Wisconsin Birth Defects Registry (WBDR)
Frequently Asked Questions

Q: What is the Wisconsin Birth Defects Registry (WBDR)?

A: The Wisconsin Birth Defects Registry is mandated by Wisconsin Statute 253.12, enacted in May 2000, to collect demographic, diagnostic and identifying information for children from birth to 2 years of age who are born with specified birth defects. Physicians and pediatric specialty clinics are mandated reporters.

Q: What is the definition of a birth defect?

A: Wisconsin Statute 253.12 defines a birth defect as a structural deformation, disruption or dysplasia or a genetic, inherited, or biochemical disease that occurs prior to or at birth and that requires medical or surgical intervention or interferes with normal growth and development. A list of reportable conditions is attached to the paper report (DPH 40054) and is included in the legislation.

Q: Can I report birth defects on a paper form?

A: Yes, a paper form was developed for users who cannot use the secure website or prefer to use a paper form. Since the website is more secure than faxing or mailing a paper form, we encourage reporters to use the website if at all possible. But if it isn't possible, then a paper form can be requested, blank copies made, and a paper report can be submitted as needed. The paper form can also be used internally to show parents what will be reported as part of obtaining consent. Facilities may also want to use the paper form as a reference for doctors and nurses, even if the final report will be submitted via the secure website.

Q: Can we report birth defects directly from our electronic patient records system?

A: Yes, we do have a process in place, one health system is reporting in this way, and two more are planning to do so in future. However, you must have trained information technology staff at your facility who can write a program to derive the reporting information from your system and you must be able to match the WBDR reporting criteria. The plus to reporting in this way, once the set-up work is complete, is that you can report for your entire system and all your physicians centrally, once a month.

Q: How do I become an approved reporter on the WBDR website?

A: There are several steps: Register for a Wisconsin user (or WAMS) i.d., register for the HAN, and fax or mail a signed user agreement to the WBDR administrator requesting that you be added to the WBDR website. To begin, go to the WBDR website at https://wbdr.han.wisc.edu. Follow the instructions. If you need help, there is contact information for the Help Desk on the website.

Q: What is the user i.d.? Do I need a different one for WAMS for HAN and for WBDR?

A: To keep our systems as secure as possible, there are three layers of security. WAMS stands for Web Access Management System and is overseen by the Department of Administration. HAN stands for Health Alert Network and is the state system that alerts healthcare workers in the event of a crisis such as a bioterrorism event or a disease outbreak. WBDR is the Wisconsin Birth Defects Registry that collects mandated birth defects reports. Each user registers for each layer. The registration process is cumbersome but the user i.d. and password are the same for WAMS, for HAN, and for WBDR once the registration process is complete.

Q: I registered for WAMS / HAN / WBDR last year but when I tried to logon and complete a report it wouldn't let me. What happened?

A: You have to logon and change your password at least once a year. If you don't, the system considers you a non-user and freezes your access rights. If you've logged on and used the system, but haven't changed your password for more than a year, the system will lock you out. You will need to contact the HAN Help Desk to have your password changed and access restored. The number is 608-264-4357.

Q: Who reports home births?

A: Nurse-midwives can register as reporters and report. If babies go for a newborn check-up to a hospital or clinic, the physician should report. Also, local public health agencies can register and report for families in their area.

Q: If we transfer a baby, who is responsible for reporting?

A: If a diagnosis has been made, the birth hospital physician should report. Otherwise, the physician responsible for the baby at the receiving hospital should report. It is appropriate to include a printed copy of the WBDR report in the chart that goes with the baby so the receiving hospital knows that a birth defects report was submitted and can see the diagnosis. If the diagnosis changes, or there is an additional reportable birth defect, the receiving hospital physician should submit another report.

Q: Can a nurse practitioner be listed as the diagnosing physician on the birth defects report?

A: Currently, a physician must be listed. The physician who oversees the nurse practitioner is an appropriate person to be listed as the diagnosing physician.

Q: Who is the primary care provider? Isn't that usually the mother?

A: No. For purposes of the report, the primary care provider is the primary healthcare provider, that is the pediatrician or family practice physician. If the child is seen in a clinic and doesn't have a specific physician, the clinic name can be listed as the primary care provider.

Q: What if we're caring for an abandoned baby, or a baby who will be adopted, and have little or no information?

A: Fill in what you have. Fields are flexible on the electronic report. For instance, you can put "unknown" in the name fields. Since some people actually name their child "Baby", avoid using that as the name. As far as we know, no one has ever named their child "Unknown".

Q: Should I register all my physicians and have them do reporting?

A: It depends. If your physicians prefer to do it this way, it is perfectly appropriate. However, in many cases physicians prefer to delegate someone at the hospital or clinic to do reporting. One of our reporting hospitals has one physician doing all their birth defects reporting. But most hospitals and clinics have a nurse or office support person or patient records staff person doing the actual data entry on the WBDR website for one or more physicians. Think of how your system works and where the best place is for reporting to occur. If it is delegated to one person or position, make it a written part of the position description so reporting doesn't get lost or forgotten when staff changes occur.

Q: Can I talk to the pediatricians in my area and encourage them to report, or work out an agreement with the clinics as to who will report?

