

1 State of Arkansas As Engrossed: H1/23/23 S3/27/23

2 94th General Assembly

# A Bill

3 Regular Session, 2023

HOUSE BILL 1102

4

5 By: Representative Pilkington

6 By: Senator C. Penzo

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## 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.

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## Subtitle

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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.

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34 ~~phenylketonuria, hypothyroidism, galactosemia, cystic fibrosis, sickle-cell~~  
35 ~~anemia, and spinal muscular atrophy~~ core medical conditions as listed in the  
36 recommended uniform screening panel recommended by the United States



1 Secretary of Health and Human Services, in order to provide appropriate  
2 newborn screening guidelines to protect the health and welfare of newborns.

3 (ii) For each core medical condition added to the  
4 list of recommended uniform screening panel by the United States Secretary of  
5 Health and Human Services, the Department of Health or its designee, in  
6 accordance with §20-15-304, shall begin testing for the newly added core  
7 medical conditions upon approval of the appropriation of funding by the  
8 General Assembly or funding under §20-15-304, if required, or within thirty-  
9 six (36) months upon introduction to the recommended uniform screening panel  
10 recommended by the United States Secretary of Health and Human Services.

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

15 (2)(A) Medicaid shall reimburse the hospital that performs the  
16 tests required under subdivision (a)(1) of this section for the cost of the  
17 tests.

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

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

22 (c)(1) The ~~department~~ Department of Health shall establish and  
23 maintain a program of reviewing and following up on positive cases so that  
24 measures may be taken to ~~prevent intellectual and other developmental support~~  
25 early diagnosis, treatment, and services for healthy development and prevent  
26 disability or other permanent disabilities morbidity.

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

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

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

1 (d)(1) The ~~department~~ Department of Health shall conduct an intensive  
2 educational and training program among physicians, hospitals, public health  
3 nurses, and the public concerning the ~~disorders covered under this section~~  
4 conditions.

5 (2) The program shall include information concerning:

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

7 (B) Testing for the detection of these ~~disorders~~  
8 conditions; and

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

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

13 ~~(f) Testing for cystic fibrosis under this section shall be~~  
14 ~~implemented only if funding is available.~~

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

17 20-15-304. Administration by Department of Health.

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

19 (1) Enforce this subchapter;

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

22 (3) Promulgate rules in conjunction with the Insurance  
23 Commissioner establishing:

24 (A) What persons and institutions shall be required to  
25 obtain specimens from newborn infants in compliance with this subchapter;

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

28 (C) The method of billing the charges to the persons and  
29 institutions;

30 (4) Furnish copies of this subchapter and the rules promulgated  
31 pursuant to this subchapter to physicians, hospitals, or other institutions  
32 or persons required by its rules to have tests administered to newborn  
33 infants;

34 (5)(A) Establish a central laboratory and to equip, staff, and  
35 operate the laboratory for the purpose of receiving specimens from  
36 physicians, hospitals, and institutions, to assure that tests are conducted,

1 and to report findings resulting from the tests.

2 (B) Initial laboratory screening tests for conditions  
3 under this subchapter shall be performed by the department or its designee;

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

7 (B) The department shall monitor infants to assure  
8 appropriate testing to confirm the condition suggested by the screening test  
9 results; and

10 (7) Disseminate information and advice to the public concerning  
11 the dangers and effects of ~~phenylketonuria, hypothyroidism, galactosemia,~~  
12 ~~sickle-cell anemia, and all other disorders of metabolism~~ conditions for  
13 which screening is performed by or for the State of Arkansas.

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

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

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22 SECTION 5. Arkansas Code § 23-79-1802 is amended to read as follows:  
23 23-79-1802. Coverage for newborn screening ~~for spinal muscular~~  
24 ~~atrophy.~~

25 (a) A health benefit plan that is offered, issued, or renewed in this  
26 state shall provide coverage for newborn screening for ~~spinal muscular~~  
27 ~~atrophy~~ conditions as determined by the Department of Health under § 20-15-  
28 302 by a healthcare professional on or after January 1, 2020.

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

31 (1) Is not subject to policy deductibles or copayment  
32 requirements; and

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

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36 /s/Pilkington