



# SURVEILLANCE BRIEF

Wisconsin Environmental Public Health Tracking Program JANUARY 2024

## BIRTH DEFECTS IN WISCONSIN, 2008–2021

Elaina Andreychak, MPH<sup>1</sup>, Megan Christenson, MS, MPH<sup>1</sup>,  
Melissa Olson, MS<sup>2</sup>, Kaitlin Tolliver, LCSW<sup>2</sup>,  
Madeline Kemp, MPH<sup>2</sup>, Jenny Camponeschi, MS<sup>1</sup>,  
Carrie Tomasallo, PhD, MPH<sup>1</sup>

<sup>1</sup>Wisconsin Environmental Public Health Tracking Program

<sup>2</sup>Birth Defects Prevention and Surveillance Program  
Wisconsin Department of Health Services



**SUMMARY** – Birth defects in Wisconsin are monitored using surveillance data from vital records and hospital discharge records. The Wisconsin Environmental Health Tracking Program closely monitors the prevalence rates and trends of 12 selected birth defects.

One birth defect, hypoplastic left heart syndrome, has a statistically significant increase over time, possibly due to changes in newborn testing requirements for heart defects. Prevalence rates for the remaining 11 birth defects have shown no statistically significant trend over time.

The causes of birth defects are not fully known, and many cannot be prevented; however, there are preventive measures that people of reproductive age can take to increase the chances of having a healthy baby. Support is available for parents and guardians of babies with birth defects through Wisconsin's state and local health departments.

---

## BACKGROUND

A birth defect is defined as a structural deformation, disruption, or dysplasia, or as a genetic, inherited, or biochemical disease.<sup>1</sup> In 2021, birth defects were the leading cause of infant deaths in Wisconsin and nationwide.<sup>2,3</sup> In Wisconsin, nearly 2,000 babies each year are born with birth defects. In the United States, the most common type of birth defects are congenital heart defects (CHDs), which affect about 40,000 births per year.<sup>4</sup> In Wisconsin, hypospadias is more common than CHDs.

We do not know what causes most birth defects; however, we do know that some measures can decrease the chances of a birth defect happening.<sup>5</sup> Birth defects may result from a complex combination of factors. Risk factors include changes in genes or chromosomes, environmental factors, maternal health conditions, use of medications and other substances before and during pregnancy, prenatal infections, and maternal age. Having risk factors does not mean that a baby will have a birth defect. There are preventive measures that people can take to decrease the chances of having a baby with a birth defect, and there are resources and supportive services available in Wisconsin for babies born with birth defects and their families.

## SURVEILLANCE AND DATA SOURCES

Public health surveillance allows us to understand prevalence and monitor trends of birth defects to detect unexpected increases, plan and promote strategies for prevention, refer affected babies and their families to specialized health care services, study risk factors, and help policymakers allocate resources and services.<sup>6</sup> In addition, surveillance data can be used to research causes of birth defects.

The Wisconsin Environmental Health Tracking Program (Wisconsin Tracking) conducts surveillance on 12 birth defects: anencephaly, spina bifida, hypoplastic left heart syndrome, transposition of the great arteries, tetralogy of Fallot, cleft lip with cleft palate, cleft lip alone, cleft palate alone, gastroschisis, limb deficiencies, hypospadias, and trisomy 21 (Down syndrome). The program tracks these 12 conditions because they are fatal, lifelong, or require urgent medical intervention, and because we have reliable data collected.

Wisconsin Tracking has access to a variety of data sources used to track and analyze birth defects. These sources include vital records and hospital discharge records.

Data from vital records and hospital discharge records are summarized to create biennial reports for the Centers for Disease Control and Prevention (CDC). Birth defects are collected from these records using the International Classification of Diseases, Tenth Revision (ICD-10) with specifications set by the National Birth Defects Prevention Network (NBDPN). Following standardized specifications allows for comparisons to be made between states in the U.S.



