

Section 8:

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Congenital and Perinatal Conditions



Birth Defects

Every 4½ minutes, a baby is born with a birth defect in the U.S. Major birth defects are conditions present at birth that cause structural changes in one or more parts of the body. They can have a serious adverse effect on health, development, or functional ability. Birth defects are one of the leading causes of infant mortality, causing one in five infant deaths. In Florida, there are approximately 220,000 live births annually and 1 out of every 28 babies is born with a major birth defect. Despite their substantial impact, only 35% of birth defects have a known cause and research suggests a complex interaction between genetic and environmental factors. In 1997, the Florida Legislature provided funding to the Florida Department of Health to operate and manage a statewide population-based birth defects registry, the Florida Birth Defects Registry (FBDR). Birth defects are reportable to the FBDR.

FBDR surveillance data are used for:

- Tracking and detecting trends in birth defects.
- Identifying when and where birth defects can possibly be prevented.
- Providing the basis for studies on the genetic and environmental causes of birth defects.
- Planning and evaluating the impact of efforts to prevent birth defects.
- Helping Florida's families whose infants and children need appropriate medical, educational, and social services.

The FBDR collects information on more than 100,000 infants born with serious birth defects. Data are collected on live infants born to mothers residing in Florida who are diagnosed with one or more structural, genetic, or other specified birth outcomes in the first year of life. The FBDR links secondary source datasets, including the Florida Division of Public Health Statistics and Performance Management birth records and the Agency for Health Care Administration hospital inpatient and ambulatory discharge databases. There is an inherent delay in FBDR data since they include all outcomes through the first year of life. At the time this report was published, the most recent FBDR data available were from 2015.

In 2015, Down syndrome was the most commonly identified birth defect among those listed. The number and rate per 10,000 live births of each type of birth defect reported in 2015 were similar to the number reported in 2014.

	2010-2014 average		2011-2015 average
Central nervous system defects	Number	Rate	Number Rate
Spina bifida without anencephalus	59	2.8	56 2.6
Anencephalus	17	0.8	18 0.9
Cardiovascular defects			
Tetralogy of Fallot	105	4.9	104 4.8
Atrioventricular septal defect	88	4.1	86 4.0
Hypoplastic left heart syndrome	69	3.2	68 3.2
Transposition of the great arteries	51	2.4	53 2.5
Orofacial defects			
Cleft palate without cleft lip	110	5.1	107 5.0
Cleft lip with cleft palate	106	5.0	110 5.1
Musculoskeletal defects			
Gastroschisis	100	4.7	96 4.4
All limb deficiencies (reduction deformities)	81	3.8	76 3.5
Chromosomal defects			
Trisomy 21 (Down syndrome)	289	13.5	283 13.1

For more information, please visit FloridaHealth.gov/diseases-and-conditions/birth-defects/index.html.

Neonatal Abstinence Syndrome

Neonatal abstinence syndrome (NAS) occurs in a newborn who was exposed to addictive opiate drugs while in the mother's womb. The most common opiate drugs that are associated with NAS are heroin, codeine, oxycodone (oxycontin), methadone, and buprenorphine. Symptoms of withdrawal depend on the drug involved.

Symptoms can begin within one to three days after birth, or may take up to 10 days to appear and may include:

- Blotchy skin coloring (mottling)

- Diarrhea
- Excessive or high-pitched crying
- Excessive sucking •
- Fever
- Hyperactive reflexes •
- Increased muscle tone •
- Irritability •
- Jitteriness .
- Poor feeding •

- Rapid breathing
- Seizures
- Sleep problems
- Slow weight gain
- Stuffy nose
- Sneezing
- Sweating
- Trembling (tremors)
- Vomiting

NAS became a reportable condition in Florida in June 2014. FBDR conducts enhanced surveillance for NAS. Surveillance incorporates multi-source passive case finding efforts and trained abstractor review of maternal and infant hospital medical records to obtain all relevant clinical information to classify potential NAS cases, determine specific agents the mother and infant were exposed to, and to develop a more complete understanding of the public health issue. Currently, there is substantial variation in the diagnosis and reporting of NAS across institutions, providers, and surveillance systems. There is an inherent delay in FBDR data since they include all outcomes through the first year of life. At the time this report was published, the most recent NAS data available were from 2016.

