



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Andrea Palm, Secretary

June 18, 2020

Senator Patrick Testin
Senate Committee on Health and Human Services Chair
Room 131 South
State Capitol
Madison, WI 53707

Dear Senator Testin:

I am pleased to send you the 2019 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.

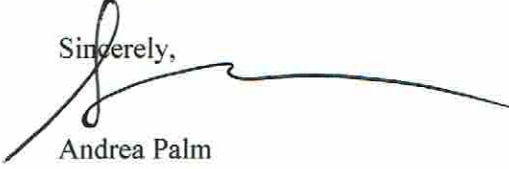
Birth defects are a substantial cause of infant mortality and childhood morbidity. In addition, these conditions have a significant fiscal and financial impact on the child and family, as well as on the service system of care, schools, and community. It is essential to have accurate, population-based 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) has continued to collect information on 87 selected birth defects identified 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 followed by genitourinary and syndromes/associations.

The 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. In September 2017, Wisconsin Act 59 amended § 253.12(4)(d) to require that identifiers be submitted with every report, unless the parent or guardian states in writing their refusal to release names and addresses. Also changed was the method of adding and deleting reportable conditions to the registry so that conditions can be added by unanimous vote by the Council on Birth Defect Prevention and Surveillance. The program addresses these changes by providing new policy and updating materials found at www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm.

The report details the following: the effectiveness, utilization, and progress of the registry; the work of the Council; and a summary of primary prevention and intervention strategies to decrease the occurrence of birth defects, including referral for early intervention initiatives that strengthen birth outcomes, enhance child health outcomes, and facilitate family access to services.

Sincerely,



Andrea Palm
Secretary-designee

Enclosures



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

2019 Report to the Legislature

The Wisconsin Birth Defect Prevention and Surveillance Program (WBDPSP) targets the core functions of public health—assessment, assurance, and policy development—in conjunction with statutory requirements.

1. Maintain an up-to-date birth defects registry that documents the diagnosis completed in Wisconsin of any infant or child who has a birth defect regardless of residence that:
 - Facilitates the identification of risk factors.
 - Assures epidemiology.
 - Provides for primary prevention to help decrease occurrence.
 - Maintains components to educate populations about birth defects and systems.
 - Refers those with birth defects to early intervention and other support 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 WBDPSP is required to maintain a birth defects registry of diagnosed birth defects of any Wisconsin child ranging from 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 one child with a birth defect at a time or upload multiple reports from an electronic medical records system. 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, DPH [F-40054](#)).

Physicians and specialty clinics are required reporters; hospitals maintain a voluntary reporter status. In practice, clinics submit reports for multiple physicians, health care systems, and certain hospitals. Since 2004, when the Department of Health Services (DHS) piloted a process allowing organizations to upload multiple reports from electronic medical records systems, organizations such as Marshfield Clinic, SSM Health Dean Medical Group, Children’s Wisconsin, Gundersen Health System, and the UW Health Foundation utilize the electronic upload option.

The 2017 Biennial Budget, (Assembly Bill 64 - 2017 Wisconsin Act 59) enacted on September 22, 2017, made significant changes to the WBDR and reporting enhancing the program’s ability to better understand the incidence of birth defects in Wisconsin. The new language improves the information in the WBDR 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. Parents or guardians can request that identifying information be removed from the WBDR at any time. This is consistent with the Newborn Screening (NBS) Program applications administered by DHS. [Wisconsin Birth Defects Registry Parent/Guardian Request to Remove Identifiers Form](#) (revised 01/2018) F-40054A; available in multiple languages

Overall this change:

- Allows linkage of the data to other data sets including vital records.
- Determines if the number and type of certain birth defects present are increasing or decreasing.
- Assures unduplicated counts of children identified with 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 lend to clusters of birth defects in a particular area of the state.

In addition, the language maintains strong protections for personal data, maintains data over time, and streamlines the process of adding or removing reportable conditions with the responsibility of annual review and determining the list of conditions charged to the Birth Defect Prevention and Surveillance Council. Once finalized through unanimous vote, the list is forwarded to and maintained by the DHS Secretary. The current list of conditions is available electronically and on the back side of the paper reporting form (DPH [F-40054](#)).