The Wisconsin Birth Defects Prevention and Surveillance Program is working to establish and populate the Wisconsin Birth Defects Registry (WBDR) as another potential source of data which may improve birth defects surveillance in the future. The WBDR is mandated by Wis. Stat. § 253.12 to collect demographic, diagnostic, risk factor, and identifying information for children from birth to two years of age for 64 conditions.<sup>1</sup> These data are reported by pediatric specialty clinics, physicians who diagnose or treat birth defects, and hospitals. Reports to the WBDR contain identifying information, which enhances birth defect surveillance data. However, parents or guardians can request that identifying information (i.e., names and addresses) be removed from the WBDR at any time.<sup>7</sup>

## METHODS

We analyzed the prevalence rates of the 12 birth defects and their trends during 2008–2021 using Wisconsin surveillance data from the sources described above. Due to the small numbers, the data were grouped in 5-year groups and rolling averages are presented. We calculated the prevalence rates by dividing the number of diagnosed birth defects by the total number of children born during each interval of time. To statistically analyze the trends, we conducted the Mann-Kendall trend test.<sup>8</sup> The result of the Mann-Kendall test is a p value, which is the probability that a trend in the data is due to random chance. A low p value means that it is unlikely that a trend observed in the data is due to chance. We considered a p value that was <0.05 to be statistically significant, which means that there is less than a 5% probability that the trend observed in the data is due to chance.

## RESULTS

The following sections describe each of the 12 birth defects that Wisconsin Tracking monitors, including prevalence rates and associated trends during 2008–2021.



## Neural tube defects

Neural tube defects occur when the neural tube, which forms the early brain and spine, does not close properly. Wisconsin Tracking conducts surveillance on two neural tube defects—anencephaly and spina bifida (without anencephaly).

**Anencephaly** is a serious birth defect in which a baby is born without parts of their brain and skull. It occurs when the upper part of the neural tube does not close all the way and parts of the brain are not covered by bone or skin. Almost all cases of anencephaly are fatal.

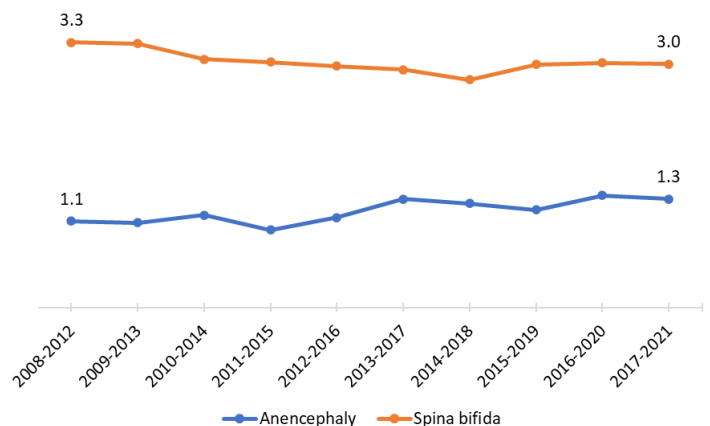
Rate: 1.3 babies per 10,000 live births  
Trend: No statistically significant trend

**Spina bifida (without anencephaly)** is a neural tube defect of the spine, where part of the meninges (membranes covering the spine), spinal cord, or both, protrude through an opening in the vertebral column. The defect can occur in the cervical, thoracic, lumbar, or sacral regions of the spine and can involve open or closed lesions. Spina bifida can cause a range of physical and intellectual disabilities.

Rate: 3.0 babies per 10,000 live births  
Trend: No statistically significant trend

Prevalence rates of anencephaly and spina bifida in Wisconsin have remained stable since 2008, as shown in Figure 1.

