



State of Wisconsin  
Department of Health Services

Scott Walker, Governor  
Linda Seemeyer, Secretary

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September 13, 2018

Honorable Joel Kitchens, Chairperson  
Committee on Children and Families  
Wisconsin State Capitol  
Room 10 West  
PO Box 8952  
Madison, WI 53708

Dear Representative Kitchens:

I am pleased to forward to you the 2018 Wisconsin Birth Defect Prevention and Surveillance Program (WBDPSP) Biennial Report as required by Wis. Stat. § 253.12 (4)(d). The report (P-01742-18) identifies surveillance activities and programmatic strategies that are critical to improving birth outcomes and the health of all children.

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 providing resources for families who have a child with a birth defect.

Since 2004, the Wisconsin Birth Defects Registry 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 2017, 26,193 birth defects were reported to the registry. The report, by type of condition, shows that cardiovascular birth defects are the most common.

The Department of Health Services (DHS) 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 (Assembly Bill 64 - Budget Bill) amended Wis. Stat. § 253.12(4)(d) requiring identifiers be submitted with every report, unless the parent or guardian states in writing their refusal to release the name and address. Also, the method of adding/deleting reportable conditions to the registry was changed so that conditions can now be added by unanimous vote by the Birth Defects Council. Currently the program is addressing these changes, providing new policy, and updating materials.

The attached report covers and details the effectiveness, utilization, and progress for the registry. In addition, primary prevention strategies to decrease occurrence and referral for early intervention are highlighted below as well as in the report.

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The Department, along with valuable partners, such as WIC, Waisman Center, Children's Health Alliance of Wisconsin, and Wisconsin Genetics Hub, continues expansion of four prevention initiatives referenced below. The WBDPSP serves to strengthen birth outcome prevention activities, enhance child health outcomes, and facilitate family access to services.

- *Nourishing Special Needs for Infants and Children* is a nutrition collaborative between WIC, WBDPSP, and the Waisman Center focusing on increasing workforce capacity in serving families of children born with a birth defect, [www2.waisman.wisc.edu/cedd/wic/](http://www2.waisman.wisc.edu/cedd/wic/).
- In collaboration with WBDPSP, the Children's Health Alliance of Wisconsin Grief and Bereavement program provides resources for families experiencing a stillbirth as well as assuring that families of children born with a birth defect or other health care needs have access to counseling and services with parent partnership with the Parent to Parent of Wisconsin program; [www.chawisconsin.org/grief/](http://www.chawisconsin.org/grief/).
- *The Folic Strong campaign* resulted from the PRAMS *Folic Acid Data-to-Action* initiative as a collaborative with Wisconsin PRAMs, WBDPSP, and Wisconsin Genetics Hub; [www.folicstrong.org/](http://www.folicstrong.org/).
- WBDPSP participates in the department's Zika virus preparedness work by providing a baseline count of infants diagnosed with microcephaly, identified through the Birth Defects Registry; [www.dhs.wisconsin.gov/zika/women.htm](http://www.dhs.wisconsin.gov/zika/women.htm).

Sincerely,



Linda Seemeyer  
Secretary

Enclosures



## WISCONSIN BIRTH DEFECT PREVENTION AND SURVEILLANCE PROGRAM 2018 Report to the Legislature

The Wisconsin Birth Defect Prevention and Surveillance Program's (WBDPSP) work 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 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 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 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 registry state administrator for inclusion in the registry. The registry 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](#).

Physicians and specialty clinics serve as 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, Dean Health System, Children's Hospital of Wisconsin, Gunderson Health System, and UW Health Foundation utilize the electronic upload option.

The 2017 Biennial Budget Bill, (Assembly Bill 64 - 2017 Wisconsin Act 59) enacted on September 22, 2017, made significant changes to the Birth Defects Prevention and Surveillance program registry and

reporting, allowing the program to better understand the incidence of birth defects in Wisconsin. The new language improves the information in the registry by making the program reporting an opt-out versus an opt-in. This means that unless a legally responsible adult request otherwise, all reports to the registry are to contain identifiers including name and address of the child. Parents or guardians can request identifying information be removed from the registry at any time. This is consistent with other newborn screening applications administered by DHS.

