5)
Rectal, anal, large intestinal atresia/stenosis	751.2	291	3.5	(3.1, 3.9)
Pyloric stenosis	750.5	51	0.6	(0.5, 0.8)
Hirschsprung disease	751.3	68	0.8	(0.6, 1.0)
Biliary atresia	751.61	12	0.1	(0.1, 0.3)
<i>Total Alimentary Tract Defects</i>		<i>1,763</i>	<i>21.2</i>	<i>(20.2, 22.2)</i>

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Defect	ICD-9-CM Codes	Number	Rate <sup>1</sup>	95% CI <sup>2</sup>
<b>Genitourinary system defects involving male and female reproductive organs and urinary tracts</b>				
Renal agenesis/hypoplasia	753.0	411	4.9	(4.5, 5.4)
Bladder exstrophy	753.5	21	0.3	(0.2, 0.4)
Hypospadias	752.61	2,214	26.6	(25.5, 27.7)
Epispadias	752.62	92	1.1	(0.9, 1.4)
<i>Total Genitourinary System Defects</i>		<i>2,738</i>	<i>32.9</i>	<i>(31.6, 34.1)</i>
<b>Musculoskeletal defects involving muscles, joints and bones</b>				
Limb reduction deformity	755.2 – 755.4	385	4.6	(4.2, 5.1)
Gastroschisis	756.73	315	3.8	(3.4, 4.2)
Omphalocele	756.72	155	1.9	(1.6, 2.2)
Developmental dysplasia of the hip	754.30,754.31754.35	242	2.9	(2.6, 3.3)
Diaphragmatic hernia	756.6	201	2.4	(2.1, 2.8)
<i>Total Musculoskeletal Defects</i>		<i>1,298</i>	<i>15.6</i>	<i>(14.7, 16.5)</i>
<b>Chromosomal trisomies in which there is an extra copy of a specific chromosome</b>				
Patau syndrome (trisomy 13)	758.1	105	1.3	(1.0, 1.5)
Down syndrome (trisomy 21)	758.0	1,028	12.3	(11.6, 13.1)
Edward syndrome (trisomy 18)	758.2	185	2.2	(1.9, 2.6)
<i>Total Chromosomal Trisomies</i>		<i>1,318</i>	<i>15.8</i>	<i>(15.0, 16.7)</i>

<sup>1</sup> Rate per 10,000 live births

<sup>2</sup> 95% confidence interval for rate

<sup>3</sup> Includes only spina bifida without anencephaly

<sup>4</sup> Includes only hydrocephaly without spina bifida or anencephaly.

Source: Illinois Department of Public Health, Adverse Pregnancy Outcomes Reporting System, January 2019

## Adverse Pregnancy Outcomes

Table 3 provides five-year prevalence rates for the state for adverse pregnancy outcomes compiled by APORS. APORS recorded 16,256 very low birth weight births during the period at a rate of 195.1 per 10,000 live births. APORS collected information from hospitals about neonatal deaths that occurred during the newborn stay and compiled information about fetal deaths from IDPH's Division of Vital Records. In all 8,367 perinatal deaths were recorded for a rate of 100.4 per 10,000 live births.

Following very low birth weight births and neonatal deaths, intrauterine growth restriction was the third most reported outcome during the period with a total of 4,424 cases reported for a rate of 53.1 per 10,000 live births. Noteworthy as the fourth most common adverse outcome reported during the period, 2,473 cases of retinopathy of prematurity were recorded for a rate of 29.7 per 10,000 live births.

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While fetal alcohol syndrome is rarely diagnosed in newborns, APORS recorded 128 cases of fetal alcohol spectrum disorders as well as those affected by or significantly exposed to alcohol as reported by Illinois hospitals.

Altogether, serious congenital infections were identified at a rate of 39.1 per 10,000 live births with confirmed septicemia and prenatal exposure to hepatitis B the most common conditions reported (19.9 and 11.5 per 10,000 live births respectively). Hypothyroidism was the most common endocrine, metabolic and immune disorder reported at a rate of 5.6 per 10,000 live births. Hereditary hemolytic anemia was the most common type of blood disorder identified at a rate of 7.0 per 10,000 live births.

