

112TH CONGRESS  
1ST SESSION

# H. R. 3015

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

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## IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 22, 2011

Ms. SPEIER (for herself, Mr. LATHAM, Mr. MCCAUL, Mr. VAN HOLLEN, Mr. MORAN, Mr. KING of New York, Ms. BORDALLO, Ms. WOOLSEY, and Ms. FUDGE) introduced the following bill; which was referred to the Committee on Energy and Commerce

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## 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 the following:

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 today, cure  
6 rates have increased to 78 percent for children and  
7 adolescents under age 20.

8 (3) The population of survivors of childhood  
9 cancers has grown dramatically, to over 300,000 in-  
10 dividuals of all ages as of 2007.

11 (4) Whereas as many as two-thirds of childhood  
12 cancer survivors are likely to experience at least one  
13 late effect of treatment, with as many as one-fourth  
14 experiencing a late effect that is serious or life-  
15 threatening. The most common late effects of child-  
16 hood cancer are neurocognitive, psychological,  
17 cardiopulmonary, endocrine, and musculoskeletal ef-  
18 fects and secondary malignancies.

19 (5) According to the Intercultural Cancer Coun-  
20 cil, because of disparities in health care delivery  
21 throughout the cancer care continuum, minority,  
22 poor, and other medically underserved communities  
23 are more likely to be diagnosed with late stage dis-  
24 ease, experience poorer treatment outcomes, have  
25 shorter survival time with less quality of life, and ex-

1 perience a substantially greater likelihood of cancer  
2 death.

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

7 (7) Despite the trauma caused by childhood  
8 cancer, there is a lack of standardized and coordi-  
9 nated psychosocial care for the children and their  
10 families, from the date of diagnosis through treat-  
11 ment and survivorship.

12 (8) The Institute of Medicine, in its reports on  
13 cancer survivorship entitled "Childhood Cancer Sur-  
14 vivorship: Improving Care and Quality of Life",  
15 states that an organized system of care and a meth-  
16 od of care for pediatric cancer survivors is needed.

17 (9) Focused and well-designed research and  
18 pilot health delivery programs can answer questions  
19 about the optimal ways to provide health care, fol-  
20 low-up monitoring services, and survivorship care to  
21 those diagnosed with childhood cancer and con-  
22 tribute to improvements in the quality of care and  
23 quality of life of those individuals.

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

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

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

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

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

15 “(1) a medical school;

16 “(2) a children’s hospital;

17 “(3) a cancer center; or

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

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

24 “(1) to use the grant to establish a pilot pro-  
25 gram to develop, study, or evaluate one or more

1 model systems for monitoring and caring for cancer  
2 survivors; and

3 “(2) in developing, studying, and evaluating  
4 such systems, to give special emphasis to the fol-  
5 lowing:

6 “(A) Design of protocols for different mod-  
7 els of follow-up care, monitoring, and other sur-  
8 vivorship programs (including peer support and  
9 mentoring programs).

10 “(B) Development of various models for  
11 providing multidisciplinary care.

12 “(C) Dissemination of information and the  
13 provision of training to health care providers  
14 about how to provide linguistically and cul-  
15 turally competent follow-up care and monitoring  
16 to cancer survivors and their families.

17 “(D) Development of support programs to  
18 improve the quality of life of cancer survivors.

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

24 “(F) Dissemination of the information and  
25 programs described in subparagraphs (A)

1 through (E) to other health care providers (in-  
2 cluding primary care physicians and internists)  
3 and to cancer survivors and their families,  
4 where appropriate.

5 “(G) Development of initiatives that pro-  
6 mote the coordination and effective transition of  
7 care between cancer care providers, primary  
8 care physicians, and mental health profes-  
9 sionals.

10 “(d) AUTHORIZATION OF APPROPRIATIONS.—To  
11 carry out this section, there is authorized to be appro-  
12 priated \$15,000,000 for each of fiscal years 2013 through  
13 2017.