**FIGURE 1. Rolling average number of babies affected by select neural tube defects per 10,000 live births, Wisconsin, 2008–2021.**





## Heart defects

Wisconsin Tracking conducts surveillance on three heart defects: hypoplastic left heart syndrome, tetralogy of Fallot, and transposition of the great arteries. These three conditions are considered critical congenital heart defects. They are detected at birth during the newborn's pulse oximetry (or pulse ox) screening, which is a routine, non-invasive, and painless test. Since July 3, 2014, the pulse ox screening has been a requirement for all newborns prior to discharge from the hospital as part of Wisconsin's Screening Hearts in Newborns (SHINE) program.<sup>3</sup> The severity of these conditions means that they all require immediate surgery or treatment.

**Hypoplastic left heart syndrome** occurs when structures on the left side of the heart do not fully develop, which affects normal blood flow through the heart. Babies with hypoplastic left heart syndrome may experience difficulties breathing, a weak pulse, or have a bluish skin color.

Rate: 3.0 babies per 10,000 live births

Trend: Statistically significant increasing trend

**Tetralogy of Fallot** is a condition made up of four defects of the heart and its blood vessels, limiting the amount of oxygen in the blood that is distributed to the body. These heart changes cause oxygen in the blood to be reduced and can cause infants to have a bluish skin color, especially while crying or feeding.

Rate: 3.2 babies per 10,000 live births

Trend: Increasing trend but not statistically significant

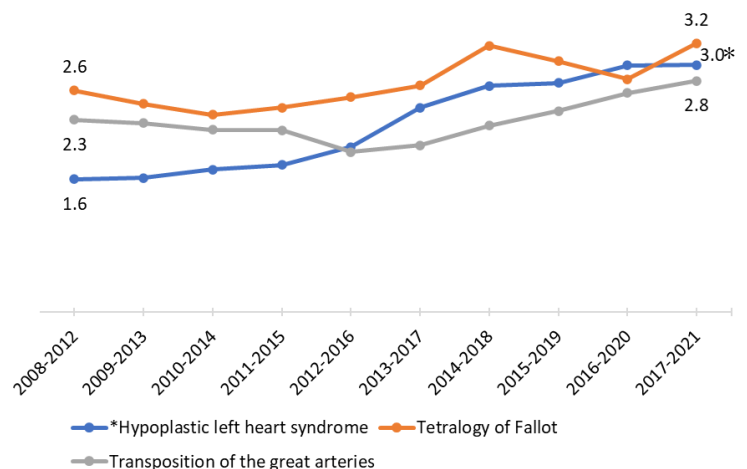
**Transposition of the great arteries** is a condition in which the positions of the two main arteries of the heart (the pulmonary artery and the aorta) are switched. Transposition of the great arteries prevents oxygen-rich blood from getting distributed throughout the body, which can cause breathing problems, weak pulse, bluish skin, and poor feeding in babies.

Rate: 2.8 babies per 10,000 live births

Trend: Increasing trend but not statistically significant

The prevalence of these heart conditions has increased over time in Wisconsin, and a statistically significant increase is seen in hypoplastic left heart syndrome ( $P = 0.009$ ) as shown in Figure 2. One likely reason for the increase is the requirement of newborn pulse ox screening, starting in 2014. With more screening tests taking place now, more heart conditions are being identified and diagnosed.

**Figure 2. Rolling average number of babies affected by select heart defects per 10,000 live births, Wisconsin, 2008–2021. Asterisk (\*) indicates statistically significant trend ( $P < 0.05$ ).**



## Orofacial defects

Wisconsin Tracking conducts surveillance on three orofacial defects: cleft lip with cleft palate, cleft lip alone, and cleft palate alone.

A **cleft lip** is a partial or complete fissure or opening in the upper lip, while a **cleft palate** is an opening on the roof of the mouth that can affect the soft and hard palate or only the soft palate. These birth defects occur when a baby's lip or mouth does not form properly during pregnancy. A baby can be born with a cleft lip, a cleft palate, or both. Babies born with these birth defects may have problems feeding, be more susceptible to ear infections, or have problems with their teeth. They can also have problems speaking, which in turn, can impact hearing. Surgery and additional procedures are needed to repair a cleft lip and cleft palate.