A: Absolutely. Reporting is mandated for all physicians and specialty clinics. Integrating it into your area's healthcare culture will ensure that reporting is consistent, all babies and children with reportable conditions who should be reported are reported, and duplication of reporting is minimized. We already have one system that includes a hospital and clinics reporting centrally and hope to encourage more systems to report in this way.

Q: If we routinely refer babies to a specific clinic, can we work out an agreement with the clinic as to who will report?

A: Absolutely. Arranging for reporting to occur routinely by an agreed-upon central reporter is an efficient way to report birth defects.

Q: If we use the Peridata System developed by the Wisconsin Association for Perinatal Care (WAPC), can we report to the WBDR directly from that system?

A: Currently, no. The two systems are separate. However, WAPC is working with DHFS to ensure that data collected via Peridata will include the WBDR reportable conditions and looking at ways to expedite birth defects reporting.

Q: If a reportable condition is present, but it is later corrected, medically or on its own, should a report be submitted.

A: Yes. To get an accurate count of birth defects, all should be reported whether they are corrected later or not.

Q: If a reportable condition is present, and a report is submitted, but later it’s determined that the birth defect was never present to begin with, or there’s a different diagnosis, what do I do?

A: If the birth defect was never present to begin with, contact the WBDR administrator who will delete the report. If the diagnosis changes, either because further analysis reveals the original diagnosis was incorrect or there’s an additional birth defect diagnosed, another report should be submitted.

Q: What happens if a parent refuses to consent to the child’s birth defect being reported to the state?

A: Reporting is mandatory. However, if a parent withholds consent, the names and addresses of the child and parents are not reported.

Q: Will the state make referrals from information submitted to the WBDR?

A: Currently, we are not using submitted reports to make referrals to Birth to 3, Children with Special Health Care Needs regional centers, or Local Public Health Departments. However, one of the purposes of the registry is to ensure that babies and parents are referred to appropriate services. Therefore, referrals could be made in future from WBDR information. Parents are not required to take advantage of services but it is important that they’re aware that services are available and have contact information.

Q: If I’m a local administrator and doing the reporting, and I want someone else to do some or all of the reporting. How do I do that?

A: Every reporting facility has to have at least one local administrator who is responsible for birth defects reporting. The local administrator can also report, or can add other reporters to the WBDR who will be able to report. Each local administrator and reporter must be registered on WAMS and HAN. The local administrator can add another local administrator and additional reporters by following the links on the WBDR.

Q: Why are fetal alcohol syndrome (FAS) and autism not on the list of reportable conditions?

A: The list of reportable conditions was developed by the Council on Birth Defect Prevention and Surveillance. The criteria they used in developing the list are as follows:

- Conforms to the statutory definition of a birth defect;
- Usually identifiable by 2 years of age;
- Has medical, surgical or developmental significance;
- Occurs at an estimated birth prevalence of 1 in 30,000 or more; and
- Likely to be ascertained through assessment in one or more specialty clinics.

FAS and autism are often not diagnosed until a child is more than 2 years of age. Therefore, they do not appear as reportable conditions on the final list.

Q: Are the WBDR forms available in other languages?

A: Currently, forms are available only in English. However, we are investigating adding forms in Spanish.

Q: Do we have to use the DHFS-provided parent permission form?

A: No. DHFS developed a form so facilities would have something to work with. You may use the form as is, may print it on your own letterhead and edit it to meet your needs, or may develop a completely different form. If you have parents who do not speak English, or are illiterate, you may get oral permission and make a note of that in the patient record. Parent permission is the responsibility of the reporting entity. Paper forms should be maintained by the reporting entity, not forwarded to DHFS.

Q: If we suspect a patient has a birth defect but don't have a diagnosis, should we report?

A: It depends. If you're relatively certain, and are just waiting for lab results to confirm, you may go ahead and report. If you think something is wrong, but don't know what it is, wait until the patient sees a specialist and you have a better idea of whether a reportable condition exists or not. You can't submit a report without including a diagnosis.

Q: If we're referring a patient to another provider, can we let him/her know a report has been submitted to the WBDR?

A: Yes. A copy of the report can be printed and included with the information you send along.

Q: If a birth defect is reported for a child and the child later dies, do I need to submit another report?

A: No.

Q: If a woman terminates a pregnancy and the fetus is determined to have a birth defect on the list of reportable conditions, should a report be submitted?

A: No. Elective terminations are not reported to the WBDR.

Q: If a fetal death occurs spontaneously, or the fetus is stillborn or dies shortly after birth, should a report be submitted?

A: Yes, if the following are both true: the fetus is 20 weeks gestation or older and a reportable condition is diagnosed.

Q: Some of our families, depending on their culture, have more than one last name. How can we report this on the WBDR website?

A: The fields for demographic information are flexible. If the child's entire name is "Mary Frances Genevieve Smith Jones" you can enter "Smith Jones" in the last name field, "Mary Frances" in the first name field, and "G" in the middle initial field. You are not restricted to one name per field.

Q: Many babies have arrhythmias at birth and a good number are mild and/or self-correcting. Do we have to report every case?

A: Yes.

Q: If there's additional information we would like to add, or comments, how can we do that?

A: Currently, there is no provision for additional information on the WBDR. We are planning to make a small revision to the website to allow a reporter to add notes. However, it is always appropriate to contact the WBDR director. Suggestions and comments will be reviewed by the Council and future changes to the WBDR may be made.