



State of Wisconsin  
Department of Health Services

Tony Evers, Governor  
Karen E. Timberlake, Secretary

July 15, 2022

The Honorable Patrick Testin, Chair  
Senate Committee on Health  
Room 8 South, State Capitol  
PO Box 7882  
Madison, WI 53707

The Honorable Joe Sanfelippo, Chair  
Assembly Committee on Health  
Room 314 North, State Capitol  
PO Box 8953  
Madison, WI 53708

The Honorable Andre Jacque, Chair  
Senate Committee on Human Services,  
Children and Families  
Room 7 South State Capitol  
PO Box 7882  
Madison, WI 53707

The Honorable Patrick Snyder, Chair  
Assembly Committee on Children and  
Families  
Room 307 North State Capitol  
Madison, WI 53708

Dear Senators and Representatives:

I am pleased to submit the 2022 Wisconsin Birth Defect Prevention and Surveillance Program Biennial Report as required by Wis. Stat. § 253.12(4)(d). The report identifies surveillance activities and programmatic strategies that are critical to improving birth outcomes and the health of all children in Wisconsin.

Birth defects are a substantial cause of infant mortality and childhood morbidity. In addition, these conditions have a significant financial impact on the child and family, as well as on the service system of care, schools, and community. It is essential to have accurate, population-based data to assess needs, plan interventions, and evaluate outcomes for prevention strategies, supportive services, and resources for families who have a child with a birth defect.

Since 2004, the Wisconsin Birth Defects Registry (WBDR) collected information on 87 selected birth defects diagnosed in children from birth to age 2. Between mid-2004 and the end of 2019, 28,888 birth defects were reported to the WBDR, with cardiovascular birth defects being the most common.

The Wisconsin Department of Health Services continues to focus on facilitating reporting through efficient data exchanges to improve compliance with the statute and completeness of the reports. The WBDR was moved into the Wisconsin Electronic Disease Reporting System (WEDSS) in 2020. WEDSS is a secure, web-based system that is used by health care providers, laboratory staff, and local health department staff throughout the state for a variety of health conditions.

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The report details the effectiveness, utilization, and progress of the WBDR; work of the Council; and a summary of prevention and intervention strategies to decrease the occurrence of birth defects, including referral for early intervention initiatives that improve child health outcomes and access to services.

Sincerely,

A handwritten signature in cursive script, appearing to read "Karen E. Timberlake", enclosed in a thin rectangular border.

Karen E. Timberlake  
Secretary-designee



## WISCONSIN BIRTH DEFECT PREVENTION AND SURVEILLANCE PROGRAM

In support of the Department's  
VISION

Everyone living their best life; and  
MISSION

To protect and promote the health and safety of the people of Wisconsin

### 2022 Report to the Legislature

The work of the Wisconsin Birth Defect Prevention and Surveillance Program (WBDPSP) focuses on the three public health core functions of assessment, assurance, and policy development in conjunction with the following requirements set out in statute.

1. Maintain an up-to-date birth defects registry that documents the diagnosis in Wisconsin of any infant or child who has a birth defect, regardless of residence that facilitates:
  - The identification of risk factors.
  - The investigation of the incidence, prevalence, and trends of birth defects using epidemiologic methods.
  - The development of primary prevention strategies to decrease the occurrence of birth defects.
  - Referrals for early intervention and other appropriate services.
2. Support an advisory council on Birth Defect Prevention and Surveillance responsible for determining the listing of reportable birth defects through unanimous vote.
3. Outline the reporting methodology requirements for data quality and establish the reporting requirements for reporters.
4. Protect the confidentiality of children born with birth defects and their families through administrative assurances.

### CURRENT STATUS OF THE BIRTH DEFECTS REGISTRY

The Wisconsin Birth Defect Prevention and Surveillance Program is required to maintain a birth defects registry of diagnosed birth defects of any Wisconsin child age birth to two years, born in Wisconsin and/or receiving health care services in Wisconsin per Wis. Stat. § 253.12. The Wisconsin Birth Defects Registry (WBDR) is a secure, web-based system that allows pediatric specialty clinics and physicians to report either one child with a birth defect at a time or upload a batch report of birth defects. Reporters may also submit a paper form to the WBDR state administrator for inclusion in the WBDR. The WBDR collects information on the child and parents, the birth, referral to services, and diagnostic information for one or more of 87 reportable conditions. The current list is available on the last page of the paper reporting form ([F-40054](#)).