Rates: 5.4 babies per 10,000 live births have a cleft lip with cleft palate,

3.0 babies per 10,000 live births have a cleft lip alone, and

6.3 babies per 10,000 live births have a cleft palate alone.

Trends: No statistically significant trends in any of the three monitored orofacial defects

Prevalence rates of cleft lip and/or cleft palate in Wisconsin have remained stable since 2008 as shown in Figure 3.

## Genitourinary Defects

Wisconsin Tracking conducts surveillance on one genitourinary defect—hypospadias.

**Hypospadias** is a condition in male babies where the opening of the urethra is not located at the tip of the penis. This is due to the abnormal formation of the urethra during the beginning of pregnancy. Complications of hypospadias may include abnormal urination and undescended testicles. Most cases of hypospadias will need surgery to correct the defect.

Rate: 69.5 male babies per 10,000 male live births

Trend: No statistically significant trend

Prevalence rates of hypospadias in Wisconsin have remained stable since 2008, as shown in Figure 4.

Figure 3. Rolling average number of babies affected by select orofacial defects per 10,000 live births, Wisconsin, 2008–2021.

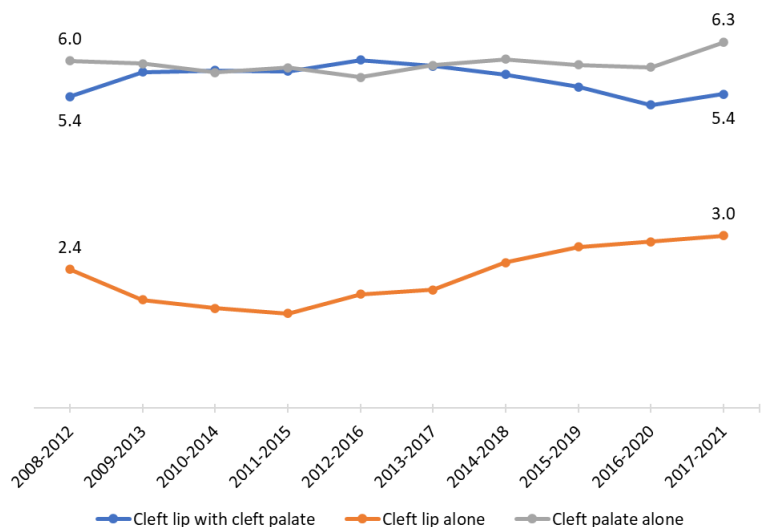
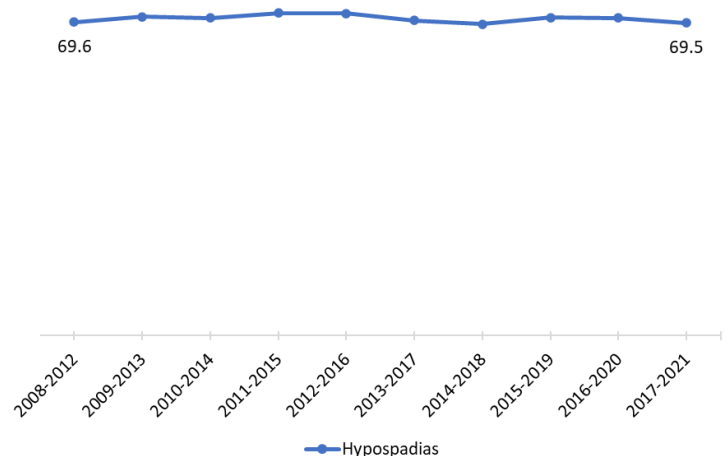


Figure 4. Rolling average number of male babies affected by hypospadias Per 10,000 male live births, Wisconsin, 2008–2021.



## Musculoskeletal defects

Wisconsin Tracking conducts surveillance on two musculoskeletal defects—gastroschisis and limb deficiencies.