**Table 3. Total Number and Prevalence Rates of Adverse Pregnancy Outcomes in Newborn Infants, Illinois, 2008-2012**

Condition	ICD-9-CM Codes	Number	Rate <sup>1</sup>	95% CI <sup>2</sup>
<b>Very Low Birth Weight Births</b>	--	16,256	195.1	(192.1, 198.2)
<b>Fetal Alcohol Exposure</b>	760.71, 760.7A, 760.7E	128	1.5	(1.3, 1.8)
<b>Perinatal Deaths</b>				
Fetal deaths	--	4,875	58.5	(56.9, 60.2)
Deaths during newborn stay	--	3492	41.9	(40.5, 43.3)
<i>Total Perinatal Deaths</i>		<i>8,367</i>	<i>100.4</i>	<i>(98.3, 102.6)</i>
<b>Serious Congenital Infections</b>				
Chlamydial infections	079.88, 079.98	4	0.0	(0.0, 0.1)
Cytomegalovirus	771.1	115	1.4	(1.1, 1.7)
Gonococcal infections	098.0 - 098.89	3	0.0	(0.0, 0.1)
Group B streptococcus	41.02	245	2.9	(2.6, 3.3)
Hepatitis B	774.4	11	0.1	(0.1, 0.2)
Prenatal exposure to hepatitis B	V01.7B	958	11.5	(10.8, 12.3)
Herpes and other infections	771.2	75	0.9	(0.7, 1.1)
Listeriosis	027.0	1	0.0	(0.0, 0.1)
Rubella	771.0	1	0.0	(0.0, 0.1)
Sepsis (confirmed septicemia)	771.8	1,657	19.9	(18.9, 20.9)
Syphilis	090.0 - 090.9	189	2.3	(2.0, 2.6)
Tetanus neonatorum	771.3	0	0.0	(0.0, 0.0)
<i>Total Serious Congenital Infections</i>		<i>3,259</i>	<i>39.1</i>	<i>(37.8, 40.5)</i>
<b>Endocrine, Metabolic, and Immune disorders</b>				

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Condition	ICD-9-CM Codes	Number	Rate <sup>1</sup>	95% CI <sup>2</sup>
Adrenogenital syndrome	255.2	52	0.6	(0.5, 0.8)
Cystic fibrosis	277.00, 277.01	176	2.1	(1.8, 2.4)
Hypothyroidism	243	465	5.6	(5.1, 6.1)
Immune deficiency disease	279.2	3	0.0	(0.0, 0.1)
Inborn errors of metabolism	270.0 - 273.9	225	2.7	(2.4, 3.1)
<i>Total Endocrine, Metabolic and Immune Disorders</i>		921	11.1	(10.4, 11.8)
<b>Blood Disorders</b>				
Coagulation defects	286.x	60	0.7	(0.5, 0.9)
Constitutional aplastic anemia	284.x	3	0.0	(0.0, 0.1)
Hereditary hemolytic anemia	282.x	584	7.0	(6.5, 7.6)
Leukemia	204.00 - 208.91	5	0.1	(0.0, 0.1)
<i>Total Blood Disorders</i>		652	7.8	(7.2, 8.5)
<b>Other Adverse Pregnancy Outcomes</b>				
Cerebral lipidoses	330.1	0	0.0	(0.0, 0.1)
Chorioretinitis	363.20-363.22	3	0.0	(0.0, 0.1)
Endocardial fibroelastosis	425.3	8	0.1	(0.0, 0.2)
Intrauterine growth restriction	764.90-764.99	4,424	53.1	(51.5, 54.7)
Neurofibromatosis	237.70-237.72	3	0.0	(0.0, 0.1)
Occlusion of cerebral arteries	434.00-434.91	170	2.0	(1.7, 2.4)
Retinopathy of prematurity	362.20-362.27	2,473	29.7	(28.5, 30.9)
Strabismus	378.00-378.9	15	0.2	(0.1, 0.3)
<i>Total Other Adverse Pregnancy Outcomes</i>		7,096	85.2	(83.2, 87.2)

<sup>1</sup> Rate per 10,000 live births

<sup>2</sup> 95% confidence interval for rate

Source: Illinois Department of Public Health, Adverse Pregnancy Outcomes Reporting System, January 2019

## Discussion

Cardiovascular system defects, involving the heart and circulatory system, were the most common group of birth defects identified in the Illinois and the U. S. during the study period, with a rate of 87.2 per 10,000 live births in Illinois from 2008-2012. Ventricular and atrial septal defects were seen most often at 40.3 and 24.7 per 10,000 live births, respectively. Heart and circulatory defects range in severity and some are diagnosed during pregnancy while others are not discovered until after birth or later in life.

