

1 State of Arkansas  
2 94th General Assembly  
3 Regular Session, 2023  
4

# A Bill

HOUSE BILL 1102

5 By: Representative Pilkington  
6 By: Senator C. Penzo  
7

## For An Act To Be Entitled

9 AN ACT TO CREATE THE UNIVERSAL NEWBORN SCREENING ACT;  
10 TO ENSURE THAT NEWBORNS ARE SCREENED FOR CONDITIONS  
11 RECOMMENDED BY THE UNITED STATES DEPARTMENT OF HEALTH  
12 AND HUMAN SERVICES; AND FOR OTHER PURPOSES.  
13

## Subtitle

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15 TO CREATE THE UNIVERSAL NEWBORN SCREENING  
16 ACT; AND TO ENSURE THAT NEWBORNS ARE  
17 SCREENED FOR CONDITIONS RECOMMENDED BY  
18 THE UNITED STATES DEPARTMENT OF HEALTH  
19 AND HUMAN SERVICES.  
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23 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:  
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25 SECTION 1. DO NOT CODIFY. Title.

26 This act shall be known and may be cited as the "Universal Newborn  
27 Screening Act".  
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29 SECTION 2. Arkansas Code § 20-15-302 is amended to read as follows:  
30 20-15-302. Testing of newborn infants.

31 (a)(1)(A) There is created an advance universal newborn screening  
32 program to be administered by the Department of Health.

33 (B) All newborn infants shall be tested for  
34 ~~phenylketonuria, hypothyroidism, galactosemia, cystic fibrosis, sickle-cell~~  
35 ~~anemia, and spinal muscular atrophy~~ medical conditions as determined by the  
36 Secretary of the Department of Health, including without limitation



1 conditions listed in the recommended uniform screening panel recommended by  
 2 the United States Secretary of Health and Human Services, in order to provide  
 3 appropriate newborn screening guidelines to protect the health and welfare of  
 4 newborns.

5 ~~(B) In addition, if reliable and efficient testing~~  
 6 ~~techniques are available, all newborn infants shall be tested for other~~  
 7 ~~genetic disorders by employing procedures approved by the State Board of~~  
 8 ~~Health.~~

9 (2)(A) Medicaid shall reimburse the hospital that performs the  
 10 tests required under subdivision (a)(1) of this section for the cost of the  
 11 tests.

12 (B) The reimbursement shall be in addition to the  
 13 hospital's per diem payments for the newborn infant.

14 (3)(A) The Department of Health shall provide necessary and  
 15 medically indicated treatment for diagnosed conditions under this subchapter  
 16 when:

17 (i) The treatment is not available through other  
 18 state agencies; and

19 (ii) The applicant has exhausted all benefits from  
 20 private third-party payers, Medicare, Medicaid, and other government  
 21 assistance programs and after consideration of the applicant's income and  
 22 assets.

23 (B) If medically necessary food treatment products for a  
 24 diagnosed condition under this subchapter must be purchased, the Department  
 25 of Health shall either:

26 (i) Reimburse the purchaser for the medically  
 27 necessary food treatment product; or

28 (ii) Purchase medically necessary food treatment  
 29 products for distribution to an individual with a diagnosed condition under  
 30 this subchapter.

31 (b) All positive test results shall be sent immediately to the  
 32 Department of Health.

33 (c)(1) ~~The department~~ Department of Health shall establish and  
 34 maintain a program of reviewing and following up on positive cases so that  
 35 measures may be taken to ~~prevent intellectual and other developmental support~~  
 36 early diagnosis, treatment, and services for healthy development and prevent

1 disability or ~~other permanent disabilities~~ morbidity.

2 (2)(A) Information on newborn infants and their families  
 3 compiled under this section may be used by the ~~department~~ Department of  
 4 Health and persons or public or private entities designated by the ~~department~~  
 5 Department of Health.

6 (B) Information used under subdivision (c)(2)(A) of this  
 7 section may not refer to or disclose the identity of any person.

8 (3) All materials, data, and information received by the  
 9 ~~department~~ Department of Health are confidential and are not subject to  
 10 examination or disclosure as public information under the Freedom of  
 11 Information Act of 1967, § 25-19-101 et seq.

