

113TH CONGRESS
1ST SESSION

H. R. 2058

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

IN THE HOUSE OF REPRESENTATIVES

MAY 20, 2013

Ms. SPEIER (for herself, Mr. RANGEL, Ms. LEE of California, Mr. MORAN, Ms. BORDALLO, Mr. McCAUL, and Mr. VAN HOLLEN) introduced the following bill; which was referred to the Committee on Energy and Commerce

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 “Childhood Cancer Sur-
5 vivors’ Quality of Life Act of 2013”.

6 **SEC. 2. FINDINGS.**

7 Congress finds the following:

1 (1) An estimated 13,500 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 over 80 percent for children
7 and adolescents under age 20.

8 (3) The population of survivors of childhood
9 cancers has grown dramatically, to over 360,000 in-
10 dividuals of all ages as of 2012.

11 (4) As many as two-thirds of childhood cancer
12 survivors are likely to experience at least one late ef-
13 fect of treatment, with as many as one-fourth expe-
14 riencing a late effect that is serious or life-threat-
15 ening. The most common late effects of childhood
16 cancer are neurocognitive, psychological, cardio-
17 pulmonary, endocrine, and musculoskeletal effects
18 and secondary malignancies.

19 (5) As a result of disparities in the delivery of
20 cancer care, minority, low-income, and other medi-
21 cally underserved children are more likely to be diag-
22 nosed with late stage disease, experience poorer
23 treatment outcomes, have shorter survival time with
24 less quality of life, and experience a substantially
25 greater likelihood of cancer death.

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

5 (7) Despite the intense stress caused by child-
6 hood cancer, there is a lack of standardized and co-
7 ordinated psychosocial care for the children and
8 their families, from the date of diagnosis through
9 treatment and survivorship.

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

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

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

23 (a) CANCER SURVIVORSHIP PROGRAMS.—Subpart 1
24 of part C of title IV of the Public Health Service Act (42

1 U.S.C. 285 et seq.) is amended by adding at the end the
2 following:

3 **“SEC. 417G. PILOT PROGRAMS TO EXPLORE MODEL SYS-**
4 **TEMS OF CARE FOR PEDIATRIC CANCER SUR-**
5 **VIVORS.**

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

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

12 “(1) a medical school;

13 “(2) a children’s hospital;

14 “(3) a cancer center; or

15 “(4) any other entity with significant experience
16 and expertise in treating survivors of childhood can-
17 cers.

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

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

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

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

8 “(B) Development of various models for
9 providing multidisciplinary care.

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

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

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

22 “(F) Dissemination of the information and
23 programs described in subparagraphs (A)
24 through (E) to other health care providers (in-
25 cluding primary care physicians and internists)

1 and to cancer survivors and their families,
2 where appropriate.

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

8 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
9 carry out this section, there is authorized to be appro-
10 priated \$15,000,000 for each of fiscal years 2015 through
11 2019.

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

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

24 “(b) GOALS AND REPORTS.—The Collaborative shall
25 submit to the Secretary a report establishing a plan to

1 meet the following objectives for medical and psychosocial
2 care workforce development:

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

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

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

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

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

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

24 “(c) AUTHORIZATION OF APPROPRIATIONS.—To
25 carry out this section, there is authorized to be appro-

1 priated \$5,000,000 for each of fiscal years 2015 through
 2 2019.”.

3 (b) TECHNICAL AMENDMENT.—

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

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

14 **SEC. 4. GRANTS TO IMPROVE CARE FOR PEDIATRIC CAN-**
 15 **CER SURVIVORS.**

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

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

21 (2) in subsection (a)—

22 (A) by redesignating paragraph (2) as
 23 paragraph (4); and

24 (B) by inserting after paragraph (1) the
 25 following:

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

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

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

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

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

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

23 “(B) BALANCED APPROACH.—In making
24 grants for research under subparagraph (A)(i)
25 on pediatric cancer survivors within minority or

1 other medically underserved populations, the
2 Director of NIH shall ensure that such research
3 addresses both the physical and the psycho-
4 logical needs of such survivors.

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

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

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

17 “(C) the identification of predictors of
18 neurocognitive and psychosocial outcomes;

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

21 “(E) transitions in care for pediatric can-
22 cer survivors;

23 “(F) training of professionals to provide
24 linguistically and culturally competent follow-up
25 care to pediatric cancer survivors; and

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

2 and

3 (3) in subsection (d)—

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

6 (B) by striking “2013” and inserting
7 “2019”; and

8 (C) by inserting after the second sentence
9 the following: “For purposes of carrying out
10 subsections (a)(2) and (a)(3), there is author-
11 ized to be appropriated \$10,000,000 for each of
12 fiscal years 2015 through 2019.”.

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

15 Part B of title III of the Public Health Service Act
16 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
17 tion 317T the following:

18 **“SEC. 317U. CLINICS FOR COMPREHENSIVE LONG-TERM**
19 **FOLLOW-UP SERVICES FOR PEDIATRIC CAN-**
20 **CER SURVIVORS.**

21 “(a) IN GENERAL.—The Secretary shall make grants
22 to eligible entities to establish and operate a clinic for com-
23 prehensive long-term follow-up services for pediatric can-
24 cer survivors.

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

3 “(1) a school of medicine;

4 “(2) a children’s hospital;

5 “(3) a cancer center; or

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

9 “(A) treating pediatric, adolescent, and
10 young adult cancers; or

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

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

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

1 appropriate outreach to medically underserved popu-
2 lations;

3 “(2) the construction, expansion, and mod-
4 ernization of facilities;

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

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

15 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
16 carry out this section, there is authorized to be appro-
17 priated \$10,000,000 for each of fiscal years 2015 through
18 2019.”.

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