**Gastroschisis** is a condition in which the muscles of the baby's stomach do not form correctly, causing a hole in the abdominal wall next to the umbilical cord. A baby with gastroschisis is born with their intestines outside of their body, requiring surgery soon after birth. Surveillance data for gastroschisis first became available in 2010.

Rate: 3.9 babies per 10,000 live births  
Trend: Decreasing trend but not statistically significant

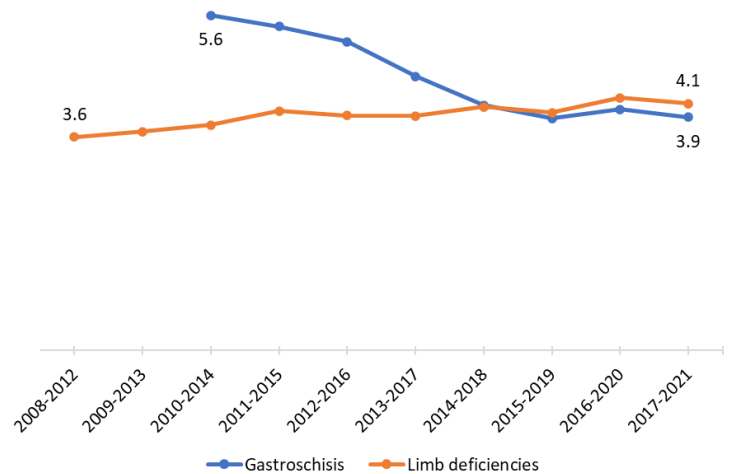
Gastroschisis data were made available beginning in 2010. Gastroschisis prevalence rates have decreased since then; however, the trend is not statistically significant

**Limb deficiencies** occur when part of or the entire arm or leg fails to form completely during pregnancy. The limb is reduced from its normal size or is missing. Babies and children with limb deficiencies may experience difficulties with motor skills or daily activities like self-care; limitations with certain movements, sports, or activities; and emotional or social issues due to physical appearance. Treatment for limb deficiencies can vary for each baby but can include prosthetics, orthotics, surgery, or rehabilitation.

Rate: 4.1 babies per 10,000 live births  
Trend: No statistically significant trend

Prevalence rates of limb deficiencies in Wisconsin have remained stable since 2008.

**Figure 5. Rolling average number of babies affected by select musculoskeletal defects per 10,000 live births, Wisconsin, 2008–2021.**





## Chromosomal defects

Wisconsin Tracking conducts surveillance on one chromosomal defect—Trisomy 21, also known as Down syndrome.

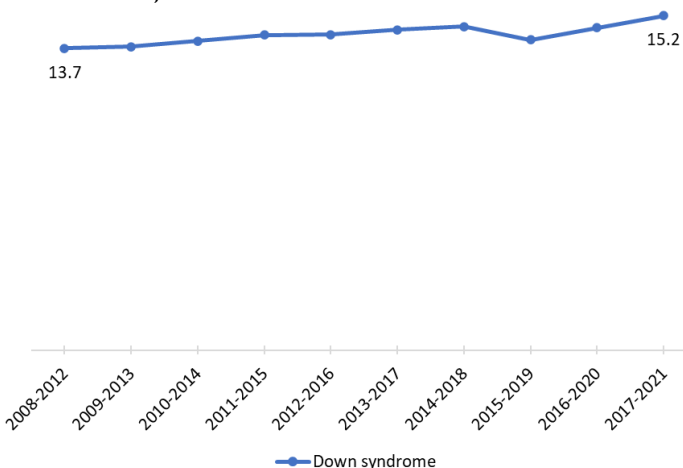
**Down syndrome** is a condition in which a baby is born with an extra copy of chromosome 21, which changes how the body and brain develop. Symptoms of Down syndrome can range from mild to severe. Usually, mental and physical development are slower in people with Down syndrome than in those without it.<sup>9</sup> Babies with Down syndrome often experience additional birth defects or other health conditions. It is the most diagnosed chromosomal condition in the United States. Down syndrome is a lifelong condition; however, services in early life, like speech, occupational, and physical therapy, can help people with Down syndrome to develop to their full potential.