Diagnosing and/or treating providers and pediatric specialty clinics are required reporters, while hospitals may report. In practice, clinics or health care systems often submit reports for multiple

physicians, clinics, and hospitals. Since 2004, when the Department of Health Services (DHS) piloted a process allowing organizations to electronically upload multiple reports through a batch report upload, organizations such as Marshfield Clinic, SSM Health Dean Medical Group, Children's Hospital of Wisconsin, and UW Health Foundation have utilized the electronic upload option.

The 2017 Biennial Budget Bill (2017 Wisconsin Act 59), enacted on September 22, 2017, made significant changes to the WBDR and reporting, allowing the program to better understand the prevalence of birth defects in Wisconsin. The new language improved the information in the registry by making the program reporting an opt-out versus an opt-in. This means that reports to the WBDR contain identifiers including name and address of the child. However, parents or guardians can request identifying information be removed from the WBDR at any time. This is consistent with other newborn screening applications administered by DHS.

Overall, this change:

- Allows linkage of the data to other data sets including vital records.
- Helps determine if the number and type of certain birth defects present are increasing or decreasing.
- Assures unduplicated counts of children identified with a birth defect(s).
- Facilitates appropriate referral to services and resources.
- Provides insight into what prevention and early intervention activities are warranted and effective.
- Helps identify environmental risk factors that may be responsible for certain birth defects or contribute to clusters of birth defects in a particular area of the state.

During 2019, the WBDPSP reviewed options for enhancing the WBDR in order to improve functionality for reporters. The program determined that the best solution would be to add the WBDR as a module to an existing DHS system called Wisconsin Electronic Disease Surveillance System (WEDSS). WEDSS is a secure, web-based system that is used by health care providers, laboratory staff, and local health department staff throughout the state for a variety of conditions. Reporting options for WBDR remain the same. For providers reporting an occasional case, they can either enter each case manually into WEDSS or complete the paper reporting form. For providers and clinics that report on a larger number of cases, there is an option to report through a batch upload. System testing was conducted in early 2020 and it went live in April 2020.

Unfortunately, the timing of the system going live coincided with the start of the global COVID-19 pandemic, impacting the ability of reporters to start reporting and shifting the information technology staff away from supporting WBDR, as WEDSS is also the system collecting COVID-19 case data. Some healthcare systems were able to start reporting, but problems were quickly identified regarding system functionality causing data collection to be put on hold until information technology staff can make the appropriate changes.

In Wisconsin, there were 355 babies born in 2019 with one or more birth defects that were reported to the WBDR. However, this is less than the expected 1 in 33 babies born with birth defects in the United States, according to the Centers for Disease Control and Prevention (CDC). This represents not only a significant gap in understanding the prevalence of birth defects, but also the WBDPSP's ability to provide the necessary family support and services, as well as outreach, education, and prevention activities. However, once necessary fixes are made in the new system and data collection resumes, data quality and completeness will improve.

A notice of funding opportunity, Advancing Population-Based Surveillance of Birth Defects, was released by the CDC on October 6, 2020. The WBDPSP developed and submitted an application and, while it scored well, it was approved but not funded. The focus of the WBDPSP grant application was to strengthen the WBDR through implementation of case-verification, which would have greatly improved data quality and surveillance capacity. In addition, the application included support for two FTE staff dedicated to birth defects prevention and surveillance. The application also included an optional component, which focused on collaborating with the Wisconsin Newborn Screening Program on the timing and method of detection for critical congenital heart defects. Reviewer comments were primarily positive, however, the main weaknesses noted by the reviewers are included below. The WBDPSP will pursue the funding again when the opportunity is released, but it is not expected to be out until late in 2025.

- Data prior to 2017 are lacking in completeness due to opt-in consent requirement, limiting ability to assess trends over time.
- The WBDR does not collect information on terminations and, while the Division of Public Health does, it does not include identifiable information or a reason for termination.
- Given the goals expressed in the application, the applicant may need more than two dedicated staff members to complete project aims.
- The applicant does not indicate personnel costs for non-dedicated staff, which indicates that those individuals would have to assist this project on top of their other duties.