CDC estimates that about 25% of congenital heart defects are considered critical<sup>6</sup>. Babies born with critical heart defects need intervention, including surgical repair, during the first year of life to restore normal circulation as much as possible. Because of advances in treatment, many people with cardiovascular defects

can live longer lives. However, they often must maintain regular visits with a doctor throughout their lives as they can develop other health problems over time.

Genitourinary defects affecting reproductive organs and the urinary tract were the second most frequent group of defects found in Illinois with 32.9 per 10,000 live births. Hypospadias, a defect of male urinary system, accounted for 80.9% of the defects identified in this group. This condition can range from mild to severe and may be surgically corrected, if necessary. Hypospadias rates have been trending upward in Illinois in recent years and several risk factors that may increase the odds of this defect have been identified including older maternal age, maternal obesity, use of Assisted Reproductive Technology (ART) and use of hormones<sup>7</sup>.

In addition to birth defects, APORS collected data on a variety of other conditions during the period of 2008-2012. Very low birth weight births were recorded at a rate of 195.1 per 10,000 live births and perinatal deaths at 100.4 per 10,000 live births. Intrauterine growth restriction (IUGR), a condition which contributes significantly to neonatal morbidity and occurring when an unborn baby is at or below the 10th weight percentile for his or her gestational age, was identified at a rate 53.1 per 10,000 live births. Congenital infections, the effects of which can range from premature birth to long term disabilities or even death, were identified at a rate of 39.1 per 10,000 live births. Retinopathy of prematurity (ROP), an eye disease with the potential to cause vision impairment in some premature babies, affected Illinois infants at a rate of 29.7 per 10,000 live infants.

Data from APORS provides an important baseline for information about birth defect and other adverse pregnancy outcomes in Illinois. When used in combination with data from other states, APORS also contributes significantly to nationwide research about birth defects. This information can be used to inform public health policy and drive program development in an effort to prevent birth defects and other adverse pregnancy outcomes, and to improve the lives of those affected by such conditions.

A limitation of this report is that observed rates may be lower than true rates for several reasons. APORS is largely a passive reporting system relying primarily on hospital reports of conditions diagnosed during the newborn stay. However, conditions may be either underreported or diagnosed after the newborn stay. Additionally, APORS does not collect information on early miscarriages or elective terminations. Some defects are so severe, that a baby will miscarry very early on. Also, some defects are detectable in pregnancy and women may elect to terminate the pregnancy.

An additional limitation is that the prevalence of infants prenatally exposed to controlled substances (reported in Table 1), is likely subject to testing bias and results may not be representative<sup>8</sup> of all Illinois newborns. Efforts are currently underway to improve reporting on prenatal drug exposure, and all infants reported with such exposures are offered follow-up services.

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## **Appendix-Definitions**

### **Birth Defects**

#### **Central Nervous System**

*Anencephaly* is a serious defect that occurs when the upper part of the neural tube fails to close, resulting in the absence of a major portion of the brain, skull, and scalp. It includes craniorachischisis in which there is incomplete closure of both the skull and the spinal column. Nearly all babies born with this condition die soon after birth.

*Encephalocele* is a defect affecting the skull resulting in the protrusion of the meninges and portions of the brain through a bony midline defect in the skull. High mortality and morbidity are associated with this condition, and overall outcomes depend on the specific site and size of the lesion as well as whether other anomalies are present.

*Hydrocephalus* is an abnormal buildup of cerebrospinal fluid in the brain causing a widening of the ventricle spaces and creating pressure on the brain. This condition can occur alone or in conjunction with other malformations and may cause a variety of symptoms including a large head, seizures, vomiting, headaches, visual problems, and abnormal reflexes. It is often treated surgically by shunting the fluid out of the brain to be reabsorbed by the body<sup>1</sup>.

*Microcephalus* is an abnormally small head due to failure of proper brain development during pregnancy. This condition can range from mild to severe and may occur alone or in conjunction with other birth defects. Microcephaly can result in a range of issues including seizures, developmental delays, intellectual disability, and feeding, hearing, and vision problems.

*Spina bifida* is a defect in which part of the spinal cord is exposed because of a bony defect in the vertebral column. It may be associated with hydrocephalus. The degree of disability depends on the extent and location of the malformation.