Rate: 15.2 babies per 10,000 live births

Trend: No statistically significant trend.

Prevalence rates of Down syndrome in Wisconsin have slightly increased since 2008; however, the trend is not statistically significant, as shown in Figure 6.

**Figure 6. Rolling average number of babies affected by down syndrome per 10,000 live births, Wisconsin, 2008–2021.**



## PREVENTION AND SUPPORT

Not all birth defects can be prevented; however, there are measures that can be taken before and during pregnancy to decrease the chances of having a baby with a birth defect such as:

- Eating a healthy diet with vitamin B9 (folate) and taking folic acid supplements daily.** Vitamin B9, or folate, helps a baby's brain and spinal cord develop properly. Folate is found in foods such as soybeans, lentils, asparagus, spinach, and broccoli.<sup>10</sup> People of reproductive age should take a vitamin that contains folic acid, which is a synthetic form of folate. The recommended daily amount of folic acid is 400 micrograms; however, the recommendation is 4,000 micrograms of folic acid for people who have had a baby with a neural tube birth defect in the past. People trying to become pregnant are advised to start taking folic acid supplements at least one month prior to trying to conceive because it can help prevent neural tube defects that occur in the first weeks of pregnancy. Most prenatal vitamins contain folic acid. In Wisconsin, Medicaid fully covers prescription prenatal vitamins that contain folic acid for all women ages 12 to 60 regardless of pregnancy status.
- Connecting with prenatal care early and throughout pregnancy.** Prenatal care is medical care received while pregnant. Prenatal care often includes education in reducing the risk of birth defects, developing a delivery plan, and discussing ways to have a healthy pregnancy. Prenatal care providers can advise expecting parents about safe medications, vaccinations, managing chronic conditions, and other prenatal care to help maximize the health of parent and baby. (List continued on the next page.)



- **Staying up to date on vaccinations and taking steps to prevent other infections.** Vaccines help prevent and protect both the pregnant person and baby from serious illness.<sup>11</sup> Expecting parents can also learn about non-vaccine preventable diseases such as Zika, listeriosis, and toxoplasmosis and how to take precautions to limit their risks of contracting these infections during pregnancy.<sup>12</sup> Read [10 Tips for Preventing Infections Before and During Pregnancy](#).
- **Avoiding harmful substances, such as tobacco, alcohol, and other drugs.** [Wisconsin Addiction Recovery Helpline](#) is a free resource available 24/7 to connect people to local services and support.
- **Getting tested for sexually transmitted infections (STIs).** STIs are infections that are spread from one person to another, usually during sex. Untreated STIs during pregnancy can cause a variety of issues including premature birth, infection after birth, and birth defects.<sup>13</sup> CDC is sounding the alarm on cases of newborn syphilis, which have increased tenfold over the last 10 years. Newborn syphilis can usually be prevented with timely testing and treatment during pregnancy. The shocking increase of this highly preventable infection is likely due to barriers to high-quality prenatal care and ongoing declines in resources for prevention and treatment.<sup>14</sup>



## CONCLUSION

Surveillance of birth defects is an important and regular function of the Wisconsin Department of Health Services and Wisconsin Tracking. Available data comes from vital records and hospital discharge records. In Wisconsin, the prevalence of most of these birth defects has remained steady over time; however, hypoplastic left heart syndrome had a statistically significant increasing trend, possibly due to a screening requirement implemented in 2014. Continued research and surveillance of birth defects can help us develop better recommendations and policies to prevent them in the future.

Although the causes of birth defects are not fully known and many cannot be prevented, there are recommendations that can increase the chances of having a healthy baby. The Wisconsin Department of Health Services also offers several resources and services for babies with birth defects.

