

INTERIM STUDY PROPOSAL 2021-120

State of Arkansas  
93rd General Assembly  
Third Extraordinary Session, 2021

**A Bill**

JMB/JMB  
HOUSE BILL

By: Representative Pilkington

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

**For An Act To Be Entitled**

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

**Subtitle**

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

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

SECTION 1. DO NOT CODIFY. Title.

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

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

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