NAS rates per 10,000 live births in Florida for 2014-2016 were highest in low-population counties, particularly in northeast Florida.



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males, whites, and non-Hispanics.

NAS rate per 10,000 live births	2
in Florida, 2014-2016	
🔲 No rate (<5 cases)	
0.1-58.7	
58.8-90.4	
90.5-128.0	
128.1-295.4	

	2014	2015	2016	3-year trend
Gender				
Female	689	715	696	
Male	772	795	784	
Race				
White	1,281	1,327	1,289	
Black	83	86	103	
Other	97	97	88	
Ethnicity				
Hispanic	74	67	47	
Non-Hispanic	1,387	1,443	1,433	
Total	1,461	1,510	1,480	

For more information, please visit FloridaHealth.gov/diseases-and-conditions/birth-defects/NeonatalAbstinenceSyndromeNAS.html.

Perinatally Acquired HIV

Perinatal HIV transmission, also known as vertical HIV transmission, can occur at any point during pregnancy, labor, delivery, or ingestion of breast milk. The Centers for Disease Control and Prevention (CDC) recommends that all women who are pregnant or planning to become pregnant be tested for HIV before pregnancy and as early as possible during every pregnancy. Per Florida Administrative Code Rule 64D-3.042, all pregnant women must be tested for HIV and other sexually transmitted infections at their at their initial prenatal care visit, at 28–32 weeks, and at labor and delivery. This testing requirement allows Florida's providers to address any potential missed opportunities for HIV prevention during the prenatal period. If a pregnant mother living with HIV is aware of her HIV status, takes HIV antiretroviral medications as prescribed throughout pregnancy, labor, and delivery, and gives antiretroviral medications to her infant for 4-6 weeks after delivery, there is less than 1% chance of perinatal HIV transmission.

Prevention for perinatally acquired HIV in Florida is focused on:

- Prevention services for women of child bearing age.
- Ensuring women of child bearing age living with HIV are virally suppressed.
- Ensuring medical and social services for pregnant women living with HIV and their infants.
- Education and technical assistance for providers who treat pregnant women.

Infants with perinatally acquired HIV born in Florida have decreased

by 93% from 1993 to 2017. Initiation of highly active antiretroviral therapy (HAART) between 1992–1994 played a significant role in this decrease. Treatment with HAART helps pregnant mothers living with HIV achieve viral suppression, which reduces vertical transmission.



The most common missed opportunity for HIV prevention among the 78 infants with perinatally acquired HIV from 2008–2017 was inadequate prenatal care (87% of exposed infants). Inadequate prenatal care means prenatal care occurring after the fourth month of pregnancy and less than five visits.



In 2017, 460 Infants were perinatally exposed to HIV throughout the state (including those who acquired HIV). South Florida, particularly Miami-Dade and Broward counties, have more perinatal exposures, likely due to the high burden of HIV in this area.



For additional information on HIV/AIDS, see the Overview of 2017, Focus in 2017: HIV/AIDS and Section 1: Data Summaries for Common Reportable Diseases/Conditions. For more information about perinatal prevention services, see FloridaHealth.gov/diseasesand-conditions/aids/prevention/topwa1.html.

Congenital Syphilis

Congenital syphilis can occur when an infant is exposed to syphilis while in the womb. The exposure can be due to a new or an untreated old infection in the mother. Although untreated infections from prior to a mother's pregnancy can still result in congenital syphilis, infant outcomes are typically worse if the mother is newly infected while pregnant, as the bacterial count in the mother is higher. An infant born with congenital syphilis can develop an array of symptoms, including failure to thrive, skeletal and facial deformities, watery fluid from the nose, rash, blindness, joint swelling, and death. Per Florida Administrative Code Rule 64D-3.042, all pregnant women must be tested for HIV and other sexually transmitted infections, including syphilis, at their initial prenatal care visit and again at 28–32 weeks gestation.