In Wisconsin, there were 355 babies born in 2019 with one or more birth defects that were reported in the registry. However, this is much less than the expected 1 in 33 babies born with birth defects in the U.S., 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 in providing the necessary family supports and services, as well as outreach, education, and prevention activities. However, it is expected that the 2017 changes in the birth defect statute language and enhancements in the WBDR will help mediate this underreporting by ensuring that the incidence of birth defects will be better monitored and tracked, while also addressing the privacy concerns of parents.

Following the statutory change, DHS established several workgroups to assure a smooth transition with full program reporting with implementation beginning July 1, 2018. This work has included developing and providing the necessary forms for providers, assuring parental notification for the option to refuse to release the name and address of the infant or child to the WBDR, a letter from DHS to parents with information regarding referral to help families connect to the five Children and Youth with Special Health Care Needs (CYSHCN) Regional Centers and other referral resources, and fact

sheets about the WBDR for providers and families. All WBDPSP forms, fact sheets, and publications can be accessed at the CYSHCN Program—[Birth Defect Prevention and Surveillance website](#).

During 2019, the WBDPSP reviewed options for enhancing the WBDR 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—the 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 the WBDR remains the same. For providers reporting an occasional case, they can either enter it case by 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 the system was live by April 2020.

In addition, the Council provided direction to DHS to establish a protocol for the Council to follow in determining the criteria policy for reportable conditions; adding or deleting conditions to the condition listing; adding emerging conditions, and establishing a timeline for the review to send the recommendations to the DHS Secretary for maintenance. See forms and the mission and bylaws of the [Council](#).

HOW SERIOUS ARE BIRTH DEFECTS IN WISCONSIN?

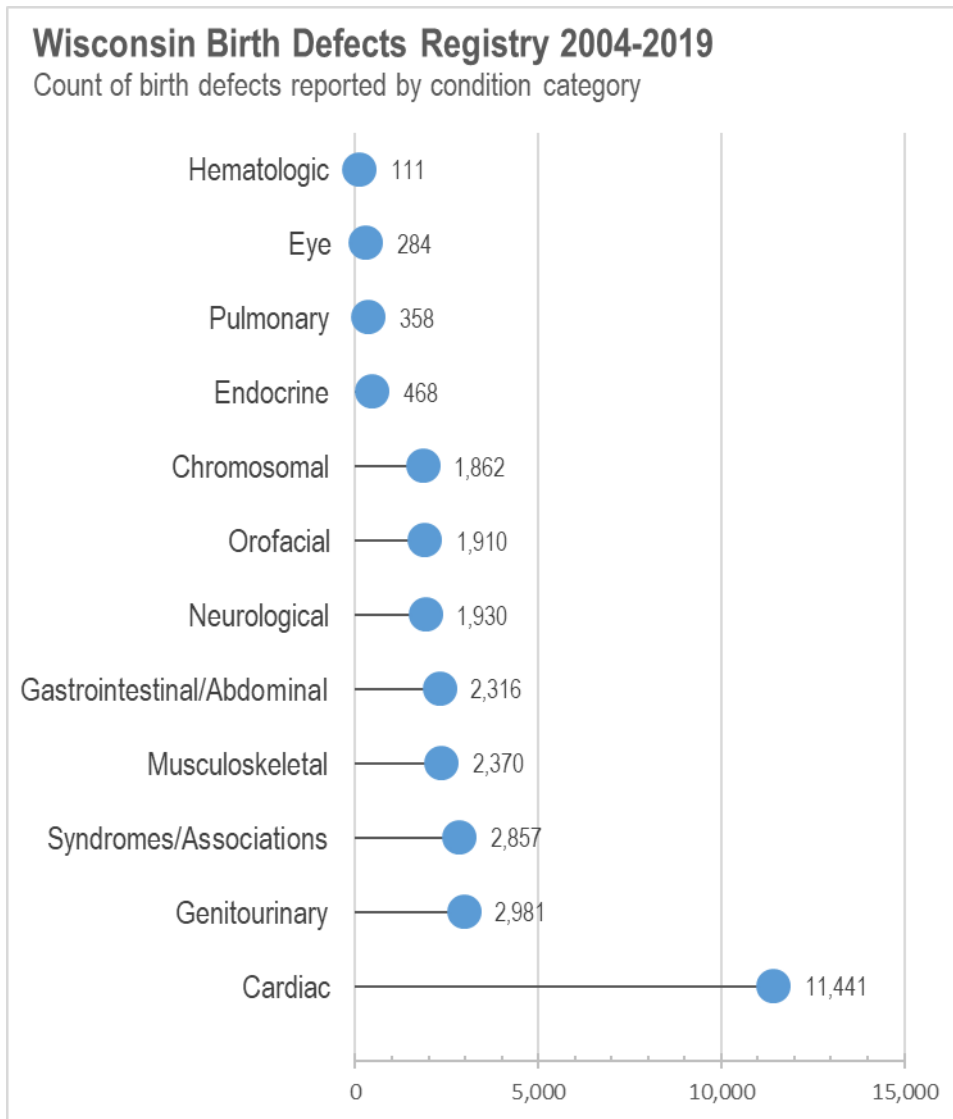
Babies born with birth defects are often born premature and have a greater chance of illness and long-term disability than babies born without birth defects; with birth defects as the fifth leading cause of years of potential life lost.^{5, 6, 8}

