

# **WISCONSIN BIRTH DEFECT PREVENTION AND SURVEILLANCE PROGRAM**

## **2016 Report to the Legislature**

The Wisconsin Birth Defects 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 requirements set out in statute: provide an up-to-date birth defects registry that facilitates the identification of risk factors, assures epidemiology, protects confidentiality, determines reportable birth defects through an advisory council, provides for primary prevention to help decrease occurrence, maintains components to educate populations about birth defects and systems, and refers those with birth defects to early intervention and other support services.

### **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 2 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. They may also submit a paper form to the WBDR state administrator for inclusion in the Registry. 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. (See Wisconsin Birth Defects Registry Count of Reports by Condition.)

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. Reporting into the Registry requires parental permission. When parental permission is not obtained, the pediatric specialty clinic or physician reports information without the full name and address of the child. Due to this required parental permission to include patient identifiable information, unduplicating counts of children with birth defects is not possible; thus making it impossible to accurately calculate the incidence for any birth defects or identify clusters of birth defects in a particular area of the state.

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, and UW Health Foundation utilize the electronic upload option.

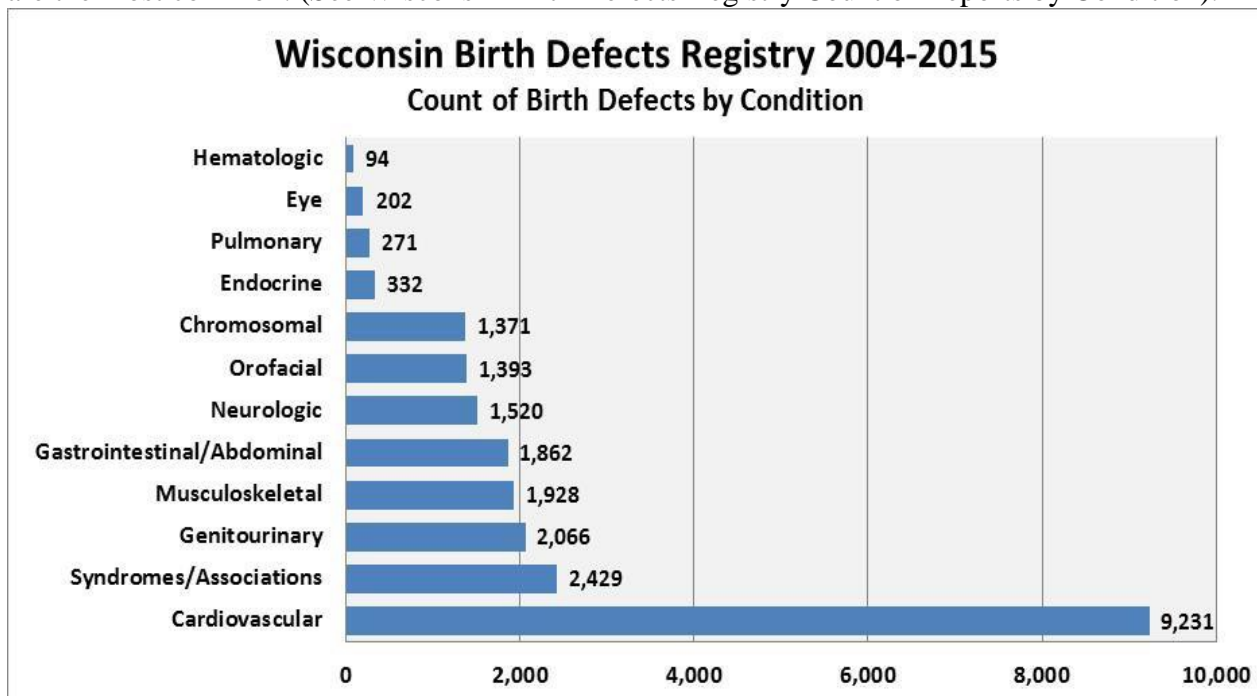
### **HOW SERIOUS ARE BIRTH DEFECTS IN WISCONSIN?**

- Birth defects are common, occurring in one of every 33 births. About 2,000 babies with birth defects are born in Wisconsin every year.