12 (d)(1) The ~~department~~ Department of Health shall conduct an intensive  
 13 educational and training program among physicians, hospitals, public health  
 14 nurses, and the public concerning the ~~disorders covered under this section~~  
 15 conditions as determined by the Secretary of the Department of Health under  
 16 subdivision (a)(1)(B) of this section.

17 (2) The program shall include information concerning:

18 (A) The nature of the ~~disorders~~ conditions;

19 (B) Testing for the detection of these ~~disorders~~  
 20 conditions; and

21 (C) Treatment modalities for these ~~disorders~~ conditions.

22 (e) The provisions of this section shall not apply if the parents or  
 23 legal guardian of a newborn infant object to the testing on medical,  
 24 religious, or philosophical grounds.

25 (f) Testing for cystic fibrosis under this section shall be  
 26 implemented only if funding is available.

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 28 SECTION 3. Arkansas Code § 20-15-304 is amended to read as follows:

29 20-15-304. Administration by Department of Health.

30 It shall be the duty of the Department of Health to:

31 (1) Enforce this subchapter;

32 (2) Prescribe the tests that may be administered in compliance  
 33 with this subchapter;

34 (3) Promulgate rules in conjunction with the Insurance  
 35 Commissioner establishing:

36 (A) What persons and institutions shall be required to

1 obtain specimens from newborn infants in compliance with this subchapter;

2 (B) The amount to be charged by the central laboratory for  
3 processing the specimens; and

4 (C) The method of billing the charges to the persons and  
5 institutions;

6 (4) Furnish copies of this subchapter and the rules promulgated  
7 pursuant to this subchapter to physicians, hospitals, or other institutions  
8 or persons required by its rules to have tests administered to newborn  
9 infants;

10 (5)(A) Establish a central laboratory and to equip, staff, and  
11 operate the laboratory for the purpose of receiving specimens from  
12 physicians, hospitals, and institutions, to assure that tests are conducted,  
13 and to report findings resulting from the tests.

14 (B) Initial laboratory screening tests for conditions  
15 under this subchapter shall be performed by the department or its designee  
16 without charge;

17 (6)(A) Monitor positive test results and assist in treatment and  
18 care of affected infants, such follow-up procedures to begin no later than  
19 ten (10) days from the time a specimen is diagnosed as positive.

20 (B) With consent of the parent or legal guardian, the  
21 department shall monitor:

22 (i) Infants to assure appropriate testing to confirm  
23 the condition suggested by the screening test results; and

24 (ii) Therapy treatment for infants with confirmed  
25 diagnosis of conditions under this subchapter; and

26 (7) Disseminate information and advice to the public concerning  
27 the dangers and effects of ~~phenylketonuria, hypothyroidism, galactosemia,~~  
28 ~~sickle-cell anemia, and all other disorders of metabolism~~ conditions for  
29 which screening is performed by or for the State of Arkansas;

30 (8) Establish ongoing education and support activities for  
31 persons with confirmed diagnosis of conditions under this subchapter and for  
32 the families of these persons; and

33 (9) Review periodically the advance universal newborn screening  
34 program to determine the efficacy and cost effectiveness of the program and  
35 whether adjustments to the program are necessary to protect the health and  
36 welfare of newborns and to maximize the number of newborn screenings that may

1 be conducted with the funding available for the program.

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 3 SECTION 4. Arkansas Code § 23-79-1801(4), concerning the definition of  
 4 "spinal muscular atrophy" regarding coverage for newborn screening for spinal  
 5 muscular atrophy, is repealed.

6 ~~(4) "Spinal muscular atrophy" means a genetic disease that~~  
 7 ~~affects the part of the nervous system that controls voluntary muscle~~  
 8 ~~movement.~~

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 10 SECTION 5. Arkansas Code § 23-79-1802 is amended to read as follows:

11 23-79-1802. Coverage for newborn screening ~~for spinal muscular~~  
 12 ~~atrophy.~~

13 (a) A health benefit plan that is offered, issued, or renewed in this  
 14 state shall provide coverage for newborn screening for ~~spinal muscular~~  
 15 ~~atrophy~~ conditions as determined by the Secretary of the Department of Health  
 16 under § 20-15-302 by a healthcare professional on or after January 1, 2020.

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

19 (1) Is not subject to policy deductibles or copayment  
 20 requirements; and

21 (2) Does not diminish or limit benefits otherwise allowable  
 22 under a health benefit plan.

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