



State of Wisconsin
2021 - 2022 LEGISLATURE

LRB-1939/1
SWB:amn

2021 SENATE BILL 194

March 10, 2021 - Introduced by Senators TESTIN, MARKLEIN, DARLING and L. TAYLOR, cosponsored by Representatives NOVAK, TRANEL, DITTRICH, KITCHENS, ROZAR, SHANKLAND, SKOWRONSKI, SPIROS, SWEARINGEN, TAUCHEN, TUSLER, VORPAGEL and SUBECK. Referred to Committee on Health.

1 **AN ACT to amend** 253.13 (1); and **to create** 253.13 (1g) of the statutes; **relating**
2 **to:** newborn screening for Krabbe disease and requiring evaluation of
3 additional lysosomal storage disorders for mandatory screening.

Analysis by the Legislative Reference Bureau

This bill requires that, in addition to the other congenital and metabolic disorders for which testing is currently required under rules established by the Department of Health Services, the attending physician, nurse-midwife, or in certain circumstances, other birth attendant, must ensure that every infant born undergoes testing for globoid cell leukodystrophy, also known as Krabbe disease, which is a lysosomal storage disorder. Current law requires that an attending physician or nurse-midwife 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, 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.

Under the bill, for infants born in a hospital or maternity home, the attending physician or nurse-midwife must ensure testing for Krabbe disease is completed before the infant is discharged or within one week of birth, if the infant has not yet

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been discharged. For births 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.

The bill also requires DHS to evaluate on a biennial basis the appropriateness of mandatory newborn testing for lysosomal storage disorders in addition to the testing for Krabbe disease. If DHS determines that testing for one or more other lysosomal storage disorders is appropriate, DHS may promulgate rules adding to the list of disorders for which newborn testing is required.

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

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 testing for globoid cell leukodystrophy,
15 also known as Krabbe disease.

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

5 (c) No later than June 1, 2022, and every 2 years thereafter, the department
6 shall evaluate the appropriateness of mandatory newborn testing for lysosomal
7 storage disorders in addition to the testing required under par. (a). If the department
8 determines that testing for one or more lysosomal storage disorders in addition to the
9 testing required under par. (a) is appropriate, the department, under the authority
10 granted under sub. (1), may promulgate rules adding to the list of disorders for which
11 newborn testing is required.

SECTION 3. Effective date.

12 (1) This act takes effect on the first day of the 3rd month beginning after
13 publication.
14

15 (END)