

115TH CONGRESS  
1ST SESSION

# S. 292

To maximize discovery, and accelerate development and availability, of  
promising childhood cancer treatments, and for other purposes.

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## IN THE SENATE OF THE UNITED STATES

FEBRUARY 2, 2017

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

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## A BILL

To maximize discovery, and accelerate development and avail-  
ability, of promising childhood cancer treatments, 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; TABLE OF CONTENTS.**

4       (a) SHORT TITLE.—This Act may be cited as the  
5       “Childhood Cancer Survivorship, Treatment, Access, and  
6       Research Act of 2017” or the “Childhood Cancer STAR  
7       Act”.

8       (b) TABLE OF CONTENTS.—The table of contents for  
9       this Act is as follows:

- Sec. 1. Short title; table of contents.  
 Sec. 2. Findings.

#### TITLE I—MAXIMIZING RESEARCH THROUGH DISCOVERY

##### Subtitle A—Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act

- Sec. 101. Children's cancer biorepositories and biospecimen research.  
 Sec. 102. Improving Childhood Cancer Surveillance.

##### Subtitle B—Pediatric Expertise at NIH

- Sec. 111. Inclusion of at least one pediatric oncologist on the National Cancer  
Advisory Board.  
 Sec. 112. Sense of Congress regarding pediatric expertise at the National Cancer  
Institute.

##### Subtitle C—NIH Report on Childhood Cancer Activities

- Sec. 121. Reporting on childhood cancer research projects.

#### TITLE II—MAXIMIZING DELIVERY: CARE, QUALITY OF LIFE, SURVIVORSHIP, AND CAREGIVER SUPPORT

##### Subtitle A—Childhood Cancer Survivors' Quality of Life Act

- Sec. 201. Cancer survivorship programs.  
 Sec. 202. Grants to improve care for pediatric cancer survivors.  
 Sec. 203. Comprehensive long-term follow-up services for pediatric cancer survivors.  
 Sec. 204. Survivorship demonstration project.

##### Subtitle B—Coverage and Payment of High Quality Care

- Sec. 211. Report by the Comptroller General.

### 1 **SEC. 2. FINDINGS.**

2 Congress makes the following findings:

3 (1) Each year in the United States there are an  
 4 estimated 15,780 children between birth and the age  
 5 of 19 diagnosed with cancer. Approximately 1 in 285  
 6 children in the United States will be diagnosed with  
 7 cancer before their 20th birthday.

8 (2) In 1960, only 4 percent of children with  
 9 cancer survived more than 5 years, but today, cure

1 rates have increased to over 80 percent for children  
2 and adolescents under age 20.

3 (3) While the cure rates for some childhood  
4 cancers are now over 80 percent, the survival rates  
5 for many types of cancers in children remain ex-  
6 tremely low.

7 (4) According to the Centers for Disease Con-  
8 trol and Prevention, cancer continues to be the lead-  
9 ing cause of death by disease in children and adoles-  
10 cents under the age of 14.

11 (5) By 2020, the population of childhood can-  
12 cers survivors is expected to be 500,000 individuals.

13 (6) As many as two-thirds of childhood cancer  
14 survivors are likely to experience at least one late ef-  
15 fect of treatment, with as many as one-fourth expe-  
16 riencing a late effect that is serious or life-threat-  
17 ening. Common late effects of childhood cancer are  
18 neurocognitive, psychological, cardiopulmonary, en-  
19 docrine, and musculoskeletal effects, secondary ma-  
20 lignancies, and early death.

21 (7) As a result of disparities in the delivery of  
22 cancer care, minority, low-income, and other medi-  
23 cally underserved children are more likely to be diag-  
24 nosed with late stage disease, experience poorer  
25 treatment outcomes, have shorter survival time with

1 less quality of life, and experience a substantially  
2 greater likelihood of cancer death.

3 (8) Collection of biospecimens, along with clin-  
4 ical and outcome data, on children and adolescents  
5 with cancer in the United States is necessary to im-  
6 prove childhood and adolescent cancer treatments  
7 and cures. Currently biospecimens, and clinical and  
8 outcome data, are collected for less than half of chil-  
9 dren in the United States with cancer.

10 (9) The late effects of cancer treatment may  
11 change as therapies evolve, which means that the  
12 monitoring and care of cancer survivors may need to  
13 be modified on a routine basis.