Overall this change will:

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

In addition, the new legislative language maintains strong protections for personal data, allows for keeping registry record 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 of the Council, the list will be 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, [F-40054](#).

In Wisconsin, 960 birth defects were reported in 2017. However, this is less than the expected 1 in 33 babies born with birth defects in the U.S., according to the CDC.<sup>1</sup> A variety of different factors can cause or contribute to birth defects: genetic processes; environmental exposures; infections; obesity; and the use of alcohol, tobacco, prescription medications, or illegal drugs. Some birth defects appear as multi-factorial, with genetic predisposition plus environmental triggers. However, the cause of approximately 80% of birth defects remains unknown.<sup>4</sup>

This represents not only a significant gap in understanding the prevalence of birth defects, but also in providing the necessary family supports and services, and outreach, education, and prevention activities. However, it is expected that the 2017 changes in the birth defect statute language 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.

Since this law change, DHS has established several administrative workgroups to assure a smooth transition, with implementation beginning July 1, 2018. Since reporters are required to notify parents of the option to refuse to release the name and address of the infant or child to the registry, DHS now provides a sample documentation form called [Wisconsin Birth Defects Registry-Request to Remove Identifiers](#), F-40054A, which is also available in [Spanish](#).

In addition, parents of children reported in the WBDR with identifying information will now receive a letter from DHS, a fact sheet about the WBDR, and brochures about the regional centers for Children and Youth with Special Health Care Needs (CYSHCN) in English or Spanish. There are five regional centers in Wisconsin that provide information and referral to help connect families of children with special needs to needed supports and services.



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

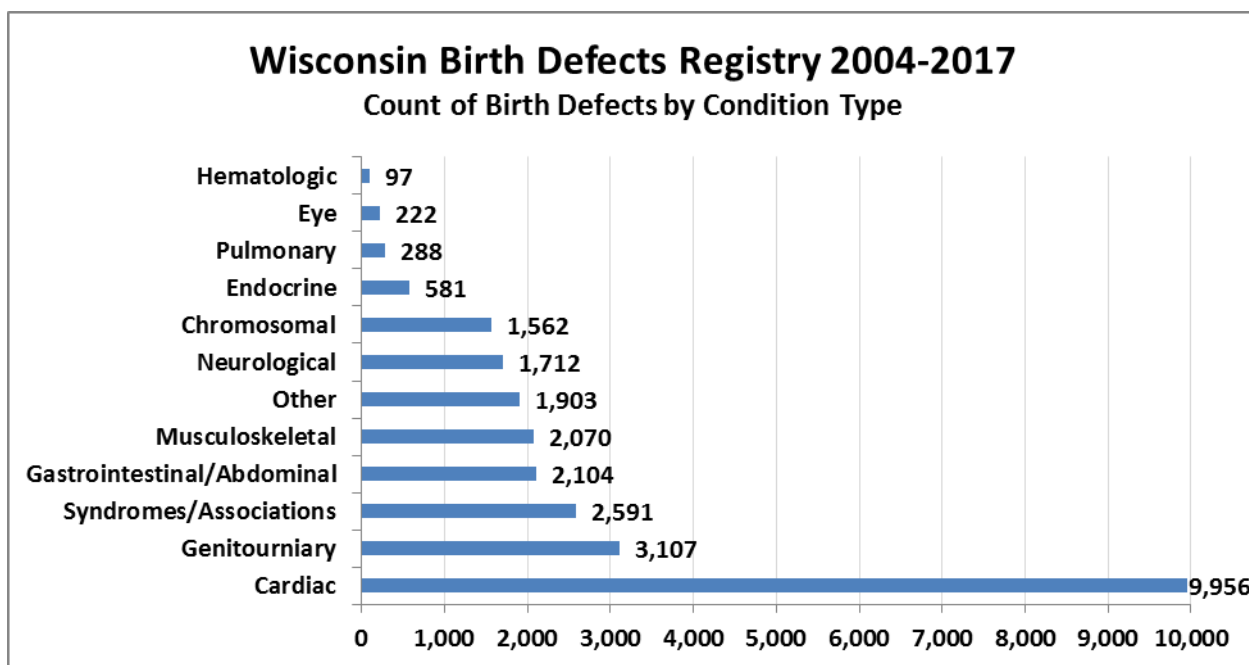
In addition, the Council has provided direction to DHS to establish a protocol for the Council to follow in determining the criteria for reportable conditions, adding or deleting conditions to the condition listing, and establishing a timeline for the review of the listing, along with policy to send the recommendations to the DHS Secretary for maintenance.