- From 2010-2014, congenital malformations/birth defects were the second leading cause of infant death at 14 per 10,000 live births for Blacks; and the first leading cause of infant death (12 per 10,000 live births) for Whites.
- Birth defects are caused by a variety of different factors: genetic processes, environmental exposures, infections, obesity, and the use of alcohol, tobacco, prescription medications, or illegal drugs. Some defects appear as multi-factorial, with genetic predisposition plus environmental triggers. The cause of approximately two out of three birth defects remains unknown.
- Birth defects are the leading cause of all infant deaths and stillbirths, accounting for approximately 150 to 200 deaths from birth defects causes and 365 stillbirths in Wisconsin.
- Approximately 20% of babies who die in the first year of life do so as a result of birth defects.
- Babies born with birth defects have a greater chance of illness and long-term disability than babies without birth defects.
- Babies with birth defects are often born preterm, which increases the risk of death.
- At least one out of three of all pediatric hospital admissions are associated with birth defects or genetic conditions.
- The estimated lifetime cost related to birth defects in Wisconsin is estimated at \$165 million each year for the 18 most significant birth defects.
- Birth defects are the fifth leading cause of years of potential life lost.

### Progress of the Registry

Between mid-2004 and the end of 2015, 15,169 babies with 22,699 birth defects were reported to the WBDR from 75 organizations. The reports by type of condition show that cardiovascular birth defects are the most common. (See Wisconsin Birth Defects Registry Count of 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 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 to the National Birth Defect Prevention Network (NBDPN) annually 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 Wisconsin Birth Defect Prevention and Surveillance Program is provided through two Maternal and Child Health (MCH) Title V, Children and Youth with Special Health Care Needs (CYSHCN) staff.

The CYSHCN epidemiologist administers the Wisconsin Birth Defects Registry and is the WBDR state administrator. The assigned epidemiologist is a member of the National Birth Defect Prevention Network and attends annual training conferences to keep apprised of new information on birth defects. In addition, this staff is a member of the NBDPN Data Committee and works with newly developed national prevalence estimates to update Wisconsin's estimated prevalence statistics.

The CYSHCN program consultant manages and administers the WBDPSP budget and agency contracts; staffs the Council on Birth Defect Prevention and Surveillance; serves as the state's birth defects point of contact; coordinates birth defect prevention programs and initiatives and is a member of the National Birth Defect Prevention Network the NBDPN Ethics and Policy Committee, working on ethical issues, bylaws, and HIPPA standards.

The CYSHCN Program—Birth Defect Prevention and Surveillance System website is available at: <https://www.dhs.wisconsin.gov/health/children/birthdefects/index.htm>.

Researchers studying birth defects may request and receive summary birth defects registry reports or a dataset with properly executed data release forms and the permission of the WBDR state administrator. Current projects supported by WBDR include:

1. Research project on cleft lip and palate.
2. Ongoing participation with the Bureau of Environmental and Occupational Health, Division of Public Health at DHS, 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.
3. Pregnancy Risk Assessment Monitoring System (PRAMS)—Research to Practice Use of Folic Acid
4. Participation in Zika Virus preparedness work; providing a baseline count of microcephaly cases.

On July 3, 2014, DHS added, by emergency rule, screening for critical congenital heart disease (CCHD) by pulse oximetry (POX) to the Wisconsin Newborn Screening 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. CCHD requires prompt diagnosis and treatment for the best outcome. Babies with undetected critical congenital heart defects are at risk for death or significant disability. The WBDR state administrator leads the surveillance effort for this project. Reportable heart defects and any other diagnosed birth defects are reported to WBDR.

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

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

The BD-NCN and NSN is a collaborative 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) 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.

The network 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 conference, the National WIC Association Conference, the National Association of County and City Health Officials conference, the Wisconsin Association for Perinatal Care, the Association of University Centers on Disabilities, the Association of Maternal and Child Health Programs (AMCHP), and the Association of State and the Territorial Public Health Nutrition Directors meeting. In addition, the network received many requests from public health agencies throughout the U.S. for copies of the CYSHCN Nutrition Toolkit.

Expansion of the network, named “Nourishing Special Needs” (NSN), began in the fall of 2009. In 2013, a structured and evaluative program began with a mentor and mentee peer nutrition consultation model utilizing the Wisconsin Public Health Association Mentor toolkit. Quarterly training is open to all WIC Project Sites, the CYSHCN Regional Centers, CYSHCN Hubs of Excellence, Birth to 3 providers, and others interested in nutrition issues for children with special needs and children with birth defects.

An initial evaluation of the NSN Program revealed that WIC-registered dietitians were frequently the first to identify the need for: 1) Initial assessment, diagnosis, and referral for suspected health care problems; 2) Additional specialized nutritional assessment and medical nutritional therapy; and 3) Special formula or formula changes based on diagnosis. Because of this, a direct referral form from NSN WIC providers to early intervention providers was developed, piloted in 2015, and rolled out statewide in 2015.

