

113TH CONGRESS
1ST SESSION

S. 424

To amend title IV of the Public Health Service Act to provide for a National Pediatric Research Network, including with respect to pediatric rare diseases or conditions.

IN THE SENATE OF THE UNITED STATES

FEBRUARY 28, 2013

Mr. BROWN (for himself, Mr. WICKER, Mr. BLUMENTHAL, Mr. BLUNT, Ms. COLLINS, Mr. PORTMAN, and Mr. WHITEHOUSE) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To amend title IV of the Public Health Service Act to provide for a National Pediatric Research Network, including with respect to pediatric rare diseases or conditions.

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 “National Pediatric Re-
5 search Network Act of 2013”.

1 **SEC. 2. NATIONAL PEDIATRIC RESEARCH NETWORK.**

2 Section 409D of the Public Health Service Act (42
3 U.S.C. 284h; relating to the Pediatric Research Initiative)
4 is amended—

5 (1) by redesignating subsection (d) as sub-
6 section (f); and

7 (2) by inserting after subsection (c) the fol-
8 lowing:

9 “(d) NATIONAL PEDIATRIC RESEARCH NETWORK.—

10 “(1) NETWORK.—In carrying out the Initiative,
11 the Director of NIH, in consultation with the Direc-
12 tor of the Eunice Kennedy Shriver National Insti-
13 tute of Child Health and Human Development and
14 in collaboration with other appropriate national re-
15 search institutes and national centers that carry out
16 activities involving pediatric research, may provide
17 for the establishment of a National Pediatric Re-
18 search Network consisting of the pediatric research
19 consortia receiving awards under paragraph (2).

20 “(2) PEDIATRIC RESEARCH CONSORTIA.—

21 “(A) IN GENERAL.—The Director of NIH
22 may award funding, including through grants,
23 contracts or other mechanisms, to public or pri-
24 vate nonprofit entities—

25 “(i) for establishing or strengthening
26 pediatric research consortia; and

“(ii) for providing support for such consortia, including with respect to—

“(I) basic, clinical, behavioral, or translational research to meet unmet pediatric research needs; and

“(II) training researchers in pediatric research techniques in order to address unmet pediatric research needs.

“(B) RESEARCH.—The Director of NIH may ensure that—

“(i) each consortium receiving an award under subparagraph (A) conducts or supports at least one category of research described in subparagraph (A)(ii)(I) and collectively such consortia conduct or support all such categories of research; and

“(ii) one or more such consortia provide training described in subparagraph (A)(ii)(II).

“(C) NUMBER OF CONSORTIA.—The Director of NIH may make awards under this paragraph for not more than 8 pediatric research consortia, with a minimum of one pediatric re-

1 search consortium that prioritizes collaboration
 2 with institutions serving rural areas.

3 “(D) ORGANIZATION OF CONSORTIUM.—
 4 Each consortium receiving an award under sub-
 5 paragraph (A) shall—

6 “(i) be formed from a collaboration of
 7 cooperating institutions;

8 “(ii) be coordinated by a lead institu-
 9 tion; and

10 “(iii) meet such requirements as may
 11 be prescribed by the Director of NIH.

12 “(E) SUPPLEMENT, NOT SUPPLANT.—Any
 13 support received by a consortium under sub-
 14 paragraph (A) shall be used to supplement, and
 15 not supplant, other public or private support for
 16 activities authorized to be supported under this
 17 paragraph.

18 “(F) DURATION OF CONSORTIUM SUP-
 19 PORT.—Support of a consortium under sub-
 20 paragraph (A) may be for a period of not to ex-
 21 ceed 5 years. Such period may be extended at
 22 the discretion of the Director of NIH.

23 “(3) COORDINATION OF CONSORTIA ACTIVI-
 24 TIES.—The Director of NIH shall—

1 “(A) as appropriate, provide for the coordi-
 2 nation of activities (including the exchange of
 3 information and regular communication) among
 4 the consortia established pursuant to paragraph
 5 (2); and

6 “(B) as appropriate, require the periodic
 7 preparation and submission to the Director of
 8 reports on the activities of each such consor-
 9 tium.

10 “(e) RESEARCH ON PEDIATRIC RARE DISEASES OR
 11 CONDITIONS.—

12 “(1) IN GENERAL.—In making awards under
 13 subsection (d)(2) for pediatric research consortia,
 14 the Director of NIH may ensure that an appropriate
 15 number of such awards are awarded to such con-
 16 sortia that agree to—

17 “(A) focus primarily on pediatric rare dis-
 18 eases or conditions (including any such diseases
 19 or conditions that are genetic disorders or are
 20 related to birth defects); and

21 “(B) conduct or coordinate one or more
 22 multisite clinical trials of therapies for, or ap-
 23 proaches to, the prevention, diagnosis, or treat-

- 1 ment of one or more pediatric rare diseases or
- 2 conditions.”.