## HOW SERIOUS ARE BIRTH DEFECTS IN WISCONSIN?

Babies born with birth defects are often born premature and have a greater chance of illness and long-term disability than babies born without birth defects.<sup>1</sup> Birth defects are caused by a variety of different factors: genetic processes; environmental exposures; infections; obesity; and the use of alcohol, tobacco, and/or prescription or non-prescription substances. Some birth defects appear as multifactorial, with genetic predisposition, plus environmental triggers. However, the cause of approximately 80 percent of birth defects remains unknown.<sup>2</sup>

In Wisconsin, approximately 2,000 infants are born with a birth defect each year, impacting three percent of all births.<sup>3,4</sup> In addition, birth defects are the second leading cause of all infant deaths in Wisconsin, accounting for approximately 80 deaths per year.<sup>5</sup> From 2016–2020 birth defects were the leading cause of death among children born to Laotian/Hmong families (23 per 10,000 live births) and white families (12 per 10,000 live births).<sup>6</sup> While birth defects were the third leading cause of death among black (18 per 10,000 live births) and Hispanic families (12 per 10,000 live births).<sup>7</sup> For infants born with a birth defect, survival is poorer among babies born to black or Hispanic families, compared to babies born to non-Hispanic white families.<sup>8</sup> While the causes of these disparities are not fully understood, it is likely that structural racism contributes through lack of access to primary and preventive healthcare among historically marginalized communities, as well as insufficient and not culturally-relevant pre- and post-natal care, and chronic stress.

The estimated annual cost of birth defect-associated hospitalizations (for patients affected by a birth defect regardless of their age) in Wisconsin is **\$386 million**.<sup>9</sup> Preventing birth defects is an important step in addressing these costs. However, because the cause of so many birth defects are unknown, investing in early intervention and long-term support and case management for these families is

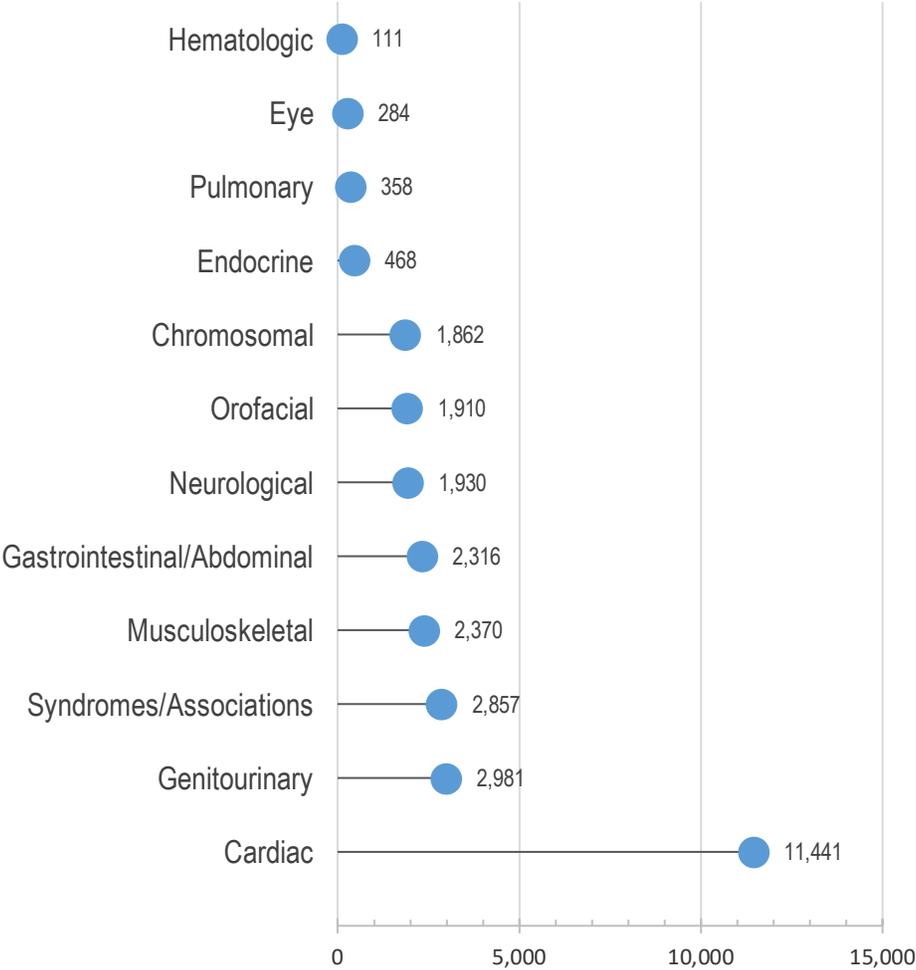
crucial. In addition, investing in a robust birth defects registry is critical in order to investigate the prevalence, trends, risk factors, and causes of birth defects.