14 **“SEC. 417G-1. WORKFORCE DEVELOPMENT COLLABO-**  
15 **RATIVE ON MEDICAL AND PSYCHOSOCIAL**  
16 **CARE FOR CHILDHOOD CANCER SURVIVORS.**

17 “(a) IN GENERAL.—The Secretary shall, not later  
18 than 1 year after the date of enactment of this Act, con-  
19 vene a Workforce Development Collaborative on Medical  
20 and Psychosocial Care for Pediatric Cancer Survivors (re-  
21 ferred to in this paragraph as the ‘Collaborative’). The  
22 Collaborative shall be a cross-specialty, multidisciplinary  
23 group composed of educators, consumer and family advo-  
24 cates, and providers of psychosocial and biomedical health  
25 services.

1       “(b) GOALS AND REPORTS.—The Collaborative shall  
2 submit to the Secretary a report establishing a plan to  
3 meet the following objectives for medical and psychosocial  
4 care workforce development:

5           “(1) Identifying, refining, and broadly dissemi-  
6 nating to health care educators information about  
7 workforce competencies, models, and preservices cur-  
8 ricula relevant to providing medical and psychosocial  
9 services to persons with pediatric cancers.

10          “(2) Adapting curricula for continuing edu-  
11 cation of the existing workforce using efficient work-  
12 place-based learning approaches.

13          “(3) Developing the skills of faculty and other  
14 trainers in teaching psychosocial health care using  
15 evidence-based teaching strategies.

16          “(4) Strengthening the emphasis on psycho-  
17 social health care in educational accreditation stand-  
18 ards and professional licensing and certification  
19 exams by recommending revisions to the relevant  
20 oversight organizations.

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

23          “(6) Evaluating the effectiveness of peer sup-  
24 port programs in the psychosocial care of pediatric  
25 cancer patients and survivors.

1       “(c) AUTHORIZATION OF APPROPRIATIONS.—To  
2 carry out this section, there is authorized to be appro-  
3 priated \$5,000,000 for each of fiscal years 2013 through  
4 2017.”.

5       (b) TECHNICAL AMENDMENT.—

6           (1) IN GENERAL.—Section 3 of the  
7 Hematological Cancer Research Investment and  
8 Education Act of 2002 (Public Law 107–172; 116  
9 Stat. 541) is amended by striking “section 419C”  
10 and inserting “section 417C”.

11           (2) EFFECTIVE DATE.—The amendment made  
12 by paragraph (1) shall take effect as if included in  
13 section 3 of the Hematological Cancer Research In-  
14 vestment and Education Act of 2002 (Public Law  
15 107–172; 116 Stat. 541).

16 **SEC. 4. GRANTS TO IMPROVE CARE FOR PEDIATRIC CAN-**  
17 **CER SURVIVORS.**

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

20           (1) in the heading, by striking “**RESEARCH**  
21 **AND AWARENESS**” and inserting “**RESEARCH,**  
22 **AWARENESS, AND SURVIVORSHIP**”;

23           (2) in subsection (a)—

24                   (A) by redesignating paragraph (2) as  
25 paragraph (4); and



1 (B) by inserting after paragraph (1) the  
2 following:

3 “(2) RESEARCH ON CAUSES OF HEALTH DIS-  
4 PARITIES IN PEDIATRIC CANCER SURVIVORSHIP.—

5 “(A) GRANTS.—The Director of NIH, act-  
6 ing through the Director of the Institute, in co-  
7 ordination with ongoing research activities,  
8 shall make grants to entities to conduct re-  
9 search relating to—

10 “(i) needs and outcomes of pediatric  
11 cancer survivors within minority or other  
12 medically underserved populations;

13 “(ii) health disparities in pediatric  
14 cancer survivorship outcomes within minor-  
15 ity or other medically underserved popu-  
16 lations;

17 “(iii) barriers that pediatric cancer  
18 survivors within minority or other medi-  
19 cally underserved populations face in re-  
20 ceiving follow-up care; and

21 “(iv) familial, socioeconomic, and  
22 other environmental factors and the impact  
23 of such factors on treatment outcomes and  
24 survivorship.

