

116TH CONGRESS
1ST SESSION

H. R. 534

To amend the Public Health Service Act, in relation to requiring adrenoleukodystrophy screening of newborns.

IN THE HOUSE OF REPRESENTATIVES

JANUARY 14, 2019

Ms. CLARKE of New York (for herself and Mr. ZELDIN) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

To amend the Public Health Service Act, in relation to requiring adrenoleukodystrophy screening of newborns.

1 *Be it enacted by the Senate and House of Representa-
2 tives of the United States of America in Congress assembled,*

3 SECTION 1. SHORT TITLE.

4 This Act may be cited as “Aidan’s Law”.

5 SEC. 2. FINDINGS.

6 Congress finds the following:

7 (1) Adrenoleukodystrophy is a deadly genetic
8 disease that destroys myelin, the protective sheath
9 that surrounds the brain’s neurons, which are the

1 nerve cells that allow us to think and to control our
2 muscles.

3 (2) Adrenoleukodystrophy affects 1 in 17,000
4 people and most severely affects boys and men.

5 (3) Adrenoleukodystrophy newborn screening
6 tests have been validated with false positive of less
7 than 0.1 percent.

8 (4) Early identification of adrenoleukodystrophy
9 allows those who are affected to be treated and have
10 the best chance at a healthy life.

11 SEC. 3. SCREENING OF ADRENOLEUKODYSTROPHY.

12 (a) IN GENERAL.—Part A of title XI of the Public
13 Health Service Act (42 U.S.C. 300b–1 et seq.) is amended
14 by adding at the end the following:

15 “SEC. 1118. ADRENOLEUKODYSTROPHY.

16 “(a) IN GENERAL.—Each hospital, child care center,
17 clinic, or other similar institution caring for infants who
18 are 28 days or less of age (as designated by the Secretary)
19 may administer, or cause to have administered, to every
20 such infant in its care a test for adrenoleukodystrophy in
21 accordance with this section.

22 “(b) PROCESS.—

23 “(1) IN GENERAL.—In carrying out this sec-
24 tion, the chief executive officer for health in each
25 State may prescribe standards and procedures for

1 the administration of testing under subsection (a),
2 including recording the results of such tests, track-
3 ing activities, conducting follow-up reviews, and car-
4 rying out educational activities.

5 “(2) DISSEMINATION OF INFORMATION.—In
6 carrying out this section, the chief executive officer
7 for health in each State may prescribe standards
8 and procedures setting forth the manner in which
9 testing information is disseminated to a parent or
10 guardian of the infant to be tested.

11 “(3) FAILURE TO PRESCRIBE.—If a State has
12 not prescribed standards and procedures that are
13 approved as provided for in paragraph (4) by the
14 date that is 2 years after the date of enactment of
15 this section, the Discretionary Advisory Committee
16 on Heritable Disorders in Newborns and Children
17 established under section 1111 (referred to in this
18 section as the ‘Advisory Committee’) shall prescribe
19 appropriate standards and procedures which may be
20 implemented by such State.

21 “(4) REVIEW AND APPROVAL.—The standards
22 and procedures prescribed under this subsection
23 shall be subject to review and approval by the Advi-
24 sory Committee. In reviewing or prescribing stand-
25 ards and procedures as required under this sub-

1 section, the Advisory Committee shall consider
2 standards and procedures adopted in other States
3 with respect to the screening of adrenoleukodystro-
4 phy, the standards and procedures adopted in such
5 State with respect to the screening of infants for
6 other heritable diseases, and any scientific evidence
7 the Advisory Committee considers relevant to pro-
8 vide for the screening of infants for adrenoleukodys-
9 trophy.”.

10 (b) REAUTHORIZATION OF HERITABLE DISORDERS
11 PROGRAM.—Section 1117 of the Public Health Service
12 Act (42 U.S.C. 300b–16) is amended—

15 (2) by redesignating paragraph (2) as para-
16 graph (3); and

19 “(2) to carry out the Heritable Disorders Pro-
20 gram under section 1109, \$15,000,000 for each of
21 fiscal years 2020 through 2023; and”.

22 SEC. 4. ADVISORY COMMITTEE ON HERITABLE DISORDERS

23 IN NEWBORNS AND CHILDREN.

24 Section 1111(b) of the Public Health Service Act (42
25 U.S.C. 300b-10(b)) is amended—

1 (1) in paragraph (7) by striking “and” after
2 the semicolon;

3 (2) by redesignating paragraph (8) as para-
4 graph (9); and

5 (3) by inserting after paragraph (7) the fol-
6 lowing:

7 “(8) carry out activities as provided for under
8 section 1118; and”.

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