Birth defects are caused by a variety of different factors: genetic processes; environmental exposures; infections; obesity; and the use of alcohol, tobacco, prescription medications, and/or illegal drugs. Some birth defects appear as multifactorial, with genetic predisposition, plus environmental triggers. However, the cause of approximately 80% of birth defects remains unknown.⁴

In Wisconsin, approximately 2,000 infants are born with a birth defect each year, impacting 3% of all births.¹ In addition: birth defects are the leading cause of all infant deaths in Wisconsin, accounting for approximately 85 deaths per year.² From 2014-2018, birth defects were the second leading cause of infant death among children born to black mothers (18 per 10,000 live births) and the leading cause of infant death for children born to white mothers (12 per 10,000 live births).² For infants born with a birth defect, survival is poorer among babies born to black or Hispanic mothers, compared to babies born to non-Hispanic white mothers.³ In Wisconsin, the estimated lifetime cost of birth defects for infants born in a given year exceeds **\$140 million**.⁷

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 common followed by genitourinary and syndromes/associations.



WHAT IS THE PURPOSE OF BIRTH DEFECT 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, diminishing, or staying the same overall and whether individual birth defects are clustered in a particular geographic area. 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 incidence 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 FTE time Maternal and Child Health (MCH) Title V CYSHCN staff. In 2018 and continuing into 2019, additional staff, under recent Zika funding were identified to assist with the implementation of the new legislative requirements. However that

support ended in 2019, when grant funding ceased. 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 FTE: a full-time epidemiologist with experience as a data system administrator and a full-time health educator/ outreach specialist with experience in birth defects and/or genetics.

Upon request and completing properly executed data release forms obtained from the WBDR state administrator, researchers studying birth defects may receive summary WBDR reports or specific datasets, per statute. Current surveillance projects supported by the WBDR include:

1. Ongoing participation with the DHS, Division of Public Health, Bureau of Environmental and Occupational Health, in a multi-year “[Environmental Public Health Tracking Program](#)” project funded by the CDC, focusing on tracking birth defects incidence and investigating any relationship between birth defects and environmental hazards.
2. Participation in the DHS Zika virus preparedness work through providing a baseline count of microcephaly and other Zika-associated birth defects cases that are identified in the WBDR. This research enhances and strengthens birth defects surveillance during emerging public health threats impacting MCH. [Zika virus-related activities](#) within the Division of Public Health (DPH) are coordinated among the Bureau of Communicable Diseases, the Bureau of Community Health Promotion, and the Office of Preparedness and Emergency Health Care.
3. Lead surveillance efforts for critical congenital heart disease (CCHD). Beginning in July 2014, DHS added screening for CCHD by pulse oximetry to the Wisconsin NBS Program’s panel of conditions. Every infant born in a hospital is required to have CCHD screening prior to discharge. Babies born out of hospital are also required to be screened. Summary reports of CCHD screening results are issued on a quarterly basis to hospitals, birth centers, and out of hospital providers. These reports identify what percentage of infants born under their care have received appropriate CCHD screening, and compares this with other facilities, and the overall statewide total.

In 2019, 98.3% of all babies born in Wisconsin had either CCHD screening, or a reason for not receiving CCHD screening documented. CCHD requires prompt diagnosis and treatment for the best outcome. Babies with undetected critical congenital heart defects are at risk for sudden death or significant disability. Reportable heart defects identified by CCHD screening are reported to the [WBDR](#).