14 (10) Despite the intense stress caused by child-  
15 hood cancer, there is a lack of standardized and co-  
16 ordinated psychosocial care for the children and  
17 their families, from the date of diagnosis through  
18 treatment and survivorship.

19 (11) The National Academy of Medicine, in its  
20 report on cancer survivorship entitled “Childhood  
21 Cancer Survivorship: Improving Care and Quality of  
22 Life”, states that an organized system of care and  
23 a method of care for pediatric cancer survivors is  
24 needed.

1           (12) Focused and well-designed research and  
2       pilot health delivery programs can answer questions  
3       about the optimal ways to provide health care, fol-  
4       low-up monitoring services, and survivorship care to  
5       those diagnosed with childhood cancer and con-  
6       tribute to improvements in the quality of care and  
7       quality of life of those individuals through adult-  
8       hood.

9           (13) The National Institutes of Health, includ-  
10      ing the National Cancer Institute, invest approxi-  
11      mately half of their annual appropriations to support  
12      basic research that serves as the foundation for  
13      translational and clinical research for all diseases  
14      and conditions, with the potential to lead to break-  
15      throughs for children with cancer. Virtually all  
16      progress against cancer—in both children and  
17      adults—has been founded in basic research, often in  
18      areas not directly related to the disease.

19          (14) The National Cancer Institute supports a  
20      number of key research programs specifically to ad-  
21      vance childhood cancer care, including precision  
22      medicine clinical trials for children with cancer, the  
23      Children’s Oncology Group (part of the National  
24      Clinical Trials Network of the National Cancer In-  
25      stitute), the Pediatric Preclinical Testing Consor-

tium, the Pediatric Brain Tumor Consortium, the Childhood Cancer Survivor Study, the Therapeutically Applicable Research to Generate Effective Treatments program and related pediatric cancer genomics research (including the Pediatric MATCH Precision Medicine trial), and the Pediatric Oncology Branch (part of the intramural program of the National Cancer Institute, whose mission is to develop new treatments for pediatric cancer).

**TITLE I—MAXIMIZING RE-  
SEARCH THROUGH DIS-  
COVERY**

**Subtitle A—Caroline Pryce Walker  
Conquer Childhood Cancer Re-  
authorization Act**

**SEC. 101. CHILDREN’S CANCER BIOREPOSITORIES AND BIO-  
SPECIMEN RESEARCH.**

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

(1) by striking subsection (a) and inserting the following:

“(a) CHILDREN’S CANCER BIOREPOSITORIES.—

“(1) AWARD.—The Secretary, acting through the Director of NIH, may make awards to an entity or entities described in paragraph (4) to build upon

1 existing initiatives to collect biospecimens and clin-  
2 ical and demographic information with a goal of col-  
3 lection for the vast majority of all children, adoles-  
4 cents, and young adults with selected cancer  
5 subtypes (and their recurrences) for which current  
6 treatments are least effective, through one or more  
7 biospecimen research efforts designed to achieve a  
8 better understanding of the cause of such cancers  
9 (and their recurrences) and the effects of treatments  
10 for such cancers.

11 “(2) USE OF FUNDS.—Amounts received under  
12 an award under paragraph (1) may be used to carry  
13 out the following:

14 “(A) Acquire, preserve, and store high-  
15 quality, donated biospecimens and associated  
16 clinical and demographic information on chil-  
17 dren, adolescents, and young adults diagnosed  
18 with cancer in the United States, focusing on  
19 children and adolescents enrolled in clinical  
20 trials for whom current treatments are least ef-  
21 fective. Activities under this subparagraph may  
22 include storage of biospecimens and associated  
23 clinical and demographic data at biorepositories  
24 supported by the National Cancer Institute,  
25 such as the Children’s Oncology Group Bio-

1 repository and the Pediatric Cooperative  
2 Human Tissue Network as well as through bio-  
3 repositories established as appropriate to sup-  
4 port the scientific needs of future research ef-  
5 forts.

6 “(B) Make such information publicly avail-  
7 able, including the repositories described in sub-  
8 paragraph (A).

9 “(C) Maintain a secure searchable data-  
10 base on stored biospecimens and associated  
11 clinical and demographic data from children,  
12 adolescents, and young adults with cancer for  
13 the conduct of research by scientists and quali-  
14 fied health care professionals.

