

Congenital and Perinatal Conditions

Section 7



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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 Department 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 2016.

	2010–2014 average		2011–2015 average		2012–2016 average	
	Number	Rate	Number	Rate	Number	Rate
Central nervous system defects						
Spina bifida without anencephalus	59	2.8	56	2.6	54	2.5
Anencephalus	17	0.8	18	0.9	19	0.9
Cardiovascular defects						
Tetralogy of Fallot	105	4.9	104	4.8	105	4.8
Atrioventricular septal defect	88	4.1	86	4.0	80	3.7
Hypoplastic left heart syndrome	69	3.2	68	3.2	74	3.4
Transposition of the great arteries	51	2.4	53	2.5	54	2.5
Crofacial defects						
Cleft palate without cleft lip	110	5.1	107	5.0	112	5.1
Cleft lip with cleft palate	106	5.0	110	5.1	113	5.2
Musculoskeletal defects						
Gastroschisis	100	4.7	96	4.4	92	4.2
All limb deficiencies (reduction deformities)	81	3.8	76	3.5	76	3.5
Chromosomal defects						
Trisomy 21 (Down syndrome)	289	13.5	283	13.1	277	12.7

In 2016, 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 2016 were similar to the number reported in 2015.

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

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Neonatal Abstinence Syndrome

Neonatal abstinence syndrome (NAS) occurs in a newborn who was exposed to addictive opiate drugs while in their 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.

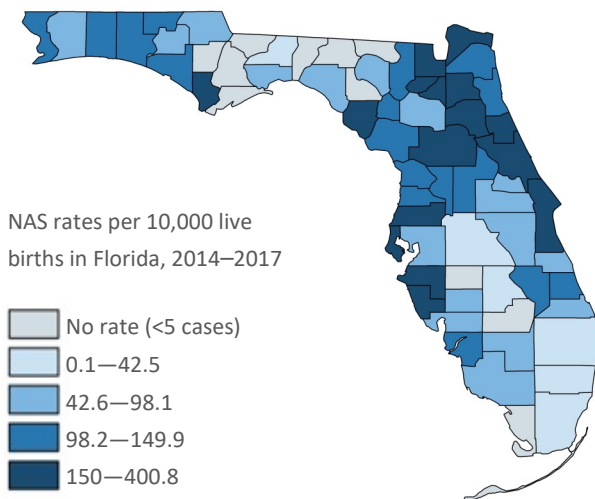
Symptoms can begin within one to three days after birth, or may take up to 10 days to appear and may include:

- 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 the case definition includes all outcomes through the first year of life. At the time this report was published, the most recent NAS data available were from 2017.

NAS rates per 10,000 live births in Florida for 2014–2017 were highest in low-population counties, particularly in northeast Florida.

Each year, most cases are identified in males, whites and non-Hispanics.



	2015	2016	2017	3-year trend
Gender				
Female	715	696	687	■ --
Male	795	784	816	■ ■ ■
Race				
White	1,327	1,289	1,252	■ ■ ■
Black	86	103	89	-- ■
Other	97	88	162	-- ■
Ethnicity				
Hispanic	67	47	97	-- ■
Non-Hispanic	1,443	1,433	1,406	■ ■ ■
Total	1,510	1,480	1,503	■ -- ■

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

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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 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.

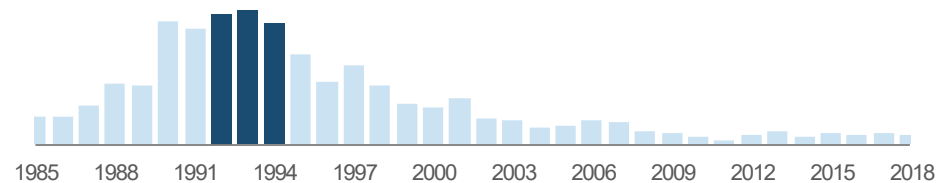
Florida’s strategic goal aims to reduce the annual number of infants born in Florida with perinatally acquired HIV to less than five. Prevention of perinatally acquired HIV in Florida is focused on:

- Prevention services for women of childbearing age (15–44 years old).
- Ensuring women of childbearing 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.