## RECOMMENDED RESOURCES

Listed below are several resources to support and connect babies and their families to services throughout the state:

[Wisconsin Medicaid and BadgerCare Programs for Pregnant People](#)

[Waisman Center](#)

[Wisconsin Genetic Systems Integration Initiative](#)

[Well Badger Resource Center](#)

[Children's Resource Centers](#)

[Wisconsin Wayfinder](#)

Additional regional resources are available. Connect with your [local health department](#) to find additional supportive services.

## MORE INFORMATION

[Environmental Public Health Tracking: Birth Defects Data](#)

[Birth Defects | CDC](#)

[Birth Defects and Your Baby | March of Dimes](#)

[Birth Defect Prevention and Surveillance](#)

[Children's Resource Centers](#)

[Newborn Screening Program](#)

[COVID-19 and Pregnancy](#)

[Wisconsin birth outcomes data resource](#)



## REFERENCES

1. Birth defect prevention and surveillance system. Wisconsin legislature: §253.12. Available from: <https://docs.legis.wisconsin.gov/statutes/statutes/253/12>
2. Centers for Disease Control and Prevention (CDC). 2023. Infant mortality. Available from: <https://www.cdc.gov/reproductivehealth/maternalinfanthealth/infantmortality.htm>
3. Wisconsin SHINE Project. 2021. University of Wisconsin. Available from: <https://wisconsinshine.org/>
4. Wisconsin Dept. of Health Services, Division of Public Health, Office of Health Informatics. Wisconsin Interactive Statistics on Health (WISH) data query system, <https://www.dhs.wisconsin.gov/wish/index.htm>, Infant Mortality Module, accessed 11/14/2023.
5. Birth defect prevention and surveillance. Wisconsin Department of Health Services. 2023. Available from: <https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm>
6. Centers for Disease Control and Prevention (CDC). 2022. State-based birth defects tracking systems. Available from: <https://www.cdc.gov/ncbddd/birthdefects/states/index.html>
7. Confidential Birth Defects Registry - request to remove identifiers. Wisconsin Department of Health Services. Available from: <https://www.dhs.wisconsin.gov/library/collection/f-40054a>
8. Glen, Stephanie. 2021. Mann Kendall trend test: Definition, running the test. Statistics How To. Available from: <https://www.statisticshowto.com/mann-kendall-trend-test/>
9. Centers for Disease Control and Prevention (CDC). 2023. Data and statistics on Down Syndrome. Available from: <https://www.cdc.gov/ncbddd/birthdefects/downsyndrome/data.html>
10. Whitbread, D. 2023. Top 10 foods highest in vitamin B9 (folate). MyFoodData. Available from: <https://www.myfooddata.com/articles/foods-high-in-folate-vitamin-B9.php>
11. Immunizations: Expecting a baby? Wisconsin Department of Health Services. 2022. Available from: <https://www.dhs.wisconsin.gov/immunization/parents.htm>
12. Centers for Disease Control and Prevention (CDC). 2022. 10 tips for preventing infections before and during pregnancy. Available from: <https://www.cdc.gov/pregnancy/infections.html>
13. Wisconsin Department of Health Services, Wisconsin STD Program. Sexually transmitted diseases (STD). Available from: <https://www.dhs.wisconsin.gov/std/index.htm>
14. Centers for Disease Control and Prevention (CDC). 2023. U.S. Syphilis Cases in Newborns Continue to Increase: A 10-Times Increase Over a Decade. Available from: <https://www.cdc.gov/media/releases/2023/s1107-newborn-syphilis.html>

## ACKNOWLEDGEMENTS

The authors would like to thank Wendy Fall for her contributions to this surveillance brief. The Wisconsin Environmental Public Health Tracking Program is funded by the Centers for Disease Control and Prevention.

## Wisconsin Environmental Public Health Tracking Program

phone | 608-267-2488

web | [dhs.wisconsin.gov/epht](https://dhs.wisconsin.gov/epht)

email | [dhstracking@wi.gov](mailto:dhstracking@wi.gov)

