

114TH CONGRESS
2D SESSION

H. R. 4692

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

IN THE HOUSE OF REPRESENTATIVES

MARCH 3, 2016

Ms. CLARKE of New York 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 the “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. REQUIRING THE SCREENING OF ADRENOLEUKO-**
12 **DYSTROPHY.**

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

16 **“SEC. 1118. ADRENOLEUKODYSTROPHY.**

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

23 “(b) PROCESS.—

24 “(1) IN GENERAL.—In carrying out this sec-
25 tion, the chief executive officer for health in each

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

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

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

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

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

11 (b) PENALTY.—A State that fails to prescribe stand-
12 ards and procedures as required under section 1118 of the
13 Public Health Service Act shall not be eligible for funds
14 under the Heritable Disorders Program established under
15 title XI of the Public Health Service Act (42 U.S.C. 300b–
16 1 et seq.).

17 (c) REAUTHORIZATION OF HERITABLE DISORDERS
18 PROGRAM.—Section 1117 of the Public Health Service
19 Act (42 U.S.C. 300b–16) is amended—

20 (1) in paragraph (1), by striking “and” at the
21 end;

22 (2) by redesignating paragraph (2) as para-
23 graph (3); and

24 (3) by inserting after paragraph (1), the fol-
25 lowing:

1 “(2) to carry out the Heritable Disorders Pro-
2 gram under section 1109, \$15,000,000 for each of
3 fiscal years 2016 through 2019; and”.

4 **SEC. 4. ADVISORY COMMITTEE ON HERITABLE DISORDERS**
5 **IN NEWBORNS AND CHILDREN.**

6 Section 1111(b) of the Public Health Service Act (42
7 U.S.C. 300b–10(b)) is amended—

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

10 (2) by redesignating paragraph (8) as para-
11 graph (9); and

12 (3) by inserting after paragraph (7) the fol-
13 lowing:

14 “(8) carry out activities are provided for under
15 section 1118; and”.

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