1           “(B) BALANCED APPROACH.—In making  
2           grants for research under subparagraph (A)(i)  
3           on pediatric cancer survivors within minority or  
4           other medically underserved populations, the  
5           Director of NIH shall ensure that such research  
6           addresses both the physical and the psycho-  
7           logical needs of such survivors.

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

14                 “(A) the development of indicators used  
15                 for long-term patient tracking and analysis of  
16                 the late effects of cancer treatment for pediatric  
17                 cancer survivors;

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

20                 “(C) the identification of predictors of  
21                 neurocognitive and psychosocial outcomes;

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

24                 “(E) transitions in care for pediatric can-  
25                 cer survivors;

1 “(F) training of professionals to provide  
2 linguistically and culturally competent follow-up  
3 care to pediatric cancer survivors; and

4 “(G) different models of follow-up care.”;  
5 and

6 (3) in subsection (d)—

7 (A) by striking “this section and” and in-  
8 serting “subsection (a)(1), subsection (b), and”;

9 (B) by striking “2013” and inserting  
10 “2017”; and

11 (C) by inserting after the second sentence  
12 the following: “For purposes of carrying out  
13 subsections (a)(2) and (a)(3), there is author-  
14 ized to be appropriated \$10,000,000 for each of  
15 fiscal years 2013 through 2017.”.

16 **SEC. 5. COMPREHENSIVE LONG-TERM FOLLOW-UP SERV-**  
17 **ICES FOR PEDIATRIC CANCER SURVIVORS.**

18 Part B of title III of the Public Health Service Act  
19 (42 U.S.C. 243 et seq.) is amended by inserting after sec-  
20 tion 317T the following:

21 **“SEC. 317U. CLINICS FOR COMPREHENSIVE LONG-TERM**  
22 **FOLLOW-UP SERVICES FOR PEDIATRIC CAN-**  
23 **CER SURVIVORS.**

24 “(a) IN GENERAL.—The Secretary shall make grants  
25 to eligible entities to establish and operate a clinic for com-

1 comprehensive long-term follow-up services for pediatric can-  
2 cer survivors.

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

5 “(1) a school of medicine;

6 “(2) a children’s hospital;

7 “(3) a cancer center; or

8 “(4) any other entity determined by the Sec-  
9 retary to have significant experience and expertise  
10 in—

11 “(A) treating pediatric, adolescent, and  
12 young adult cancers; or

13 “(B) integrating medical and psychosocial  
14 services for pediatric, adolescent, and young  
15 adult cancer survivors and their families.

16 “(c) USE OF FUNDS.—The Secretary may make a  
17 grant under this section to an eligible entity only if the  
18 entity agrees to use the grant to pay costs incurred during  
19 the first 4 years of establishing and operating a clinic for  
20 comprehensive, long-term, follow-up services for pediatric  
21 cancer survivors, which may include the costs of—

22 “(1) providing medical and psychosocial follow-  
23 up services, including coordination with the patient’s  
24 primary care provider and oncologist in order to en-  
25 sure that the medical needs of survivors are ad-

1 dressed, and providing linguistically and culturally  
2 competent information to survivors and families with  
3 appropriate outreach to medically underserved popu-  
4 lations;

5 “(2) the construction, expansion, and mod-  
6 ernization of facilities;

7 “(3) acquiring and leasing facilities and equip-  
8 ment (including paying the costs of amortizing the  
9 principal of, and paying the interest on, loans for  
10 such facilities and equipment) to support or further  
11 the operation of the grantee; and

12 “(4) the construction and structural modifica-  
13 tion (including equipment acquisition) of facilities to  
14 permit the integrated delivery of ongoing medical  
15 and psychosocial care to pediatric cancer survivors  
16 and their families at a single service site.

17 “(d) AUTHORIZATION OF APPROPRIATIONS.—To  
18 carry out this section, there is authorized to be appro-  
19 priated \$10,000,000 for each of fiscal years 2013 through  
20 2017.”.

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