PREVENTION AND EARLY INTERVENTION INITIATIVES FUNDED BY WBDPSP

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 (WIC) to build nutrition education competency and services capacity (including case management and information and referral) for the identification, intervention, and referral of infants and children in WIC, diagnosed with birth defects.

In 2019, 23% of WIC agencies, including dietitians, participated in the WIC-NSNN. While the number of participating agencies has remained fairly constant, locations have changed and almost half of all of the 72 WIC agencies in the state have had dietitians participate in the WIC-NSNN since it’s inception.

The current participating WIC agencies serve over 15,000 children, of which approximately 3,000 have special needs, including an estimated 450 with birth defects, <https://wic.waisman.wisc.edu/>

The WIC-NSNN provides:

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

Expansion of the WIC-NSNN continues with a structured and evaluative program utilizing best practices in addition to mentoring and peer nutrition consultation models.

The WIC NSNN received state and national attention via multiple presentations and most recently the program was highlighted in the [AMCHP Spring 2018 Pulse Newsletter](#).

Stillbirth Services - Children's Health Alliance of Wisconsin (CHAW) Infant Death Center

Through an integrative contract objective, to assure statewide availability of bereavement and counseling services, the [CHAW Infant Death Center](#) collaborates on several projects to include opportunities and strategies to form common messaging, promote grief and bereavement materials, ensure information and referral to supportive services, and distribute resources statewide on stillbirth. This program continues to be requested for conference breakouts and most recently was awarded a blue ribbon at the NBDPN Annual Meeting for the most innovative program.

With regard to disparities related to infant mortality and support for families in Wisconsin, the CHAW Infant Death Center and the WBDPSP are working with African American parents who have experienced an infant loss to establish grief and bereavement support groups for African American families.

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 Surveillance System. The folic acid module assesses awareness of why folic acid is recommended, the consumption of multivitamins and supplements containing folic acid, and frequency of taking those vitamins or supplements. According to the most recent data about 28% of nonpregnant women aged 18-44 take folic acid and 23% report that they take it daily. Overall about 38% of nonpregnant women aged 18-44 know why women should take folic acid. However, women were significantly more likely to take folic acid and 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 folic acid supplements for free through a prescription from their doctor regardless of pregnancy status. This is essential since neural tube defects occur very early in pregnancy. 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 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.

Children and Youth with Special Health Care Needs Regional Centers

Assuring Access to Services through Communication and Information and Referral (I/R)

To ensure access to services, the CYSHCN Program contracts with five Regional Centers for CYSHCN in Wisconsin:

- Northeastern Regional Center for CYSHCN, Children’s Wisconsin-Fox Valley
- Northern Regional Center for CYSHCN, Marathon County Health Department
- Southeastern Regional Center for CYSHCN, Children’s 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 CYSHCN (including children born with birth defects) and the providers who serve them. The regional centers are staffed by I/R specialists who can help get answers, find services, and connect providers, families, and youth to community resources. Their services are free and private. Physicians may refer CYSHCN to a regional center using the [Consent to Release Medical Information Referral form](#) (F-01238). Resources can be found at: www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm.

FAMILY HEALTH PARTNERSHIPS THAT SUPPORT BIRTH DEFECT PREVENTION AND INTERVENTION

- **Wisconsin New Born Blood Screening (NBS) Program**: Screens all newborns for 44 disorders and plays a crucial part in the care of infants who are diagnosed with these conditions through access to specialty clinics. NBS has prevented death and disability for hundreds of Wisconsin residents since its inception.
- **Wisconsin Sound Beginnings – Early Hearing and Detection Program**: Ensures that all babies born in Wisconsin are screened for hearing loss, receive timely diagnosis of hearing loss, and receive quality early intervention, by meeting the Joint Committee on Infant Hearing recommendations for newborn hearing screening and intervention.
- **Wisconsin First Breath**: The Wisconsin First Breath program targets eligible pregnant women who smoke by connecting them to trained tobacco cessation counselors for face-to-face tobacco cessation counseling.
- **Well Badger Resource Center**: Provides information and referral services for WIC and other nutrition programs, financial assistance, health care coverage including BadgerCare Plus, mental health services, children and youth with special health care needs, and pregnancy and parenting services. To contact an information and referral specialist call 1-800-642-7837, text 608-360-9328 or email HELP@WELLBADGER.ORG

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