Baseline data revealed the NSN sites have expanded to currently serve only 25% of the Wisconsin statewide WIC client caseload, so continual spread to other WIC agencies is essential to help meet access to service needs for this population. Supporting this, it is estimated within the state WIC agency caseload, there may be 5,000 infants and children with special health care needs of which 600-700 may have birth defects. In addition, sites demonstrated the following outcomes: 1) A three-fold increase in identifying infants and young children with birth defects and other health care needs, which accounted for almost half of the referrals to the Wisconsin Regional CYSHCN Centers; 2) Increased communication and collaboration with other local agencies and medical providers; and 3) Improved nutritional care integration with early intervention programs resulting in one fifth of the referrals to Wisconsin Birth to 3 Program.

In addition, the state program of the BD-NCN provides:

- Training, technical assistance, monthly educational outreach programs and networking teleconferences/“live” meetings, and workshop trainings.

- Annual pre-conference training coordination for BC-NCN and other attendees at the National WIC Association Conference or State WIC Association conference.
- Maintenance of the BD-NCN materials on state websites.
- Contract monitoring, oversight, and funding to 12 project sites and the Waisman Center.
- Participatory educational opportunities for the BD-NCN at three tertiary neonatal and pediatric centers—birth defect medical/nutrition specialty clinics.

Through this quality improvement initiative, the BD-NCN developed a system that addresses:

- Communication and facilitation of referrals to primary care, pediatric specialty care, Birth to3, Wisconsin CYSHCN Regional Centers, economic assistance, and local dietitians providing medical nutritional therapy.
- 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.
- Training and technical assistance including the development of a Toolkit and Workbook, and a link to the Wisconsin CSHCN website.
- Data collection and utilization reports for program evaluation.

### **The Wisconsin Stillbirth Service Program (WiSSP)**

The Wisconsin Stillbirth Service Program, located at the Marshfield Clinic Research Foundation, investigates the causes of stillbirth through referrals; provides diagnostic information and educational materials to medical personnel for counseling families with a child who died prior to birth; provides families with other support resources; provides scientific and medical data to families and medical personnel; and distributes “Grand Rounds” presentation on stillbirth evaluations to birth centers in Wisconsin. The WiSSP submits birth defect reports to the WBDR for any stillbirth in which a reportable condition is diagnosed: <http://www2.marshfieldclinic.org/wissp/>.

Through an integrative and parallel contract objective, to assure statewide availability of bereavement and counseling services, the WiSSP and the Infant Death Center Children’s Health Alliance of Wisconsin collaborate on several projects to include opportunities and strategies to form common messaging, promote each other’s grief and bereavement materials, assure information and referral to supportive services, and distribute resources statewide: <http://www.chawisconsin.org/grief-resources/>.

### **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 the folic acid message was communicated, knowledge of folic acid benefits, and consumption of multi-vitamins containing folic acid. Information from the folic acid module indicates that providing vitamins and education to low income women is beneficial. Some reproductive health providers have changed their practice of care guidelines to assure client access to multivitamins with folic acid.

In 2014, the WBDPSP, in collaboration with the Wisconsin Genetics Council, the Genetics Hub at Waisman Center, PRAMS, and Wisconsin Association of Perinatal Care (WAPC), promoted a call to action based on the PRAMS data to promote the use of folic acid among women of childbearing age. WAPC updated their position statement for providers on the importance of folic acid: <https://www.dhs.wisconsin.gov/library/calltoaction.htm>.

As of May 1, 2015, the Medicaid diagnosis restriction on prenatal vitamins was removed, thus allowing prenatal vitamins (which contain folic acid) to be prescribed for ALL women ages 12-60, regardless of whether they are pregnant or not, assuring women have access to the vitamins prior to, into, during and after their pregnancy.

In 2015, MCH/CYSHCN Program staff presented testimony to the Wisconsin Assembly Committee on Children and Families and answered questions.

### **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 and the Great Lakes Intertribal Council (GLITC) CYSHCN Program:

- 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
- Great Lakes Inter-Tribal Council, Lac du Flambeau

Each regional center maintains designated staff, following confidentiality and HIPPA standards, to access birth defect reports from WBDR for their respective counties and regions. The information is used to contact children with birth defects and refer children and their families to appropriate services.