#### **Cardiovascular System**

*Common truncus* is the failure of the fetal truncus arteriosus to divide into the aorta and pulmonary artery. It can be corrected surgically, usually during the first months of life.

*Transposition of great arteries* is a defect in which the position of the aorta and the pulmonary artery is transposed. Immediate surgical correction is needed.



*Tetralogy of Fallot* is a defect consisting of four abnormalities that result in poorly oxygenated blood being pumped to the body. It can be treated surgically, usually soon after birth.

*Ventricular septal defect* is a hole in the wall between the lower chambers of the heart. The opening may resolve without treatment or may require surgical treatment.

*Atrial septal defect* is a hole in the wall between the upper chambers of the heart. The opening may resolve without treatment or may require surgical treatment.

*Atrioventricular septal defect* is a spectrum of septal defects arising from imperfect fusion of the endocardial cushions in the fetal heart. These defects are repaired surgically.

*Pulmonary valve atresia and stenosis* is an absence or narrowing of the valve between the right ventricle and the pulmonary artery. Mild forms are relatively well tolerated and require no intervention. More severe forms are surgically corrected.

*Tricuspid atresia and stenosis* is the absence or pathological narrowing of the valve between the right atrium and ventricle. Severe cases are corrected surgically.

*Ebstein anomaly* is a deformation or displacement of the tricuspid valve with the septal and posterior leaflets being attached to the wall of the right ventricle. Only disabling cases are corrected surgically.

*Aortic valve stenosis* is a narrowing or obstruction of the aortic heart valve. This condition can be repaired surgically in some cases.

*Hypoplastic left heart syndrome* is a form of congenital heart disease in which the entire left half of the heart is underdeveloped. This condition can be surgically repaired or treated by transplantation. This condition is usually fatal in the first month of life if not treated.

*Coarctation of the aorta* is a defect in which the aorta is narrowed somewhere along its length. Surgical correction is recommended even for mild defects.

*Total anomalous pulmonary venous return (TAPVR)* occurs when all four pulmonary veins are abnormally connected to the heart. It results in poorly oxygenated blood being pumped to the body and must be surgically corrected.

## **Alimentary Tract**

*Cleft palate* is an opening in the roof of the mouth (the palate) due to a failure of the palatal shelves to fuse fully during embryonic development.

*Cleft lip* is the presence of one or two openings in the upper lip resulting from failure of the normal process of

fusion of the lip during embryonic development. The opening can range in size and can be on one or both sides of the lip. Rarely, the opening is in the middle of the lip.

*Choanal atresia* is the narrowing or blockage of the nasal airway by membranous or bony tissue. Bilateral choanal atresia is a surgical emergency.

*Esophageal atresia* is a defect of the esophagus in which there are two separate sections that do not connect. It often occurs with a *tracheoesophageal fistula*, in which part of the esophagus is connected to the trachea. With these conditions, a baby is not able to pass food to the stomach and may have difficulty breathing. Surgical repair is necessary soon after diagnosis.

*Rectal, anal, and large intestinal atresia or stenosis* is the absence, abnormal localization, or blockage of the rectum, anus, or large intestine. It may be corrected surgically or bypassed.

*Pyloric Stenosis* is a narrowing of the opening (pylorus) between the stomach and small intestine.

*Hirschsprung disease* is the absence of nerves in the large intestine (bowel).

*Biliary atresia* is a congenital absence or closure of the major bile ducts that drain bile from the liver.

## **Genitourinary System**

*Renal agenesis/hypoplasia* is the absence or maldevelopment of the kidneys; it may be bilateral or unilateral. Newborns with bilateral renal agenesis often die of respiratory failure within a few hours of birth. Unilateral renal agenesis may not be detected during the perinatal period.

*Bladder exstrophy* occurs when the bladder is formed inside-out. Part of the abdominal wall and bladder wall are missing. This condition is usually repaired surgically.

*Hypospadias* is a relatively common abnormality that appears as an abnormal penile opening on the underside of the penis rather than at the end. The condition may be surgically corrected if needed for cosmetic, urologic, or reproductive reasons.

*Epispadias* is a rare congenital defect in which the urethra opens on the top surface of the penis. Surgical correction is aimed at correcting incontinence and permitting sexual function.

## **Musculoskeletal**

*Reduction deformities* may affect upper or lower limbs. They may result in a shortening or absence of one or both limbs.