15 “(D) Establish procedures for evaluating  
16 applications for access to such biospecimens  
17 and clinical and demographic data from re-  
18 searchers and other qualified health care pro-  
19 fessionals.

20 “(E) Make available and distribute bio-  
21 specimens and clinical and demographic data  
22 from children, adolescents, and young adults  
23 with cancer to researchers and qualified health  
24 care professionals for peer-reviewed research at  
25 a minimal cost.



1           “(3) NO REQUIREMENT.—No child, adolescent,  
2           or young adult with cancer shall be required under  
3           this subsection to contribute a specimen to a bio-  
4           repository or share clinical or demographic data.

5           “(4) APPLICATION; CONSIDERATIONS.—

6           “(A) APPLICATION.—To be eligible to re-  
7           ceive an award under paragraph (1) an entity  
8           shall submit an application to the Secretary at  
9           such a time, in such manner, and containing  
10          such information as the Secretary may reason-  
11          ably require.

12          “(B) CONSIDERATIONS.—In evaluating the  
13          applications in subparagraph (A), the Secretary  
14          shall consider the existing infrastructure of the  
15          entity that would allow for the timely capture of  
16          biospecimens and related clinical and demo-  
17          graphic information for children, adolescents,  
18          and young adults with cancer.

19          “(5) PRIVACY PROTECTIONS; CONSENT.—

20          “(A) IN GENERAL.—The Secretary may  
21          not make an award under paragraph (1) to an  
22          entity unless the Secretary ensures that such  
23          entity—

24                  “(i) collects biospecimens and associ-  
25                  ated clinical and demographic information

1 from children and adolescents with appro-  
 2 priate permission from parents or legal  
 3 guardians in accordance with Federal and  
 4 State law; and

5 “(ii) adheres to strict confidentiality  
 6 to protect the identity and privacy of pa-  
 7 tients in accordance with Federal and  
 8 State law.

9 “(B) CONSENT.—The Secretary shall es-  
 10 tablish an appropriate process for achieving  
 11 consent from the patient, parent, or legal  
 12 guardian.

13 “(6) SINGLE POINT OF ACCESS; STANDARD  
 14 DATA; GUIDELINES AND OVERSIGHT.—

15 “(A) SINGLE POINT OF ACCESS.—The Sec-  
 16 retary shall ensure that each biorepository sup-  
 17 ported under paragraph (1) has electronically  
 18 searchable data for use by researchers and  
 19 other qualified health care professionals in the  
 20 manner and to the extent defined by the Sec-  
 21 retary.

22 “(B) STANDARD DATA.—The Secretary  
 23 shall require all recipients of an award under  
 24 paragraph (1) to make available a standard  
 25 dataset for the purposes of subparagraph (A) in

1 a standard electronic format that enables re-  
2 searchers and qualified health care professionals  
3 to search.

4 “(C) GUIDELINES AND OVERSIGHT.—The  
5 Secretary shall develop and disseminate appro-  
6 priate guidelines for the development and main-  
7 tenance of the biorepositories supported under  
8 this subsection, including appropriate oversight.

9 “(7) COORDINATION.—The Secretary shall en-  
10 sure that clinical and demographic information col-  
11 lected in accordance with this subsection is collected  
12 in coordination with the information collected under  
13 section 399E–1.

14 “(8) PROHIBITION ON USE OF FUNDS.—Funds  
15 made available to carry out this subsection shall not  
16 be used to acquire, preserve, or maintain a biospeci-  
17 men collected from a patient if such activity is al-  
18 ready covered by funds available from the National  
19 Cancer Institute for such purpose.

20 “(9) REPORT.—Not later than 4 years after the  
21 date of enactment of the Childhood Cancer Survivor-  
22 ship, Treatment, Access, and Research Act of 2017,  
23 the Secretary shall submit to Congress a report on—

24 “(A) the number of biospecimens and cor-  
25 responding clinical demographic data collected

1 through the biospecimen research efforts sup-  
 2 ported under paragraph (1);

3 “(B) the number of biospecimens and cor-  
 4 responding clinical demographic data requested  
 5 for use by researchers;

6 “(C) any barriers to the collection of bio-  
 7 specimens and corresponding clinical demo-  
 8 graphic data;

9 “(D) any barriers experienced by research-  
 10 ers or health care professionals in accessing the  
 11 biospecimens and corresponding clinical demo-  
 12 graphic data necessary for use in research; and

13 “(E) any recommendations with respect to  
 14 improving the biospecimen and biorepository re-  
 15 search efforts under this subsection.

