



Scott Walker
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June 1, 2018

Dear Wisconsin Birth Defects Registry Partners and Stakeholders,

The Wisconsin Birth Defects Registry (WBDR), a part of the Wisconsin Birth Defects Prevention and Surveillance Program (WBDPSP) in the Department of Health Services (DHS), 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. Wis. Stat. § 253.12 specifies that information collected in the registry should facilitate referrals for early intervention or other appropriate services.

How has WBDR reporting 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. The statute was changed in late 2017 so that identifying information is 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. DHS will implement this change starting July 1, 2018.

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. Reporters should retain documentation when parents refuse to include identifying information with any report submitted to the registry. This documentation should be retained per hospital/clinic policy, with a minimum of three years. A sample documentation form called Wisconsin Birth Defects Registry-Request to Remove Identifiers F-40054A is available at <https://www.dhs.wisconsin.gov/forms/f4/f40054a.docx> (English) and <https://www.dhs.wisconsin.gov/forms/f4/f40054as.docx> (Spanish).

Parents of children reported in the WBDR with identifying information will receive a letter from DHS, a fact sheet about the WBDR, and regional centers for Children and Youth with Special Health Care Needs (CYSHCN) brochures in English and 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.

Where can I find additional information?

More information about the WBDR, including fact sheets for providers (P-02147A) and families (P-02147) are available at the WBDPSP website:

<https://www.dhs.wisconsin.gov/cyshcn/birthdefects/index.htm>.

To learn more about the regional centers for CYSHCN:
<https://www.dhs.wisconsin.gov/cyshcn/regionalcenters.htm>

If you have questions about these changes, contact the Wisconsin Birth Defects Registry help line at 608-267-2911 or by email at dhswbdr@dhs.wisconsin.gov.

Sincerely,

A handwritten signature in black ink, appearing to read "Karen McKeown", with a long horizontal flourish extending to the right.

Karen McKeown
State Health Officer and Administrator