*Abdominal wall defects* include gastroschisis (a herniation of the abdominal contents through a defect in the abdominal wall) and omphalocele (protrusion of the intestines or other organs through the belly button in

which the organs are covered by a thin layer of tissue). For both conditions, surgery is usually needed soon after birth to put the organs back in the abdomen. For extensive conditions the intervention may be done in stages.

*Developmental dysplasia of the hip* is an abnormal development of the hip joint, in which a neonate's hips easily become dislocated.

*Club foot* is a congenital structural foot deformity that may involve the lower leg, ankle and foot joints, ligaments, and tendons. The condition can usually be treated without surgery.

*Diaphragmatic hernia* occurs when contents of the abdomen protrude through a defect in the diaphragm, impeding lung growth. Surgical repair is needed soon after birth.

## **Chromosomal**

*Patau syndrome (trisomy 13)* is associated with the presence of a third number 13 chromosome. Newborns have numerous organ defects, physical abnormalities, and profound developmental disabilities. Most die in the first days or weeks of life due to severe life-threatening medical problems.

*Down syndrome (trisomy 21)* is associated with the presence of a third number 21 chromosome. This causes distinctive physical features, including short stature and a characteristic facial appearance. Most individuals with Down syndrome have mild to moderate intellectual disability. They may also have other health problems such as hearing loss, sleep apnea, ear infections, and congenital heart defects. Early and ongoing interventions, including speech, physical, and occupational therapies are helpful in assuring everyone will attain his or her potential.

*Edward syndrome (trisomy 18)* is associated with the presence of a third number 18 chromosome. It causes heart and other organ defects, major physical abnormalities, and severe developmental disabilities. Few children afflicted with this disease survive beyond one year of life, and those who do survive usually have profound disabilities.

## **Adverse Outcomes**

### **Serious Congenital Infections**

*Chlamydia* is caused by the *Chlamydia trachomatis* bacterium. Infection can lead to dangerous complications during pregnancy and birth. If a pregnant woman is untreated, her baby can develop conjunctivitis (threatening eyesight) or pneumonia. Chlamydia also can lead to premature birth or low birth weight.

*Cytomegalovirus (CMV)* is a common virus that infects many people but may show no symptoms. Pregnant women can pass the virus to their baby through the placenta when infected for the first time or if infected again during pregnancy. The baby may or may not show signs of infection at birth. Congenital infection may

cause hearing loss, intellectual disability, vision loss, and seizures. Tests may be done on a baby within a few weeks of birth to determine whether the baby is infected, and the baby may be treated to lessen the severity of health problems associated with the disease.

*Gonorrhea* is caused by the *Neisseria gonorrhoeae* bacterium. Gonorrhea can be passed from an infected woman to her newborn infant during delivery, causing neonatal conjunctivitis. Most states require that the eyes of newborns be treated with silver nitrate or other medication immediately after birth to prevent gonococcal infection of the eyes, which can lead to blindness.

*Group B streptococcus (GBS)* is a bacterium that can be part of normal flora in the body and is carried by about 25% of women. The bacteria can cause pneumonia and meningitis in infants who are exposed during delivery. All pregnant women should be tested for the bacteria, and, if positive, treated with antibiotics during labor to prevent disease in the baby.

*Hepatitis B virus (HBV)* can be passed to a baby during delivery. A baby may be asymptomatic, but as he or she grows up, liver damage may be present. About 80% of liver cancers are caused by HBV infections. A vaccine has been used since 1982 to prevent hepatitis B.

*Herpes* in a newborn is usually a result of exposure to the herpes simplex virus II (HSV-2) during vaginal delivery. The infection rate is about 50% in primary maternal infection and about 5% in a recurrent infection. The most common clinical symptom is the presence of cutaneous vesicles. In 20% of cases, there is major systemic involvement, central nervous system involvement, or both. Less than 10% of babies with neurologic disease develop normally. The overall mortality rate among infants with untreated infection is 65%.

*Listeriosis* is caused by infection with the bacterium *Listeria monocytogenes*; half of all infected newborns will die from the illness. Babies infected during pregnancy may be born prematurely, have a blood infection (sepsis), and may have a serious, whole body infection called granulomatosis infantisepticum. When a baby is infected during childbirth, symptoms usually appear about two weeks after birth; these babies typically have meningitis or sepsis.

