



WISCONSIN BIRTH DEFECTS REGISTRY

Information for Providers

What is the Wisconsin Birth Defects Registry (WBDR)?

The Wisconsin Birth Defects Registry is mandated by Wis. Stat. § 253.12 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. The statute 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 complete list of reportable conditions for the WBDR can be found in the paper report and on the program website below.

How have WBDR and its reporting process changed?

When the WBDR was created, state statute required documentation of parental consent in order for identifying information (names, addresses) to be submitted to the registry. This stipulation was removed in late 2017, and now identifiers are to be submitted with every report unless the parent or guardian of the infant or child states in writing that he or she refuses to release the name or address. A template form to document parental refusal to submit identifiers can be found at the “program website” link below. The scheduled implementation date for these changes is July 1, 2018. Reporters are required to notify parents of this option to refuse to release the name and address of their infant or child to the registry. Reporters should retain documentation of the parental refusal to include identifiers for any report submitted to the registry that does NOT include identifiers per hospital or clinic policy, a minimum of three years.

Providers are expected to:

1. Register to be a reporter with the WBDR.
2. Identify and diagnose birth defects.
3. Refer children with birth defects and their families to appropriate clinical and support services.
4. Notify parents of children diagnosed with birth defects of the Wisconsin Birth Defects Registry and their ability to opt to remove identifiers from their child's record in the WBDR.
5. Submit birth defect reports (individually or in batch) via the WBDR secure website or paper form.
6. Retain documentation of parental refusal for each report submitted without identifying information.

Is the WBDR confidential?

Yes, the WBDR is confidential and the information submitted is kept in a secure system. The Wisconsin Department of Health Services is responsible for protecting confidential information in the WBDR, as outlined in the statute.

Where can I learn more about the WBDR?

Program website:

www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm

Where can I learn more about birth defects?

Centers for Disease Control and Prevention:

<https://www.cdc.gov/ncbddd/birthdefects/index.html>