

Stricken language would be deleted from and underlined language would be added to present law.

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

As Engrossed: H1/23/23

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
14

Subtitle

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.
20
21
22

23 BE IT ENACTED BY THE GENERAL ASSEMBLY OF THE STATE OF ARKANSAS:
24

25 SECTION 1. DO NOT CODIFY. Title.

26 This act shall be known and may be cited as the "Universal Newborn
27 Screening Act".
28

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

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

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

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

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

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

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

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

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

33 (2) The program shall include information concerning:

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

35 (B) Testing for the detection of these ~~disorders~~
36 conditions; and

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

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

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

7

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

9 20-15-304. Administration by Department of Health.

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

11 (1) Enforce this subchapter;

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

14 (3) Promulgate rules in conjunction with the Insurance
15 Commissioner establishing:

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

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

20 (C) The method of billing the charges to the persons and
21 institutions;

22 (4) Furnish copies of this subchapter and the rules promulgated
23 pursuant to this subchapter to physicians, hospitals, or other institutions
24 or persons required by its rules to have tests administered to newborn
25 infants;

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

30 (B) Initial laboratory screening tests for conditions
31 under this subchapter shall be performed by the department or its designee
32 without charge to the patient or the patient's family;

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

36 (B) With consent of the parent or legal guardian, the

1 department shall monitor infants to assure appropriate testing to confirm the
2 condition suggested by the screening test results; and

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

7 (8) Review periodically the advance universal newborn screening
8 program to determine the efficacy and cost effectiveness of the program and
9 whether adjustments to the program are necessary to protect the health and
10 welfare of newborns and to maximize the number of newborn screenings that may
11 be conducted with the funding available for the program.

12
13 SECTION 4. Arkansas Code § 23-79-1801(4), concerning the definition of
14 "spinal muscular atrophy" regarding coverage for newborn screening for spinal
15 muscular atrophy, is repealed.

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

19
20 SECTION 5. Arkansas Code § 23-79-1802 is amended to read as follows:

21 23-79-1802. Coverage for newborn screening ~~for spinal muscular~~
22 ~~atrophy.~~

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

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

29 (1) Is not subject to policy deductibles or copayment
30 requirements; and

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

33
34 /s/Pilkington