*Rubella*, or German measles, is caused by the rubella virus. If a woman contracts this virus during pregnancy, the baby may miscarry or be born with birth defects including deafness, cataracts, heart defects, low birthweight, intellectual disabilities, and damage to the liver and spleen.

*Sepsis* may be caused by any of several infections. It is reportable if the infection is confirmed and is invasive. Once the organism has invaded the bloodstream, the infection may lead to pneumonia, septicemia, arthritis, endocarditis, or meningitis.

*Syphilis (congenital)* is caused by the *Treponema pallidum* bacterium. It can infect the baby either by transplacental passage of bacteria or from contact with an infectious lesion during delivery. Congenital syphilis can cause miscarriage, stillbirth, prematurity or death shortly after birth. Without immediate treatment, infection can cause many health problems in the baby including deformed bones, anemia, blindness, deafness,

enlarged liver and spleen, and meningitis<sup>2</sup>.

*Tetanus infection* in newborns is caused when an infant is exposed to the bacterium *Clostridium tetani* during delivery. The bacteria produce a neurotoxin that selectively blocks inhibitory nerve transmission from the spinal cord to the muscles, allowing the muscles to go into severe spasm. Without treatment, two out of three newborns with tetanus will die.

## **Endocrine, Metabolic, and Immune disorders**

*Adrenogenital syndrome* is a group of disorders that lead to an overproduction of androgens. Female newborns have ambiguous genitalia; male newborns have no obvious abnormality but appear to enter puberty as early as two to three years of age. Some forms are more severe – in the salt-losing form, babies develop symptoms (dehydration, electrolyte changes, and cardiac arrhythmias) soon after birth. Untreated, this condition can lead to death within days.

*Cystic fibrosis* is a genetic disease that causes the body to produce an abnormally thick, sticky mucus due to the faulty transport of sodium and chloride within cells lining organs such as the lungs and pancreas. The thick mucus also obstructs the pancreas, preventing enzymes from reaching the intestines to help digest food. This leads to malnutrition and stunted growth.

*Immune deficiency diseases* occur when one or more parts of the immune system are missing. There are more than 100 known forms of congenital immune deficiencies (HIV infections do not fit in this category). Many children with immune deficiencies must avoid contagious situations. If a child is diagnosed at birth or soon after with a severe combined immune deficiency, he or she can receive a bone marrow transplant with hopes of reconstituting the missing immune system.

*Inborn errors of metabolism* include hundreds of genetic disorders affecting metabolism. These errors interfere with the synthesis of proteins, carbohydrates, fats, and enzymes. Absence or excesses of normal or abnormal metabolites can lead to disease and death. Many inborn errors of metabolism are untreatable; others require restrictions or extremely high dosages of certain nutrients.

*Neonatal hypothyroidism* is characterized by decreased thyroid hormone production at birth. If untreated, hypothyroidism leads to severe defects including poor vision, developmental disabilities, muscle weakness, and severe lethargy. If diagnosed and treated soon after birth, growth and mental development can proceed relatively normally.

## **Blood Disorders**

*Leukemia* is cancer of the blood cells. When it develops, the body produces large numbers of abnormal white blood cells. Acute lymphocytic leukemia is seen most commonly in children. Children with leukemia may have anemia; swollen lymph nodes, liver, or spleen; and bone or joint pain. In acute leukemia, the abnormal cells

may collect in the central nervous system leading to headaches, confusion, loss of muscle control, and seizures. Leukemia also can affect the eyes, skin, testicles, digestive tract, kidneys, lungs, or other parts of the body.

*Hereditary hemolytic anemia* is a condition characterized by an inadequate number of circulating red blood cells (anemia), caused by premature destruction of red blood cells. There are several types of hereditary hemolytic anemia including sickle cell anemia, hemoglobin SC disease, sickle beta thalassemia, and spherocytosis. Symptoms include fatigue, shortness of breath, rapid heart rate, and jaundice.

*Constitutional aplastic anemia* is a hereditary, often fatal bone marrow failure disease that occurs when the bone marrow is hypoplastic. Bone marrow transplantation replaces the defective bone marrow of a patient with healthy cells from a normal donor and can cure the disease in about 80% of cases where a sibling with identical tissue type is the donor. Growth factors are also being used in treatment.

