



## 2015 SENATE BILL 39

February 19, 2015 – Introduced by Senators LASSA, L. TAYLOR, C. LARSON, RINGHAND, WIRCH, MILLER, RISSER and HANSEN, cosponsored by Representatives NOVAK, SPIROS, BERCEAU, MILROY, SUBECK, RIEMER, OHNSTAD, SINICKI, BOWEN, KAHL, SARGENT, BROSTOFF, HESSELBEIN, MEYERS, JOHNSON, KESSLER, ZAMARRIPA, TRANEL, KITCHENS, VANDERMEER, DANOU, WACHS, C. TAYLOR, BILLINGS, TAUCHEN and KLEEFISCH. Referred to Committee on Health and Human Services.

- 1 **AN ACT to amend 253.13 (1); and to create 253.13 (1g) of the statutes; relating**  
2 **to: newborn screening for certain lysosomal storage disorders.**

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### *Analysis by the Legislative Reference Bureau*

Under current law, the attending physician or nurse–midwife must ensure that every infant born undergoes testing for certain congenital and metabolic disorders prior to the infant’s discharge from the hospital or maternity home. For infants born elsewhere, the attending physician, nurse–midwife, or other birth attendant must ensure that the infant is tested within a week of birth. As authorized by current law, the Department of Health Services (DHS) specifies by rule the congenital and metabolic disorders for which newborn infants are to be screened. Current law allows an exception to the testing requirement if the parents or legal guardian object on the basis of a conflict with religious tenets and practices or with their personal convictions.

This bill requires that, in addition to the other congenital and metabolic disorders for which testing is currently required under DHS rules, the attending physician, nurse–midwife, or in certain circumstances, other birth attendant, must ensure that every infant born undergoes testing for certain lysosomal storage disorders, specifically, globoid cell leukodystrophy, also known as Krabbe disease; Fabry disease, Pompe disease; Niemann–Pick disease; Gaucher disease, and Hurler syndrome, also known as mucopolysaccharidosis type I (MPS I). For infants born in a hospital or maternity home, the attending physician or nurse–midwife must ensure this testing is completed before the infant is discharged from the hospital or within one week of birth, if the infant has not yet been discharged. For births

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occurring outside a hospital or maternity home setting, the attending physician, nurse–midwife, or other birth attendant must ensure testing is done within one week of birth. The parental objection exemption under current law also applies to the testing required under this bill.

For further information see the *state* fiscal estimate, which will be printed as an appendix to this bill.

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*The people of the state of Wisconsin, represented in senate and assembly, do enact as follows:*

1           **SECTION 1.** 253.13 (1) of the statutes is amended to read:

2           253.13 (1) TESTS; REQUIREMENTS. The attending physician or nurse licensed  
3 under s. 441.15 shall cause every infant born in each hospital or maternity home,  
4 prior to ~~its~~ the infant's discharge ~~therefrom~~, to be subjected to tests for congenital and  
5 metabolic disorders, as specified in rules promulgated by the department. If the  
6 infant is born elsewhere than in a hospital or maternity home, the attending  
7 physician, nurse licensed under s. 441.15, or birth attendant who attended the birth  
8 shall cause the infant, within one week of birth, to be subjected to these tests.

9           **SECTION 2.** 253.13 (1g) of the statutes is created to read:

10           253.13 (1g) SCREENING FOR CERTAIN LYSOSOMAL STORAGE DISORDERS. (a) In  
11 addition to the testing required under sub. (1), the attending physician or nurse  
12 licensed under s. 441.15 shall cause every infant born in each hospital or maternity  
13 home, prior to the infant's discharge or within one week of the birth if the infant has  
14 not yet been discharged, to be subjected to tests for the following lysosomal storage  
15 disorders:

- 16           1. Globoid cell leukodystrophy, also known as Krabbe disease.
- 17           2. Fabry disease.
- 18           3. Pompe disease.
- 19           4. Niemann–Pick disease.

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1           5. Gaucher disease.

2           6. Hurler syndrome, also known as mucopolysaccharidosis type I.

3           (b) If the infant is born elsewhere than in a hospital or maternity home, the  
4 attending physician, nurse licensed under s. 441.15, or birth attendant who attended  
5 the birth shall cause the infant, within one week of birth, to be subjected to the tests  
6 under par. (a).

7           (c) No later than June 1, 2018, and every 2 years thereafter, the department  
8 shall evaluate the appropriateness of mandatory newborn testing for lysosomal  
9 storage disorders in addition to those listed under par. (a). If the department  
10 determines that testing for one or more lysosomal storage disorders in addition to  
11 those listed under par. (a) is appropriate, the department, under the authority  
12 granted under sub. (1), may promulgate rules adding to the list of disorders for which  
13 newborn testing is required.

14           **SECTION 3. Effective date.**

15           (1) This act takes effect on the first day of the 3rd month beginning after  
16 publication.

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(END)