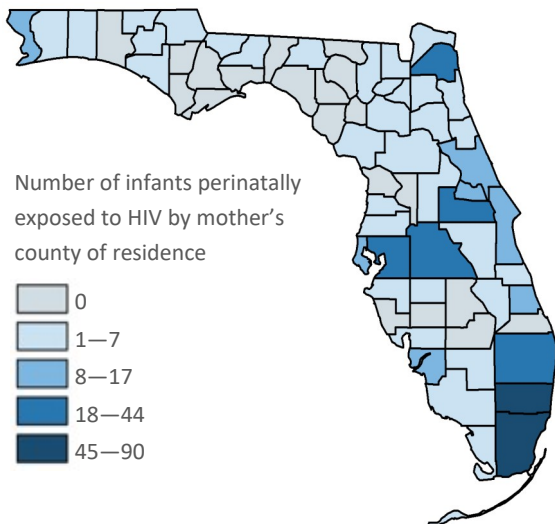
Florida 2018

- 497** infants perinatally exposed to HIV
- 8** infants born with perinatally acquired HIV
- 2** infants developed AIDS

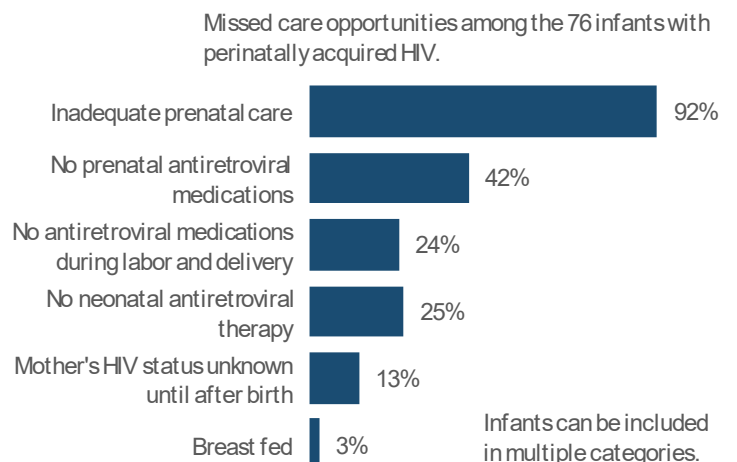
Perinatal HIV transmission has decreased substantially in Florida over the past few decades. This decrease is largely thanks to the **initiation of antiretroviral therapy (ART) between 1992 and 1994**. When pregnant women living with HIV are using ART they can achieve viral suppression (<200 copies/mL), which greatly reduces HIV transmission to infants.



In 2018, 497 Infants were perinatally exposed to HIV throughout the state (including the 8 infants who acquired HIV). South Florida, particularly Miami-Dade and Broward counties, has more perinatal exposures (Broward n=85, Miami-Dade n=90), likely due to the high burden of HIV in this area.



The most common missed opportunity for HIV prevention among the 76 infants with perinatally acquired HIV from 2009–2018 was inadequate prenatal care; 92% of mothers whose infants acquired HIV did not receive adequate prenatal care. Inadequate prenatal care is defined as prenatal care occurring after the fourth month of pregnancy and less than five prenatal visits during pregnancy.



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

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Congenital Syphilis

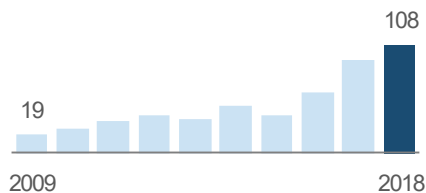
Congenital syphilis can occur when a fetus is exposed during pregnancy. The exposure can be due to new or previous untreated infections in pregnant women. While previous untreated infections can result in congenital syphilis, infant outcomes are typically worse if women are newly infected during pregnancy, as the bacterial count 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 and section 384.31, Florida Statutes, all pregnant women must be tested for HIV and other sexually transmitted infections, including syphilis, at their initial prenatal care visit, at 28–32 weeks gestation and at delivery if not tested at 28–32 weeks.