## How Serious Are Birth Defects in Wisconsin?

- In Wisconsin, from 2012-2016, birth defects were the leading cause of infant death among children born to white mothers (12 per 10,000 births) and the second leading cause of infant death for children born to black mothers (18 per 10,000 births), accounting for approximately 100 deaths per year.<sup>2</sup> Prematurity alone remains the leading cause of death for black infants.
- In Wisconsin, the estimated lifetime cost of birth defects for infants born in a given year exceeds \$140 million.<sup>7</sup>
- 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.<sup>3</sup>
- Babies born with birth defects have a greater chance of illness and long-term disability than babies born without birth defects.<sup>5</sup>
- Babies with birth defects are often born preterm.<sup>6</sup>
- Birth defects are the fifth leading cause of years of potential life lost.<sup>8</sup>

Between mid-2004 and the end of 2017, 18,269 birth defects were reported to the registry. Cardiovascular birth defects are the most common. See chart below “Wisconsin Birth Defects Registry 2004-2017 Count of Birth Defects by Condition Type Reports by Condition.”

## 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 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 Centers for Disease Control and Prevention (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 Maternal and Child Health (MCH) Title V, Children and Youth with Special Health Care Needs (CYSHCN) program. Additional staff have recently been identified (MCH chief medical director, CYSHCN medical director, Zika epidemiologist, PRAMS epidemiologist, CDC epidemiologist) to assist with implementation of the new legislative requirements.

After meeting the confidentiality requirements of Wis. Stat. § 253.12, researchers studying birth defects may receive summary birth defects registry reports or specific datasets. Current surveillance projects supported by the registry include:

1. Ongoing participation with DPH's 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 defect cases identified in the Birth Defects Registry. This research enhances and strengthens birth defect surveillance during emerging public health threats impacting maternal and child health.
3. Beginning in July 2014, DHS added screening for Critical Congenital Heart Defects (CCHD) by pulse oximetry to the Wisconsin Newborn Screening Program's panel of conditions and are a reportable condition. In 2017, 97.5% of all babies born in Wisconsin had a CCHD screening. CCHD requires prompt diagnosis and treatment for the best outcome. Babies with undetected CCHD are at risk for sudden death or significant disability.

## **Prevention and Early Intervention Initiatives Funded by WBDPSP**

In addition to supporting the Council meetings, data requests, and maintenance of the Registry IT functions, the following initiatives are funded from a surcharge on birth certificates in the amount of \$95,000 annually.

### **Birth Defects—Nutrition Consultant Network (BD-NCN) including WIC Nourishing Special Needs workforce development training and mentorship program (WIC-NSN)**

The BD-NCN and WIC-NSN is a collaborative quality improvement initiative developed by the Wisconsin CYSHCN Program, WBDPSP, the Waisman Center, and the Wisconsin Special Supplemental Nutrition Program for Women, Infants and Children (WIC) program to build nutrition 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. Data reveal the

WIC-NSN sites currently serve 25% of the Wisconsin statewide WIC client caseload, so continual engagement and access to other WIC agencies is essential to help meet access to service needs for this population. Of the 5,000 infants and children estimated to have special health care needs, 600-700 who are part of WIC caseloads may have birth defects.