16 “(10) DEFINITIONS.—For purposes of this sub-  
 17 section:

18 “(A) AWARD.—The term ‘award’ includes  
 19 a grant, contract, cooperative agreement, or  
 20 other transaction determined by the Secretary.

21 “(B) BIOSPECIMEN.—The term ‘biospeci-  
 22 men’ includes—

23 “(i) solid tumor tissue or bone mar-  
 24 row;

25 “(ii) normal or control tissue;

1 “(iii) blood and plasma;  
2 “(iv) DNA and RNA extractions;  
3 “(v) familial DNA; and  
4 “(vi) any other sample required by the  
5 Secretary.

6 “(C) CLINICAL AND DEMOGRAPHIC INFOR-  
7 MATION.—The term ‘clinical and demographic  
8 information’ includes—

9 “(i) date of diagnosis;  
10 “(ii) age at diagnosis;  
11 “(iii) the patient’s gender, race, eth-  
12 nicity, and environmental exposures;  
13 “(iv) extent of disease at enrollment;  
14 “(v) site of metastases;  
15 “(vi) location of primary tumor coded;  
16 “(vii) histologic diagnosis;  
17 “(viii) tumor marker data when avail-  
18 able;  
19 “(ix) treatment and outcome data;  
20 “(x) information related to specimen  
21 quality; and  
22 “(xi) any other information required  
23 by the Secretary.”; and  
24 (2) in subsection (d)—

1 (A) by striking “and section 399E–1” and  
 2 inserting “and sections 317U, 399E–1, 417H,  
 3 and 417H–1”;

4 (B) by striking “2009 through 2013” and  
 5 inserting “2018 through 2022”; and

6 (C) by striking “such purpose” and insert-  
 7 ing “such purposes”.

8 **SEC. 102. IMPROVING CHILDHOOD CANCER SURVEIL-**  
 9 **LANCE.**

10 Section 399E–1 of the Public Health Service Act (42  
 11 U.S.C. 280e–3a) is amended—

12 (1) by redesignating subsection (b) as sub-  
 13 section (d); and

14 (2) by striking subsection (a) and inserting the  
 15 following:

16 “(a) IN GENERAL.—The Secretary, acting through  
 17 the Director of the Centers for Disease Control and Pre-  
 18 vention, may make awards to State cancer registries to  
 19 enhance and expand infrastructure to track the epidemi-  
 20 ology of cancer in children, adolescents, and young adults.  
 21 Such registries may be updated to include each occurrence  
 22 of such cancers within a period of time designated by the  
 23 Secretary.

24 “(b) ACTIVITIES.—The grants described in sub-  
 25 section (a) may be used for—

1           “(1) identifying, recruiting, and training all po-  
2           tential sources for reporting childhood, adolescent,  
3           and young adult cancer cases;

4           “(2) developing procedures to implement early  
5           inclusion of childhood, adolescent, and young adult  
6           cancer cases on State cancer registries through the  
7           use of electronic reporting;

8           “(3) purchasing infrastructure to support the  
9           early inclusion of childhood, adolescent, and young  
10          adult cancer cases on such registries;

11          “(4) submitting deidentified data to the Centers  
12          for Disease Control and Prevention for inclusion in  
13          a national database of childhood, adolescent, and  
14          young adult cancers; and

15          “(5) tracking the late effects of childhood, ado-  
16          lescent, and young adult cancers.

17          “(c) COORDINATION.—The Secretary shall ensure  
18          that information collected through State cancer registries  
19          under this section is collected in coordination with clinical  
20          and demographic information collected under section  
21          417E(a), as appropriate.”.

1     **Subtitle B—Pediatric Expertise at**  
 2                                   **NIH**

3     **SEC. 111. INCLUSION OF AT LEAST ONE PEDIATRIC**  
 4                                   **ONCOLOGIST ON THE NATIONAL CANCER AD-**  
 5                                   **VISORY BOARD.**

6             Clause (iii) of section 406(h)(2)(A) of the Public  
 7     Health Service Act (42 U.S.C. 284a(h)(2)(A)) is amended  
 8     to read as follows:

9                     “(iii) of the members appointed to the Board—

10                    “(I) not less than 5 members shall be indi-  
 11                    viduals knowledgeable in environmental carcino-  
 12                    genesis (including carcinogenesis involving occu-  
 13                    pational and dietary factors); and

14                    “(II) not less than one member shall be an  
 15                    individual knowledgeable in pediatric oncol-  
 16                    ogy;”.