Congenital syphilis prevention in Florida is focused on:

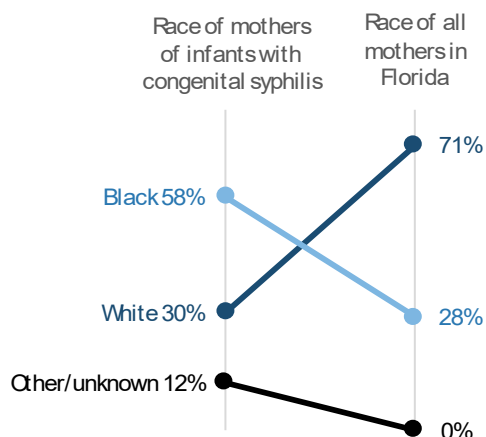
- Ensuring pregnant women have access to prenatal care and sexually transmitted disease prevention services.
- Increased testing during the first and last trimesters and at delivery for pregnant women without prenatal testing or who had reactive tests during pregnancy.
- Educating and training providers on the importance of testing and the recommended treatment for pregnant women.
- Partnering with local organizations, for example Healthy Start, to collaborate and work with patients and providers to ensure appropriate follow-up for testing and treatment.

To prevent congenital syphilis, a pregnant woman who has an infection must begin adequate treatment more than 30 days prior to delivery. In 2018, 59% of the 108 infants in Florida with congenital syphilis were born to women who were not tested for syphilis more than 30 days prior to delivery and therefore could not begin timely treatment to prevent congenital syphilis.

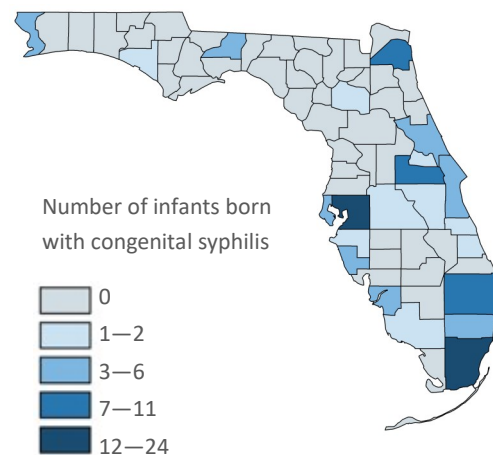
Over the past 10 years, congenital syphilis cases have increased 468% in Florida. In 2018, 377 pregnant women were diagnosed with syphilis and 108 infants were born with congenital syphilis, including two stillbirths.



Compared to the race distribution of all women who gave birth in Florida, **black women were disproportionately more likely to have an infant with congenital syphilis than white women** in 2018.



In 2018, congenital syphilis cases occurred primarily in central and south Florida. The highest-burdened counties were Miami-Dade (24), Hillsborough (13), Duval (11) and Orange (9).



Most women (59%) who gave birth to infants with congenital syphilis were <30 years old, which is comparable to the statewide age breakdown of all women who gave birth (52% <30 years old).

Mother's age	Number	Percent
15–19	5	4.6%
20–24	26	24.1%
25–29	33	30.6%
30–34	28	25.9%
35–39	10	9.3%
40–44	6	5.6%

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

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Perinatal Hepatitis B

Hepatitis B virus (HBV) infection 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:

- 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.

The 2017 National Immunization Survey estimates that HBV vaccination coverage for birth dose administered from birth through 3 days of age was 73.6% in the U.S. and 66% 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.

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.

Centers for Disease Control and Prevention. 2017 Childhood Hepatitis B (HepB) Vaccination Coverage Report. www.cdc.gov/vaccines/imz-managers/coverage/childvaxview/data-reports/hepb/reports/2017.html. Accessed November 18, 2019.

