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.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

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

SEC. 2. FINDINGS.

Congress finds the following:

(1) Adrenoleukodystrophy is a deadly genetic disease that destroys myelin, the protective sheath that surrounds the brain’s neurons, which are the
nerve cells that allow us to think and to control our muscles.

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

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

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

SEC. 3. REQUIRING THE SCREENING OF ADRENOLEUKODYSTROPHY.

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

"SEC. 1118. ADRENOLEUKODYSTROPHY.

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

"(b) Process.—

"(1) In General.—In carrying out this section, the chief executive officer for health in each
State shall prescribe standards and procedures for the administration of testing under subsection (a), including recording the results of such tests, tracking activities, conducting follow-up reviews, and carrying out educational activities.

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

“(3) Failure to prescribe.—If a State has not prescribed standards and procedures that are approved as provided for in paragraph (4) by the date that is 2 years after the date of enactment of this section, the Discretionary Advisory Committee on Heritable Disorders in Newborns and Children established under section 1111 (referred to in this section as the ‘Advisory Committee’) shall prescribe appropriate standards and procedures for such State.

“(4) Review and approval.—The standards and procedures prescribed under this subsection shall be subject to review and approval by the Advisory Committee. In reviewing or prescribing stand-
ards and procedures as required under this sub-
section, the Advisory Committee shall consider
standards and procedures adopted in other States
with respect to the screening of adrenoleukodystro-
phy, the standards and procedures adopted in such
State with respect to the screening of infants for
other heritable diseases, and any scientific evidence
the Advisory Committee considers relevant to pro-
vide for the screening of infants for adrenoleukodys-
trophy.”.

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

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

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

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

(3) by inserting after paragraph (1), the fol-
lowing:
“(2) to carry out the Heritable Disorders Pro-
gram under section 1109, $15,000,000 for each of
fiscal years 2016 through 2019; and’’.

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

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

(1) in paragraph (7) by striking ‘‘and’’ after
the semicolon;

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

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

‘‘(8) carry out activities are provided for under
section 1118; and’’.