17     **SEC. 112. SENSE OF CONGRESS REGARDING PEDIATRIC EX-**  
 18                                   **PERTISE AT THE NATIONAL CANCER INSTI-**  
 19                                   **TUTE.**

20             It is the sense of Congress that the Director of the  
 21     National Cancer Institute should ensure that all applicable  
 22     study sections, committees, advisory groups, and panels  
 23     at the National Cancer Institute include one or more  
 24     qualified pediatric oncologists, as appropriate.



## **Subtitle C—NIH Report on Childhood Cancer Activities**

### **SEC. 121. REPORTING ON CHILDHOOD CANCER RESEARCH PROJECTS.**

Section 409D(c)(3) of the Public Health Service Act (42 U.S.C. 284h(c)(3)) is amended by—

(1) striking “public on” and inserting “public on—

“(A)”;

(2) striking the period at the end and inserting “; and”; and

(3) inserting at the end the following:

“(B) childhood cancer research projects conducted or supported by the National Institutes of Health.”.

## **TITLE II—MAXIMIZING DELIV- ERY: CARE, QUALITY OF LIFE, SURVIVORSHIP, AND CARE- GIVER SUPPORT**

### **Subtitle A—Childhood Cancer Survivors’ Quality of Life Act**

#### **SEC. 201. CANCER SURVIVORSHIP PROGRAMS.**

(a) CANCER SURVIVORSHIP PROGRAMS.—The Public Health Service Act is amended by inserting after section 399N of such Act (42 U.S.C. 280g–2) the following:

1 **“SEC. 399N-1. PILOT PROGRAMS TO EXPLORE MODEL SYS-**  
 2 **TEMS OF CARE FOR PEDIATRIC CANCER SUR-**  
 3 **VIVORS.**

4 “(a) IN GENERAL.—Not later than 1 year after the  
 5 date of enactment of the Childhood Cancer Survivorship,  
 6 Treatment, Access, and Research Act of 2017, the Sec-  
 7 retary may make awards to eligible entities to establish  
 8 pilot programs to develop, study, or evaluate model sys-  
 9 tems for monitoring and caring for childhood cancer sur-  
 10 vivors throughout their lifespan, including evaluation of  
 11 shared care and medical home and clinic based models for  
 12 transition to adult care.

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;
- 18 “(4) a community-based medical facility; or
- 19 “(5) any other entity with significant experience  
 20 and expertise in treating survivors of childhood can-  
 21 cers.

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

- 25 “(1) to use the award to establish a pilot pro-  
 26 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—

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

9 “(B) development of various models for  
 10 providing multidisciplinary care;

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

16 “(D) development of psychosocial interven-  
 17 tions and support programs to improve the  
 18 quality of life of cancer survivors and their fam-  
 19 ilies;

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

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

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

12 **“SEC. 399N-2. 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 the Childhood  
 17 Cancer Survivorship, Treatment, Access, and Research  
 18 Act of 2017, convene a Workforce Development Collabo-  
 19 rative on Medical and Psychosocial Care for Pediatric  
 20 Cancer Survivors (referred to in this section as the ‘Col-  
 21 laborative’). The Collaborative shall be a cross-specialty,  
 22 multidisciplinary group composed of educators, consumer  
 23 and family advocates, and providers of psychosocial and  
 24 biomedical health 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 curricula rel-  
8 evant to providing medical and psychosocial services  
9 to persons surviving 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 (b) TECHNICAL AMENDMENT.—

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

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

12 **SEC. 202. GRANTS TO IMPROVE CARE FOR PEDIATRIC CAN-**  
13 **CER SURVIVORS.**

14 (a) IN GENERAL.—Section 417E of the Public  
15 Health Service Act (42 U.S.C. 285a–11), as amended by  
16 section 101, is further amended—

17 (1) in the section heading, by striking “**RE-**  
18 **SEARCH AND AWARENESS**” and inserting “**RE-**  
19 **SEARCH, AWARENESS, AND SURVIVORSHIP**”;  
20 and

21 (2) by striking subsection (b) and inserting the  
22 following:

23 “(b) IMPROVING CARE FOR PEDIATRIC CANCER SUR-  
24 VIVORS.—

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

3           “(A) RESEARCH AWARDS.—The Director  
4           of NIH, in coordination with ongoing research  
5           activities, may conduct or support pediatric  
6           cancer survivorship research including in any of  
7           the following areas:

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.