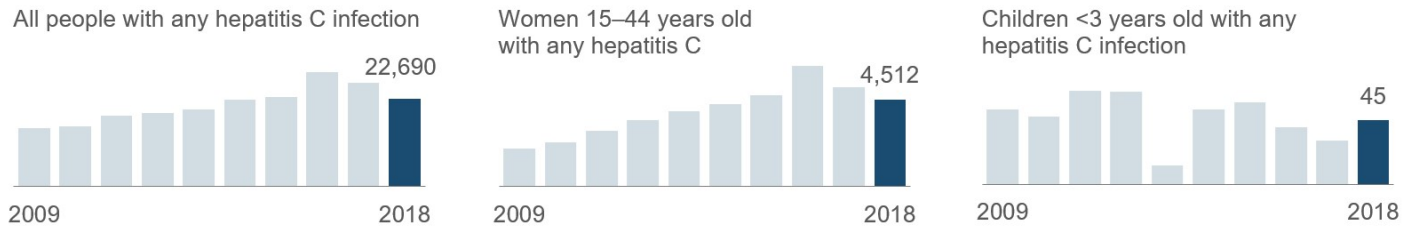
Hill HA, Elam-Evans LD, Yankey D, Singleton JA, Kang Y. 2017. Vaccination coverage among children aged 19–35 months — United States, 2016. *Morbidity and Mortality Weekly Report*. 2017; 66(43):1171–1177. doi: 10.15585/mmwr.mm6539a4. Available at www.cdc.gov/mmwr/volumes/66/wr/mm6643a3.htm.

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 by 43% among women across the U.S. from 2013 to 2017, 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.

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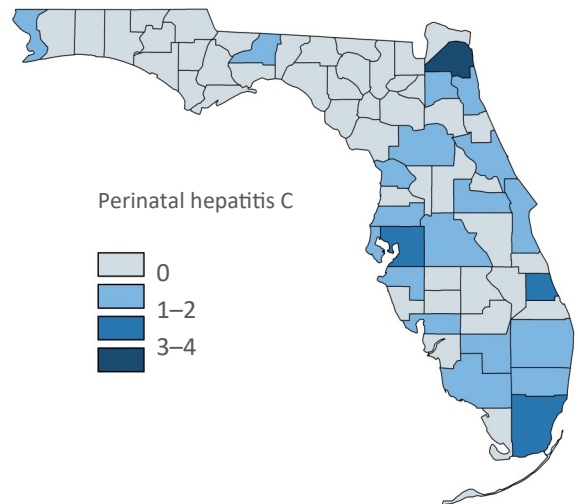
Changes in treatment options for HCV have led to an increased focus on identifying HCV infections. Given the large number of chronic hepatitis C cases reported and limited county health department resources, there have been concerns regarding data completeness and case ascertainment in the past. Earlier 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. In 2018, Florida added a suspect case classification for perinatal hepatitis C to include cases that did not have any confirmatory testing reported.



The number of cases with acute or chronic hepatitis C increased by 50% from 2009 to 2018. The number of women of childbearing age with acute or chronic hepatitis C increased 128% 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

The number of perinatal hepatitis C cases almost doubled from 22 in 2017 to 40 in 2018. In 2018, more cases were in males, whites and non-Hispanics. Race was unknown in 48% of cases. 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 map).

Perinatal hepatitis C cases occurred in counties throughout the state in 2018. Duval (7) and St. Lucie (4) had the most cases in 2018.



Summary	Number	Ethnicity	Number
Cases in 2017	22	Non-Hispanic	18
Cases in 2018	40	Unknown ethnicity	22
Gender	Number	Case Classification	Number
Female	19	Confirmed	36
Male	21	Probable	4
Unknown gender	0		
Race	Number		
White	17		
Other	4		
Unknown race	19		

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.

Centers for Disease Control and Prevention. Surveillance for Viral Hepatitis – United States, 2017. Available at www.cdc.gov/hepatitis/statistics/2017surveillance/index.htm. Accessed September 10, 2019.

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.