

112TH CONGRESS
1ST SESSION

S. 1613

To improve and enhance research and programs on childhood cancer survivorship, and for other purposes.

IN THE SENATE OF THE UNITED STATES

SEPTEMBER 22, 2011

Mr. REED (for himself and Mrs. HUTCHISON) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

A BILL

To improve and enhance research and programs on childhood cancer survivorship, and for other purposes.

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 “Pediatric, Adolescent,
5 and Young Adult Cancer Survivorship Research and Qual-
6 ity of Life Act of 2011”.

7 **SEC. 2. FINDINGS.**

8 Congress finds as follows:

1 (1) An estimated 12,400 children and adoles-
2 cents under age 20 are diagnosed with cancer each
3 year.

4 (2) In 1960, only 4 percent of children with
5 cancer survived more than 5 years, but by 2011,
6 cure rates have increased to 78 percent for children
7 and adolescents under age 20.

8 (3) The population of survivors of childhood
9 cancers has grown dramatically, to more than
10 300,000 individuals of all ages as of 2007.

11 (4) As many as $\frac{2}{3}$ of childhood cancer survivors
12 are likely to experience at least one late effect of
13 treatment, with as many as $\frac{1}{4}$ experiencing a late
14 effect that is serious or life-threatening. The most
15 common late effects of childhood cancer are
16 neurocognitive, psychological, cardiopulmonary, en-
17 docrine, and musculoskeletal effects and secondary
18 malignancies.

19 (5) The late effects of cancer treatment may
20 change as treatments evolve, which means that the
21 monitoring and treatment of cancer survivors may
22 need to be modified on a routine basis.

23 (6) The Institute of Medicine, in its reports on
24 cancer survivorship entitled “Childhood Cancer Sur-
25 vivorship: Improving Care and Quality of Life”,

1 states that an organized system of care and a meth-
2 od of care for pediatric cancer survivors is needed.

3 **SEC. 3. CANCER SURVIVORSHIP PROGRAMS.**

4 (a) CANCER SURVIVORSHIP PROGRAMS.—Subpart 1
5 of part C of title IV of the Public Health Service Act (42
6 U.S.C. 285 et seq.) is amended by adding at the end the
7 following:

8 **“SEC. 417G. PILOT PROGRAMS TO EXPLORE MODEL SYS-**
9 **TEMS OF CARE FOR PEDIATRIC CANCER SUR-**
10 **VIVORS.**

11 “(a) IN GENERAL.—The Secretary may make grants
12 to eligible entities to establish pilot programs to develop,
13 study, or evaluate model systems for monitoring and car-
14 ing for childhood cancer survivors.

15 “(b) ELIGIBLE ENTITIES.—In this section, the term
16 ‘eligible entity’ means—

17 “(1) a medical school;

18 “(2) a children’s hospital;

19 “(3) a cancer center; or

20 “(4) any other entity with significant experience
21 and expertise in treating survivors of childhood can-
22 cers.

23 “(c) USE OF FUNDS.—The Secretary may make a
24 grant under this section to an eligible entity only if the
25 entity agrees—

1 “(1) to use the grant to establish a pilot pro-
2 gram to develop, study, or evaluate one or more
3 model systems for monitoring and caring for cancer
4 survivors; and

5 “(2) in developing, studying, and evaluating
6 such systems, to give special emphasis to—

7 “(A) the design of protocols for different
8 models of follow-up care, monitoring, and other
9 survivorship programs (including peer support
10 and mentoring programs);

11 “(B) the development of various models for
12 providing multidisciplinary care;

13 “(C) the dissemination of information and
14 the provision of training to health care pro-
15 viders about how to provide linguistically and
16 culturally competent follow-up care and moni-
17 toring to cancer survivors and their families;

18 “(D) the development of support programs
19 to improve the quality of life of cancer sur-
20 vivors;

21 “(E) the design of systems for the effective
22 transfer of treatment information and care
23 summaries from cancer care providers to other
24 health care providers (including risk factors and
25 a plan for recommended follow-up care);

1 “(F) the dissemination of the information
2 and programs described in subparagraphs (A)
3 through (E) to other health care providers (in-
4 cluding primary care physicians and internists)
5 to cancer survivors and their families, where ap-
6 propriate; and

7 “(G) the development of initiatives that
8 promote the coordination and effective transi-
9 tion of care between cancer care providers, pri-
10 mary care physicians, and mental health profes-
11 sionals.

12 “(d) FUNDING.—For each of fiscal years 2013
13 through 2017, the Secretary may transfer out of funds
14 otherwise appropriated to the Department of Health and
15 Human Services for a fiscal year the amount necessary
16 to carry out this section.

17 **“SEC. 417G-1. WORKFORCE DEVELOPMENT COLLABO-**
18 **RATIVE ON MEDICAL AND PSYCHOSOCIAL**
19 **CARE FOR CHILDHOOD CANCER SURVIVORS.**

20 “(a) IN GENERAL.—Not later than 1 year after the
21 date of enactment of the Pediatric, Adolescent, and Young
22 Adult Cancer Survivorship Research and Quality of Life
23 Act of 2011, the Secretary may convene a Workforce De-
24 velopment Collaborative on Medical and Psychosocial Care
25 for Pediatric Cancer Survivors (referred to in this para-

1 graph as the ‘Collaborative’). The Collaborative shall be
2 a cross-specialty, multidisciplinary group composed of edu-
3 cators, consumer and family advocates, and providers of
4 psychosocial and biomedical health services.