*Coagulation defects* are a group of inherited blood disorders characterized by a deficiency in one or more of the factors that make up the blood clotting system. Each condition may be severe, moderate, or mild. In hemophilia, easy bruising and internal bleeding are characteristic. In the severe forms, repeated bleeding into joints is a problem and can lead to long-term joint damage. Treatment consists of intravenous replacement of the missing clotting factors.

## **Other Adverse Outcomes**

*Very low birth weight* refers to a birth weight of less than 1,500 grams (about 3 pounds 5 ounces).

*Perinatal Deaths* refer to a combination of fetal deaths of at least 20 weeks gestation and neonatal deaths (under 28 days old). APORS collects information from hospitals about neonatal deaths that occur while the baby is still in the hospital for the newborn stay. Additionally, information about fetal deaths is obtained from the IDPH's Division of Vital Records. Data on elective abortions are not included.

*Fetal alcohol exposure* includes babies diagnosed with fetal alcohol spectrum disorders as well as those affected by or significantly exposed to alcohol as reported by Illinois hospitals

*Neurofibromatosis (NF)* is a genetic disease in which patients develop multiple soft tumors under the skin and throughout the nervous system. NF occurs in about one of every 4,000 births and may cause speech impairment, learning disabilities, and attention deficit disorder in children, as well as loss of hearing, weakness of facial muscles, headache, poor balance, and uncoordinated walking. Cataracts frequently develop at an unusually early age. The chance of brain tumors developing is unusually high.

*Retinopathy of prematurity (ROP)* is an eye disease that occurs in some premature babies. The last 12 weeks of a full-term pregnancy are particularly active for the growth of the fetal eye. In premature infants, the normal growth of the retinal vessels stops, and abnormal new vessels begin to grow and spread in the retina. The

infant may become blind. Most infants with mild ROP usually develop normal central vision. However, some may have late complications, including strabismus, amblyopia, myopia, glaucoma, and late onset retinal detachment.

*Chorioretinitis* is an inflammation of the uveal tract, which lines the inside of the eye behind the cornea. It almost always affects the retina, usually following an active microbial invasion of the tissues. Toxoplasmosis and cytomegalovirus are the most common causes. Onset is insidious: vision gradually becomes blurred, pain is minimal, mild photophobia is present, and the pupil is often constricted and/or irregular in shape. The disease can last months to years, sometimes with remissions and exacerbations, and may cause permanent damage with marked visual loss.

*Strabismus* is a condition in which the eyes do not point in the same direction. Esotropia (crossed eyes) is the most common type of strabismus in infants. Sometimes the eye turn is always in the same eye; however, sometimes the turn alternates from one eye to the other. An eye doctor needs to determine whether the eye turn is true or pseudo strabismus. A baby's eyes should be straight and parallel by three or four months of age. Strabismus can be caused by a defect in muscles or the part of the brain that controls eye movement. It is especially common in children who have disorders that affect the brain.

*Endocardial fibroelastosis (EFE)* is a rare heart disorder that affects infants and children. It is characterized by a thickening within the muscular lining of the heart chambers due to an increase in the amount of supporting connective tissue and elastic fibers. The symptoms of EFE are related to the overgrowth of fibrous tissues causing abnormal enlargement of the heart (cardiac hypertrophy), especially the left ventricle. Impaired heart and lung function eventually lead to congestive heart failure.

*Intrauterine growth restriction (IUGR)* occurs when the unborn baby is at or below the 10th weight percentile for his or her gestational age. There are many IUGR risk factors involving the mother and the baby. A mother is at risk for having an infant with IUGR if she has poor weight gain and nutrition during pregnancy, uses substances (like tobacco, narcotics, or alcohol) that can cause abnormal development, or if she has preeclampsia or chronic kidney disease. Additionally, an unborn baby may suffer from IUGR if it is exposed to an infection, has a birth defect, or has placenta or umbilical cord defects. Babies who suffer from IUGR are at an increased risk for death, hypoglycemia, hypothermia, and abnormal development of the nervous system.

*Cerebral lipidoses* are inherited genetic defects that result in a deficiency in different enzymes involved with fat storage. The absence of the enzyme prevents the lysosome in the cells of the body from performing its natural recycling function, and various materials are inappropriately stored in the cells of the brain and central nervous system. This leads to a variety of progressive mental and physical deterioration over time. Some patients survive into adulthood, but others with more severe symptoms or conditions die in their teens or earlier.

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