### Birth Defect Trends in Wisconsin

Between mid-2004 and the end of 2019, 28,888 birth defects were reported to the WBDR. The graph below shows that cardiovascular birth defects are the most commonly reported birth defects in Wisconsin.

### Wisconsin Birth Defects Registry 2004-2019

Count of birth defects reported by condition category



### WHAT IS THE PURPOSE OF BIRTH DEFECTS SURVEILLANCE?

To prevent birth defects, it is important to know the cause of birth defects. To identify causes, researchers and analysts need to know the frequency of individual birth defects and need to compare the occurrence of specific birth defects to the presence of potential causative factors. Ongoing, real-time collection of birth defect data is needed to continually assess whether the occurrence of birth defects is increasing, decreasing, or staying the same overall and whether individual birth defects are clustered in a particular geographic area or population. A core list of birth defects is reported annually to the National Birth Defect Prevention Network (NBDPN) and used to report on national birth defect

prevalence and trends. The CDC cites birth defect surveillance systems as a leading contributor to reducing birth defects.

## **HOW IS WISCONSIN WORKING TO ADDRESS BIRTH DEFECTS?**

Support for the WBDPSP is provided through two 0.25 full time equivalent (FTE) employees with the Maternal and Child Health (MCH) Title V, Children and Youth with Special Health Care Needs (CYSHCN) Program. In addition, an information system specialist provides technical support for the WBDR. Following the recommendations of the [NBDPN](#), it has been identified that for a basic and fully functional birth defects surveillance system to meet all current legislative requirements would require at least 2.0 FTE.

## **PREVENTION AND EARLY INTERVENTION INITIATIVES FUNDED BY WBDPSP**

### **Women, Infants, and Children (WIC) Nourishing Special Needs Network Workforce Development Training and Mentorship Program (WIC-NSNN)**

The WIC-NSNN is a collaborative professional workforce development quality improvement initiative developed by the Wisconsin CYSHCN Program, the WBDPSP, the Waisman Center, and the Wisconsin Special Supplemental Nutrition Program for Women, Infants and Children to build nutrition services capacity, including case management and information, for the identification, intervention, and referral of infants and children participating in WIC that are diagnosed with birth defects. During 2021, WIC-NSNN presented on nutrition management for children with birth defects or other special health care needs at two conferences, as well as at their annual meeting.

As of 2021, WIC-NSNN sites currently serve 25 percent of the Wisconsin statewide WIC client caseload. Continual growth to other WIC agencies is essential to help meet access to service needs for this population. The current participating WIC agencies serve over 15,000 children, of which approximately 3,000 have special health care needs, including an estimated 450 with birth defects.

The WIC-NSNN provides:

- Training, technical assistance, and educational outreach programs for WIC dietitians throughout Wisconsin who chose to participate. Over 30 WIC dietitians have participated.
- Collaboration with health care providers and newborn screening specialty clinics to ensure documentation for the provision of special infant and pediatric formulas through WIC and for Medicaid reimbursement of nutritional products.

### **Stillbirth Services through the Children’s Health Alliance of Wisconsin (CHAW) Infant Death Center**

Through an integrative contract objective to assure statewide availability of bereavement and counseling services, CHAW Infant Death Center collaborates on several projects to include opportunities and strategies to form common messaging, promote grief and bereavement materials, assure information and referral to supportive services, and distribute resources statewide on stillbirths, [www.chawisconsin.org/grief-resources](http://www.chawisconsin.org/grief-resources). This program has been presented at the Wisconsin Association for Perinatal Care, Wisconsin Public Health Association, and the NBDPN meeting obtaining a blue ribbon for most innovative program.

### **Folic Acid Awareness: Survey and Module to Address Prevention of Neural Tube Defects**

Biennially, Wisconsin includes a folic acid module in the Behavioral Risk Factor Survey. The folic acid module assesses awareness of why folic acid is recommended, consumption of multi-vitamins and supplements containing folic acid, and frequency of taking those vitamins or supplements. According to the most recent data from 2018-2020, about 30 percent of non-pregnant women ages 18 to 44 years take folic acid and 26 percent reported that they take it daily. Overall, about 39 percent of non-pregnant women ages 18 to 44 know why women should take folic acid. However, women were significantly more likely to take folic acid and to take it daily if they knew why it was recommended.

