

1 HOUSE BILL NO. 423

2 INTRODUCED BY D. LENZ

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 4 A BILL FOR AN ACT ENTITLED: "AN ACT GENERALLY REVISING LAWS RELATED TO SCREENING
 5 NEWBORNS FOR GENETIC OR METABOLIC DISORDERS; CREATING A NEWBORN SCREENING
 6 COMMITTEE; REQUIRING THE DEPARTMENT TO ADD NEW CONDITIONS TO THE NEWBORN
 7 SCREENING PANEL WHEN CERTAIN CONDITIONS ARE MET; PROVIDING RULEMAKING AUTHORITY;
 8 AND AMENDING SECTION 50-19-203, MCA."
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10 WHEREAS, the Montana Legislature has become aware that there are newborn screening tests
 11 available and treatments that can improve quality of life in conjunction with early diagnosis for certain lysosomal
 12 storage disorders including MPS I, Pompe, Gaucher, Fabry, and Krabbe diseases; and

13 WHEREAS, it is the intent of the Montana Legislature that these disorders be added to the newborn
 14 screening panel provided for each infant born in the State of Montana and that additional diseases be added to
 15 the panel in response to technological advancements; and

16 WHEREAS, to ensure that MPS I, Pompe, Gaucher, Fabry, and Krabbe diseases are ~~added~~
 17 CONSIDERED FOR ADDITION to the newborn screening panel and THAT other diseases are added as new testing
 18 and treatment methods become available, the creation of an advisory committee and protocols for adding new
 19 diseases to the newborn screening panel is necessary.
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21 BE IT ENACTED BY THE LEGISLATURE OF THE STATE OF MONTANA:
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23 NEW SECTION. Section 1. Newborn screening advisory committee -- membership -- duties. (1)

24 There is a newborn screening advisory committee. The committee consists of ~~six~~ EIGHT members appointed by
 25 the director of the department as follows:

26 (a) ~~one member who is a person~~ TWO MEMBERS WHO ARE PERSONS affected by or ~~a family member~~
 27 FAMILY MEMBERS of a person affected by a disorder tested for pursuant to 50-19-203;

28 (b) ~~one member who is a physician or nurse practitioner~~ TWO MEMBERS WHO ARE PHYSICIANS OR NURSE

1 PRACTITIONERS WHO ARE board-certified in obstetrics, pediatrics, FAMILY MEDICINE, or neonatology;

2 (c) one member who is a representative of a birthing center;

3 (d) one member who is a representative of medicaid or the insurance industry;

4 (e) one member who is a representative of an advocacy association regarding newborns with medical
5 conditions or rare disorders; and

6 (f) one member ~~with~~ WHO IS A MEDICAL GENETICIST OR WHO HAS at least 5 years of experience working
7 in a testing laboratory.

8 (2) (a) Except as provided in subsection (2)(b), each ~~board~~ COMMITTEE member shall serve a
9 staggered 3-year term and is subject to reappointment for one succeeding term.

10 (b) The director shall appoint the first six members to an initial term of 1, 2, ~~or 3,~~ OR 4 years so that the
11 terms of no more than two members expire in any given year.

12 (3) The committee shall meet at least two times each year.

13 (4) The committee shall report its findings to the director at least once a year, if applicable, including
14 providing recommendations that the department initiate rulemaking to add an additional metabolic or genetic
15 disorder to the newborn screening protocol.

16 (5) Members of the committee are not entitled to compensation for their services, but they are entitled
17 to a mileage allowance, as provided in 2-18-503, and travel and meal expenses, as provided in 2-18-501 and 2-
18 18-502.

19 (6) The ~~board~~ COMMITTEE shall gather information on recent developments in testing technology,
20 investigate staff and equipment requirements of new tests, and perform other activities related to newborn
21 screening. The ~~board~~ COMMITTEE may make recommendations to the director regarding conditions that should
22 be added to the newborn screening panel.

23 (7) The ~~board~~ COMMITTEE is attached to the department of public health and human services for
24 administrative purposes, and the department shall provide staff support to the ~~board~~ COMMITTEE.

25 (8) THE COMMITTEE SHALL GIVE PRIORITY AT ITS FIRST MEETING TO REVIEWING KRABBE DISEASE AND SHALL
26 RECOMMEND THAT THE DISEASE BE ADDED TO THE NEWBORN SCREENING PANEL. IF THE COMMITTEE FAILS TO MAKE THE
27 RECOMMENDATION, THE DIRECTOR SHALL DISBAND THE COMMITTEE.

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