

2 State of Arkansas

3 93rd General Assembly

4 Third Extraordinary Session, 2021

A Bill

JMB/JMB

HOUSE BILL

5
6 By: Representative Pilkington

7 Filed with: House Committee on Public Health, Welfare, and Labor
8 pursuant to A.C.A. §10-3-217.

9 For An Act To Be Entitled

10 AN ACT TO CREATE LUCILLE'S LAW; TO REQUIRE NEWBORN
11 SCREENING FOR KRABBE DISEASE, ALSO KNOWN AS "GLOBOID
12 CELL LEUKODYSTROPHY"; TO MANDATE THAT INSURANCE
13 POLICIES COVER NEWBORN SCREENINGS FOR KRABBE
14 DISEASE, ALSO KNOWN AS "GLOBOID CELL LEUKODYSTROPHY";
15 AND FOR OTHER PURPOSES.

16 17 18 Subtitle

19 TO CREATE LUCILLE'S LAW; TO REQUIRE
20 NEWBORN SCREENING FOR KRABBE DISEASE,
21 ALSO KNOWN AS "GLOBOID CELL
22 LEUKODYSTROPHY"; AND TO MANDATE THAT
23 INSURANCE POLICIES COVER NEWBORN
24 SCREENINGS FOR KRABBE DISEASE.

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27 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:

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29 SECTION 1. DO NOT CODIFY. Title.

30 This act shall be known and may be cited as "Lucille's Law".

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32 SECTION 2. Arkansas Code § 20-15-302(a)(1)(A), concerning the testing of newborn infants, is
33 amended to read as follows:

34 (a)(1)(A) All newborn infants shall be tested for phenylketonuria, hypothyroidism, galactosemia,
35 cystic fibrosis, sickle-cell anemia, ~~and~~ spinal muscular atrophy, and Krabbe disease, also known as
36 "globoid cell leukodystrophy".

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SECTION 3. Arkansas Code § 23-79-1801, concerning definitions related to coverage for newborn screening for spinal muscular atrophy, is amended to add an additional subdivision to read as follows:

- (5)(A) "Krabbe disease" means a genetic disease that:
 - (i) Affects the nervous system; and
 - (ii) Is caused by deficiency of a particular enzyme.
- (B) "Krabbe disease" is also known as "globoid cell leukodystrophy".

SECTION 4. Arkansas Code § 23-79-1802 is amended to read as follows:

23-79-1802. Coverage for newborn screening ~~for spinal muscular atrophy.~~

(a) A health benefit plan that is offered, issued, or renewed in this state shall provide coverage for newborn screening ~~for spinal muscular atrophy~~ by a healthcare professional ~~on or after January 1, 2020;~~

- (1) For spinal muscular atrophy; and
- (2) On and after, January 1, 2024, for Krabbe disease.

(b) The coverage for newborn screening ~~for spinal muscular atrophy~~ under this section:

- (1) Is not subject to policy deductibles or copayment requirements; and
- (2) Does not diminish or limit benefits otherwise allowable under a health benefit plan.

Referred by Representative Pilkington
Prepared by: JMB/JMB