Data regarding folic acid use before and during pregnancy are captured through the Wisconsin Pregnancy Risk Assessment Monitoring System (PRAMS). Prior to 2015, Wisconsin Medicaid would only pay for folic acid-containing vitamins and supplements for pregnant women. However, as of May 2015 all Wisconsin women between the ages of 12 and 60 can receive prenatal vitamins for free through a prescription from their doctor regardless of pregnancy status. This is essential since neural tube defects occur very early in pregnancy and folic acid has been shown to have a significant protective factor against this. PRAMS data were used in a difference-in-differences analysis to determine the effect of the policy change. A significant difference was found in pre-pregnancy folic acid use among Medicaid enrolled women compared to privately insured women initially following the policy change. However, when the full time period was assessed, the change was not statistically significant. This indicates that policy change alone may not result in long-term change in provider or public behavior. The findings were presented as a poster at the NBDPN annual meeting and received a blue ribbon.

The WBDPSP began discussions in 2021 to implement a birth defects prevention education campaign in collaboration with the Wisconsin Women's Health Foundation, Well Badger Resource Center. The social media campaign will provide educational messaging regarding folic acid along with other topics related to birth defects, such as substance use during pregnancy, prenatal care access, medication management during pregnancy, maintaining a healthy weight during pregnancy, and vaccinations during pregnancy. The campaign planning and pilot will take place the first six months of 2022, with the full project implemented in July 2022 through June 2023.

### **Children and Youth with Special Health Care Needs Regional Centers**

To ensure access to services, the CYSHCN Program contracts with five regional centers for children and youth with special health care needs in Wisconsin:

- Northeastern Regional Center for CYSHCN, Children's Hospital of Wisconsin-Fox Valley
- Northern Regional Center for CYSHCN, Marathon County Health Department
- Southeastern Regional Center for CYSHCN, Children's Hospital of Wisconsin-Milwaukee
- Southern Regional Center for CYSHCN, University of Wisconsin-Waisman Center
- Western Regional Center for CYSHCN, Chippewa County Department of Public Health

Each CYSHCN Regional Center is dedicated to supporting families with children and youth with special health care needs (including children born with birth defects) and the providers who serve them. The CYSHCN Regional Centers are staffed by specialists who can answer questions, find services, provide training, and connect providers, families, and youth to community resources. Their services are free and private. Physicians may refer a child with special health care needs to a CYSHCN Regional Center using the [Consent to Release Medical Information Referral form](#) (F-01238). Other resources can be found at [www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm](http://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm).

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- <sup>1</sup> Honein, M. A., Kirby, R. S., Meyer, R. E. et al. (2009). The association between major birth defects and preterm birth. *Maternal Child Health J.*, 13, 164-175.
- <sup>2</sup> Feldkamp, M. L., Carey, J. C., Byrne, J. L., Krikov, S., and Botto, L. D. (2017). Etiology and clinical presentation of birth defects: population based study. *bmj*, 357, j2249.
- <sup>3</sup> Centers for Disease Control and Prevention (CDC). (2008, January 11). Update on Overall Prevalence of Major Birth Defects – Atlanta, Georgia, 1978-2005. *MMWR. Morbidity and Mortality Weekly Reports*. Retrieved from [www.cdc.gov/mmwr/preview/mmwrhtml/mm5701a2.htm](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm5701a2.htm).
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- <sup>5</sup> Ibid.
- <sup>6</sup> Ibid.
- <sup>7</sup> Ibid.
- <sup>8</sup> Wang, Y., et al. (2015). Racial/ethnic differences in survival of United States children with birth defects: a population-based study. *The Journal of Pediatrics*, 166(4), 819-826. Retrieved from <https://doi.org/10.1016/j.jpeds.2014.12.025>.
- <sup>9</sup> Arth, A. C., Tinker, S. C., Simeone, R. M., Ailes, E. C., Cragan, J. D., and Grosse, S. D. (2017). Inpatient hospitalization costs associated with birth defects among persons of all ages – United States, 2013. *MMWR Morb Mortal Wkly Rep* 66:41-46. Retrieved from <http://dx.doi.org/10.15585/mmwr.mm6602a1>