Congenital syphilis prevention in Florida is focused on:

- Ensuring pregnant women have access to prenatal care and STD prevention services.
- Increased testing of pregnant females during the first and last trimester.
- Educating and training providers on the importance of testing and the recommended treatment for pregnant females.

To prevent congenital syphilis, an infected mother must begin adequate treatment more than 30 days prior to delivery. In 2017, 37% of the 93 infants in Florida with congenital syphilis were born to mothers who were not tested for syphilis more than 30 days prior to delivery, and therefore could not begin treatment in time to prevent congenital syphilis.

Congenital syphilis cases have increased in Florida. In 2017, 361 pregnant women were diagnosed with syphilis and 93 infants were born with congenital syphilis, including five stillbirths.



Compared to the race distribution of all mothers in Florida, black mothers were disproportionately more likely to have an infant with congenital syphilis than white mothers in 2017.



In 2017, congenital syphilis cases occurred primarily in central and south Florida. The most cases occurred in Miami-Dade (31) and Broward (11) counties.



Most mothers (58%) who gave birth to infants with congenital syphilis were <30 years old, which is comparable to the statewide age breakdown of mothers (54% <30 years old).

Mother's age	Number	Percent	
15-19	8	8.6%	
20-24	23	24.7%	
25-29	23	24.7%	
30-34	22	23.7%	
35-39	14	15.1%	
40-44	3	3.2%	

For additional information on syphilis, see the Overview of 2017, Focus in 2017: Syphilis, Section 1: Data Summaries for Common Reportable Diseases/Conditions, and FloridaHealth.gov/diseases-and-conditions/sexually-transmitted-diseases/std-fact-sheets/ congenital-syphilis.html.

Perinatal Hepatitis B

Hepatitis B virus (HBV) during pregnancy poses a serious risk to the infant at birth. Without post-exposure prophylaxis (PEP), approximately 40% of infants born to mothers with HBV in the U.S. will develop chronic HBV infection, approximately one-fourth of whom will eventually die from chronic liver disease. Perinatal HBV transmission can be prevented by identifying pregnant women with HBV and providing hepatitis B immune globulin and hepatitis B vaccine to their infants within 12 hours of birth. Preventing perinatal HBV transmission is an integral part of the national strategy to eliminate hepatitis B in the U.S.

National guidelines call for the following:

- Universal screening of pregnant women for HBV surface antigen during each pregnancy.
- Case management of mothers and their infants with HBV.
- Provision of immunoprophylaxis for infants born to mothers with HBV, including hepatitis B vaccine and hepatitis B immune globulin.
- Routine hepatitis B vaccination for all infants, with the first dose administered at birth.

Please see Hepatitis B, Pregnant Women in Section 1: Data Summaries for Common Reportable Diseases/Conditions for additional information on HBV surveillance in pregnant women. The 2016 National Immunization Survey estimates that HBV vaccination coverage for birth dose administered from birth through 3 days of age was 71.1% in the U.S. and 59.0% in Florida. Birthing hospitals have a standing order to administer the birth dose of hepatitis B vaccine; however, pediatricians sometimes choose to wait to give the first dose in their private offices. With lower-than-expected vaccination rates, Florida is currently working with the Florida Chapter of the American Academy of Pediatrics to provide education reminding health care providers that the recommendation is now to provide the vaccine birth dose within 24 hours to help decrease HBV infections in newborns. Despite low compliance with administering the birth dose of HBV vaccine, only 10 perinatal hepatitis B cases have been reported over the past 10 years, with one case reported in 2017 and the most recent cases prior to that in 2014.

Hill HA, Elam-Evans LD, Yankey D, Singleton JA, Kang Y. 2017. Vaccination coverage among children aged 19–35 months – United States, 2016. *Morbidity and Mortality Weekly Report*. 2017; 66(43):1171–1177. doi: 10.15585/mmwr.mm6539a4. Available at www.cdc.gov/mmwr/volumes/66/wr/mm6643a3.htm.

Centers for Disease Control and Prevention. 2016 Childhood Hepatitis B (HepB) Vaccination Coverage Report. www.cdc.gov/vaccines/ imz-managers/coverage/childvaxview/data-reports/hepb/reports/2016.html. Accessed November 15, 2018.