5 “(b) GOALS AND REPORTS.—The Collaborative shall
6 submit to the Secretary a report establishing a plan to
7 meet the following objectives for medical and psychosocial
8 care workforce development:

9 “(1) Identifying, refining, and broadly dissemi-
10 nating to healthcare educators information about
11 workforce competencies, models, and preservices cur-
12 ricula relevant to providing medical and psychosocial
13 services to individuals with pediatric cancers.

14 “(2) Adapting curricula for continuing edu-
15 cation of the existing workforce using efficient work-
16 place-based learning approaches.

17 “(3) Developing the skills of faculty and other
18 trainers in teaching psychosocial health care using
19 evidence-based teaching strategies.

20 “(4) Strengthening the emphasis on psycho-
21 social healthcare in educational accreditation stand-
22 ards and professional licensing and certification
23 exams by recommending revisions to the relevant
24 oversight organizations.

1 “(5) Evaluating the effectiveness of patient
2 navigators in pediatric cancer survivorship care.

3 “(6) Evaluating the effectiveness of peer sup-
4 port programs in the psychosocial care of pediatric
5 cancer patients and survivors.

6 “(c) FUNDING.—For each of fiscal years 2013
7 through 2017, the Secretary may transfer out of funds
8 otherwise appropriated to the Department of Health and
9 Human Services for a fiscal year the amount necessary
10 to carry out this section.”.

11 (b) TECHNICAL AMENDMENT.—

12 (1) IN GENERAL.—Section 3 of the
13 Hematological Cancer Research Investment and
14 Education Act of 2002 (Public Law 107–172; 116
15 Stat. 541) is amended by striking “section 419C”
16 and inserting “section 417C”.

17 (2) EFFECTIVE DATE.—The amendment made
18 by paragraph (1) shall take effect as if included in
19 section 3 of the Hematological Cancer Research In-
20 vestment and Education Act of 2002 (Public Law
21 107–172; 116 Stat. 541).

22 **SEC. 4. GRANTS TO IMPROVE CARE FOR PEDIATRIC CAN-**
23 **CER SURVIVORS.**

24 Section 417E of the Public Health Service Act (42
25 U.S.C. 285a–11) is amended—

1 (1) in the heading, by striking “**RESEARCH**
2 **AND AWARENESS**” and inserting “**RESEARCH,**
3 **AWARENESS, AND SURVIVORSHIP**”;

4 (2) in subsection (a)—

5 (A) by redesignating paragraph (2) as
6 paragraph (4); and

7 (B) by inserting after paragraph (1) the
8 following:

9 “(2) **RESEARCH ON CAUSES OF HEALTH DIS-**
10 **PARITIES IN PEDIATRIC CANCER SURVIVORSHIP.**—

11 “(A) **GRANTS.**—The Director of NIH, act-
12 ing through the Director of the Institute, in co-
13 ordination with ongoing research activities, may
14 make grants to entities to conduct research re-
15 lating to—

16 “(i) needs and outcomes of pediatric
17 cancer survivors within minority or other
18 medically underserved populations;

19 “(ii) health disparities in pediatric
20 cancer survivorship outcomes within minor-
21 ity or other medically underserved popu-
22 lations;

23 “(iii) barriers that pediatric cancer
24 survivors within minority or other medi-

1 cally underserved populations face in re-
2 ceiving follow-up care; and

3 “(iv) familial, socioeconomic, and
4 other environmental factors and the impact
5 of such factors on treatment outcomes and
6 survivorship.

7 “(B) BALANCED APPROACH.—In making
8 grants for research under subparagraph (A)(i)
9 on pediatric cancer survivors within minority or
10 other medically underserved populations, the
11 Director of NIH shall ensure that such research
12 addresses both the physical and the psycho-
13 logical needs of such survivors.

14 “(3) RESEARCH ON LATE EFFECTS AND FOL-
15 LOW-UP CARE FOR PEDIATRIC CANCER SUR-
16 VIVORS.—The Director of NIH, in coordination with
17 ongoing research activities, shall conduct or support
18 research on follow-up care for pediatric cancer sur-
19 vivors, with special emphasis given to—

20 “(A) the development of indicators used
21 for long-term patient tracking and analysis of
22 the late effects of cancer treatment for pediatric
23 cancer survivors;

24 “(B) the identification of risk factors asso-
25 ciated with the late effects of cancer treatment;

1 “(C) the identification of predictors of
2 neurocognitive and psychosocial outcomes;

3 “(D) initiatives to protect cancer survivors
4 from the late effects of cancer treatment;

5 “(E) transitions in care for pediatric can-
6 cer survivors;

7 “(F) training of professionals to provide
8 linguistically and culturally competent follow-up
9 care to pediatric cancer survivors; and

10 “(G) different models of follow-up care.”;

11 and

12 (3) in subsection (d), by striking “2013” and
13 inserting “2017”.

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