

# The Wisconsin Birth Defect Prevention and Surveillance System

## Wisconsin Council on Birth Defect Prevention and Surveillance Diagnosed Condition Review Criteria Policy and Procedure

### Policy

The Wisconsin Council on Birth Defects Prevention and Surveillance (Council), as outlined in Wis. Stat. § 253.12 is responsible for making recommendations to the Department of Health Services (DHS) regarding the Birth Defects Registry (Registry). This includes generating a list of reportable conditions through a unanimous vote and providing that list to the DHS Secretary who maintains the list. Communication of the revised list is sent to mandated reporters (physicians, specialty clinics and hospitals may report). Reporting forms are updated to reflect the revised list of reportable conditions and are posted to DHS' [Birth Defect Prevention and Surveillance webpage](#).

### Background

The Registry has the following characteristics:

- It is a *passive* surveillance system, dependent upon reporting by physicians and specialty clinics.
- It is *selective* and *closed*. Reporting of only certain birth defects is mandated, and the list of reportable conditions is explicit. The list is reviewed annually by the Council following a review of the list of reportable conditions.
- It is an *opt-out* registry. Infants and children's identifying information is automatically included in the registry (provided their condition is reported), unless the child's parent or guardian opts out of including that information. However, all other information is required to be reported.
- It is *age limited*. Reports are submitted only for children up to two years of age who have been diagnosed with or are being treated for birth defects.

The list of reportable conditions was developed in 2004, based on a set of primary criteria outlined in this procedure, and updated in 2021. The list mirrors a list of birth defects developed by the Center for Disease Control and Prevention and the National Birth Defects Prevention

Network. That list includes core, recommended, and extended conditions. All of these conditions are included in the Wisconsin list of reportable conditions for the Wisconsin Registry, plus some additional conditions that were added in 2004 which meet the Wisconsin condition criteria.

## **Procedure for reportable condition review**

### **A. Nomination of new conditions**

1. Proposed new conditions to be added to the Registry, (identified by the public and/or health care professionals) shall be forwarded to the Wisconsin Birth Defects Prevention and Surveillance Program (Program) staff using the Wisconsin Birth Defects Condition Nomination Form ([F02541](#)), by the end of January each calendar year.
2. All nominated conditions are collected throughout the year and presented to the Council at the first meeting of the calendar year.
3. Each condition is benchmarked against the 2004 established primary birth defect criteria outlined below:
  - Conforms to the Wis. Stat. § 253.12(1)(a) definition of a birth defect.

*"(a) "Birth defect" means any of the following conditions affecting an infant or child that occurs prior to or at birth and that requires medical or surgical intervention or interferes with normal growth and development:*

    - 1. A structural deformation, disruption or dysplasia.*
    - 2. A genetic, inherited or biochemical disease."*
    - Usually identifiable by two years of age.
    - Be a major anomaly (having medical, surgical, or developmental significance).
    - Be of 'sufficient' frequency which is estimated as a birth prevalence of one in 30,000 or more. This means that in Wisconsin, approximately two or more occurrences per year.
    - Is likely to be ascertained through assessment in one or more specialty clinics.
4. The Council votes on the nominated condition(s) at the first meeting in the calendar year designated as the Annual Business Meeting. A unanimous vote by Council members is needed for the condition(s) to be forwarded to the Department of Health Services (DHS) Secretary for inclusion on the list of reportable conditions.

5. Within 45 days of the Council vote, condition(s) that are unanimously approved by the Council are forwarded by letter to the DHS Secretary for approval. The letter, drafted by Program staff, is signed by the Council Chairperson or Co-Chairperson or, in the absence of both, a Council member chosen by the Council.
6. Program staff informs the person or agency that submitted the nomination of the outcome once the DHS Secretary has responded (generally by the second regular business meeting of the Council).
7. After the DHS Secretary has responded with approval, correspondence is sent to mandatory reporters (physicians and specialty clinics) informing them of the revised list of reportable conditions, which goes into effect January of the following year.

**B. Deletion of conditions**

Conditions recommended to be deleted by the Council follow the same procedure as above.

**C. Emerging conditions of public health interest**

An emerging condition is one that is of public health interest, newly discovered, or has unexpectedly increased in prevalence and requires prompt action. This emerging condition may be identified by the public or health care professional.

1. At any time that it is determined, an emerging condition of public health interest can be forwarded to Program staff using the "[Birth Defect Condition Nomination Form](#)." Emerging conditions of public health interest can be submitted at any time throughout the year and the Council will address them at the next meeting. Nomination forms can be sent to:

Email: [DHSWBDR@dhs.wisconsin.gov](mailto:DHSWBDR@dhs.wisconsin.gov).

Mail: Wisconsin Department of Health Services  
Division of Public Health  
Birth Defects Prevention and Surveillance Program  
1 W Wilson Street, Rm 233  
Madison, WI 53703

2. An emerging condition may or may not meet the established primary birth defect criteria.

3. An emerging condition(s) is then evaluated by Program staff and then recommended for addition to the Reportable Condition listing, which is forwarded to the DHS Secretary.
4. Upon DHS Secretary approval, communication of these emerging condition(s) that have now been added to the list of reportable conditions will be made to the Council and to mandated reporters (physicians and specialty clinics).
5. Reporting forms are updated to reflect emerging condition(s).
6. A emerging condition(s) is then evaluated and voted on by the Council at the next regular business meeting of the Council to determine if the condition(s) should be permanently added to the list of reportable conditions. A unanimous vote by Council members is needed for the condition(s) to be forwarded to the DHS Secretary for inclusion on the list of reportable conditions.
7. Within 45 days of the Council vote, emerging condition(s) that are unanimously approved by the Council are forwarded by letter to the DHS Secretary for approval. The letter, drafted by Program staff, is signed by the Council Chairperson or Co-Chairperson or, in the absence of both, a Council member chosen by the Council.
8. Program staff informs the person or agency that submitted the nomination of the outcome once the DHS Secretary has responded (generally by the second regular business meeting of the Council).
9. After the DHS Secretary has responded with approval, correspondence is sent to mandatory reporters (physicians and specialty clinics) informing them of the revised list of reportable conditions, which goes into effect immediately along with the revised date.

July 11, 2023