The BD-NCN provides:

- Training, technical assistance, and educational outreach programs for the BD-NCN members at three tertiary neonatal and pediatric centers—birth defect medical/nutrition specialty clinics.
- Collaboration with health care providers 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-NSN continues into 2018 with a structured and evaluative program utilizing best practice mentoring and peer nutrition consultation models. The U.S. Department of Agriculture requires states and local agencies to develop a nutrition services plan that establishes nutrition priorities and focuses activities to improve participant health and nutrition outcomes. To address this requirement, Wisconsin WIC provides five nutrition services mentoring education work plan options for local agencies to better serve children with special health care needs.

Evaluation of the program revealed that WIC dietitians frequently identify the need for: 1) assessment, diagnosis, and referral for suspected health care problems; 2) specialized nutritional assessment and medical nutritional therapy; and 3) special formula or formula changes based on diagnosis. In addition, WIC sites demonstrated the following outcomes: 1) a threefold increase in identifying infants and children with birth defects and other health care needs, accounting for almost half of the referrals to the CYSHCN regional centers; 2) increased communication and collaboration with other agencies and medical providers; and 3) improved nutritional care with early intervention programs resulting in one-fifth of the referrals to the Wisconsin Birth to 3 Program.

The BD-NCN and WIC NSN received state and national attention via presentations at the Wisconsin Public Health Association conference, the Wisconsin Dietetic Association conference, the National Birth Defects Prevention Network (NBDPN) conference, the National WIC Association Conference, the National Association of County and City Health Officials conference, the Wisconsin Association for Perinatal Care (WAPC), the Association of University Centers on Disabilities, the Association of Maternal and Child Health Programs (AMCHP), and the Association of State and Territorial Public Health Nutrition Directors meeting. Most recently the program is highlighted in the [AMCHP March/April 2018 Pulse Newsletter](#).

### **Stillbirth Services through the CHAW Infant Death Center**

Through an integrative contract objective, to assure statewide availability of bereavement and counseling services, [Children's Health Alliance of Wisconsin—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 stillbirth. This program has been presented at WAPC, WPHA, 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 survey module in the Behavioral Risk Factor Surveillance System survey. The folic acid module assesses folic acid awareness, how folic acid messages are communicated, knowledge of folic acid benefits, and consumption of multivitamins containing folic acid. Information from the module indicates that providing vitamins and education to low income

women is beneficial, and that some reproductive health providers have changed their practice of care guidelines, assuring client access to multivitamins with folic acid through prescriptions.

Beginning in 2014, WBDPSP, in collaboration with the Wisconsin Genetics Council, the Genetics Hub at Waisman Center, the Pregnancy Risk Assessment Monitoring System (PRAMS), and WAPC, promoted a call to action based on PRAMS data that 51% of all Wisconsin mothers surveyed during 2009-2012 reported taking a vitamin containing folic acid in the month before pregnancy.

In May 2015, the removal of the Medicaid diagnosis restriction on prenatal vitamins allowing prenatal vitamins (containing folic acid) to be prescribed for all women ages 12-60 occurred, regardless of whether they were pregnant or not, assuring that women have access to vitamins prior to, during, and after their pregnancy.

Most recently, a social media campaign called Folic Strong links to information for women on how to obtain free vitamins, using Facebook, Twitter, and Instagram. As a result of this campaign, there was a 28% increase in the number of women taking prenatal vitamins with folic acid three months after the vitamin giveaway. Upon evaluation, it was found that for women to continue to take vitamins with folic acid, policy change alone is not effective; provider education is critical and social media only works if it's actively promoted by an expert. The [Folic Strong](#) initiative continues to foster partnerships to improve provider and public awareness of the importance of folic acid and to drive policy change that increases access to folic acid for all women of reproductive age.

### **Assuring Access to Services through Communication/Information and Referral**

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 centers are staffed by 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 a child with special health care needs to a regional center using the [Consent to Release Medical Information Referral form](#) F-01238. Additional resources can be found at: [www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm](http://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm)

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