Perinatal Hepatitis C

Hepatitis C virus (HCV) infection is a leading cause of liver-related morbidity and mortality. Transmission of HCV is primarily via parenteral blood exposure, and HCV can be transmitted vertically from mother to child. Compared to vertical transmission for infants born to mothers with HBV, the rate of vertical transmission for HCV is much lower. Vertical transmission occurs in approximately 6% of infants born to mothers with HCV, although that rate can double for women who are also living with HIV or who have high HCV viral loads. According to the CDC, the rate of acute hepatitis C increased three-fold among women across the U.S. from 2010 to 2016, and women of childbearing age testing positive for HCV increased by 22% from 2011 to 2014. CDC recommends that health care providers assess all pregnant women for risk factors associated with hepatitis C and test those who may be at risk. CDC also recommends testing for all infants born to mothers with HCV. Having a pediatric specialist can assist in monitoring disease progression in babies and aid in intervention when needed. These children should be vaccinated against hepatitis A and B, and specialists should monitor any medication that could potentially harm the already fragile liver. More research is needed to better understand if treatment for hepatitis C is safe for pregnant women and children. Florida enhanced its efforts to identify and perform outreach to those mothers and infants at highest risk for HCV transmission. Infants born to mothers with HCV should be tested for HCV at the first well-baby visit, again at 2 months, and followed up to identify any adverse health outcomes.

Changes in treatment options for HCV have led to an increased focus on identifying HCV infections. Given the large number of chronic hepatitis C cases reported and limited county health department resources, there have been concerns regarding data completeness and case ascertainment in the past. Earlier data are less reliable. Over the past few years, improvements in electronic laboratory reporting and increased focus on surveillance are believed to have improved case ascertainment. To improve case ascertainment of perinatal infections, Florida developed and implemented a surveillance case definition for perinatal hepatitis C in 2016. Previously, these cases were captured within the chronic hepatitis C case definition.

The number of people with acute or chronic hepatitis C increased by 43% from 2008 to 2017. The number of women of childbearing age with acute or chronic hepatitis C increased 122% in that same period. Despite this increase among women, the number of children <3 years old identified with acute, chronic, or perinatal hepatitis C has not increased over the past 10 years.

2017



Women 15–44 years old with any hepatitis C infection

Children <3 years old with any hepatitis C infection



The number of perinatal hepatitis C cases decreased from 34 in 2016 to 22 in

2017. In 2017, more cases were in males, whites, and non-Hispanics. Most cases were confirmed. Note that perinatal hepatitis C has only been reportable since 2016. Acute and chronic hepatitis C cases can still be reported in children <3 years old if the infections are determined not to be perinatal (not included in this table or

Perinatal hepatitis C cases occurred in counties throughout the state in 2017. No county had more than three cases.



- map). Summary Ethnicity Number Number of cases in 2017 22 Non-Hispanic 13 Number of cases in 2016 34 Hispanic 1 Gender Number Unknown ethnicity 8 Female 9 **Case Classification** Number Confirmed 19 Male 13 0 Probable Unknown gender 3 Number Race 15 White Black 1 Other 1 5 Unknown race
 - Koneru A, Nelson N, Hariri S, Canary L, Sanders KJ, Maxwell JF, et al. Increased hepatitis C virus (HCV) detection in women of childbearing age and potential risk for vertical transmission United States and Kentucky, 2011–2014. *Morbidity and Mortality Weekly Report*. 2016; 65(28):705-710. doi: 10.15585/mmwr.mm652. Available at www.cdc.gov/mmwr/volumes/65/wr/mm6528a2.htm.
 - Centers for Disease Control and Prevention. Surveillance for Viral Hepatitis United States, 2016. Available at www.cdc.gov/hepatitis/ statistics/2016surveillance/commentary.htm. Accessed November 15, 2018.
 - Centers for Disease Control and Prevention. Increases in Hepatitis C Threaten Young Women and Babies. www.cdc.gov/nchhstp/ newsroom/2016/hcv-perinatal-press-release.html. Accessed November 15, 2018.