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 con-  
24           ducting or supporting research under subpara-  
25           graph (A)(i) on pediatric cancer survivors with-

1 in minority or other medically underserved pop-  
2 ulations, the Director of NIH shall ensure that  
3 such research addresses both the physical and  
4 the psychological needs of such survivors, as ap-  
5 propriate.

6 “(2) RESEARCH ON LATE EFFECTS AND FOL-  
7 LOW-UP CARE FOR PEDIATRIC CANCER SUR-  
8 VIVORS.—The Director of NIH, in coordination with  
9 ongoing research activities, may conduct or support  
10 research on follow-up care for pediatric cancer sur-  
11 vivors, including in any of the following areas:

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

16 “(B) The identification of risk factors as-  
17 sociated with the late effects of cancer treat-  
18 ment.

19 “(C) The identification of predictors of ad-  
20 verse neurocognitive and psychosocial outcomes.

21 “(D) The identification of the molecular  
22 underpinnings of long-term complications.

23 “(E) The development of risk prediction  
24 models to identify those at highest risk of long-  
25 term complications.



1           “(F) Initiatives to protect cancer survivors  
 2           from the late effects of cancer treatment, by de-  
 3           veloping targeted interventions to reduce the  
 4           burden of morbidity borne by cancer survivors.

5           “(G) Transitions in care for pediatric can-  
 6           cer survivors.

7           “(H) Training of professionals to provide  
 8           linguistically and culturally competent follow-up  
 9           care to pediatric cancer survivors.

10          “(I) Different models of follow-up care.

11          “(J) Examining the cost-effectiveness of  
 12          the different models of follow-up care.”.

13 **SEC. 203. 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. STANDARDS FOR COMPREHENSIVE LONG-TERM**  
 19 **CARE FOR PEDIATRIC CANCER SURVIVORS**  
 20 **THROUGH THE LIFESPAN.**

21          “The Secretary may establish a task force to develop  
 22          and test standards, outcomes, and metrics for high-quality  
 23          childhood cancer survivorship care in consultation with a  
 24          full spectrum of representation of experts in late effects  
 25          of disease and treatment of childhood cancers, including—

1           “(1) oncologists who treat children and adoles-  
2       cents;

3           “(2) oncologists who treat adults;

4           “(3) primary care providers engaged in survi-  
5       vorship care;

6           “(4) survivors of childhood cancer;

7           “(5) parents of children who have been diag-  
8       nosed with and treated for cancer and parents of  
9       long-term survivors;

10          “(6) professionals who are engaged in the devel-  
11       opment of clinical practice guidelines;

12          “(7) nurses and social workers;

13          “(8) mental health professionals;

14          “(9) allied health professionals, including phys-  
15       ical therapists and occupational therapists;

16          “(10) experts in health care quality measure-  
17       ment and improvement; and

18          “(11) others, as the Secretary determines ap-  
19       propriate.”.

20   **SEC. 204. SURVIVORSHIP DEMONSTRATION PROJECT.**

21       (a) IN GENERAL.—Not later than 1 year after the  
22       date of the enactment of this Act, the Secretary of Health  
23       and Human Services (referred to in this section as the  
24       “Secretary”) may carry out a demonstration project over  
25       a 3-year period, designed to improve the quality and effi-

1 ciency of care provided to childhood cancer survivors  
 2 throughout their lifespan, through improved care coordi-  
 3 nation as survivors transitions to adult care.

4 (b) SELECTION OF DEMONSTRATION SITES.—

5 (1) MAXIMUM NUMBER OF SITES.—The max-  
 6 imum number of sites at which the demonstration  
 7 project under subsection (a) is carried out may not  
 8 exceed 10.

9 (2) DIVERSITY OF SITES.—In selecting entities  
 10 to participate in the demonstration project, the Sec-  
 11 retary may, to the extent practicable, include in such  
 12 selection—

13 (A) small-, medium-, and large-sized sites;  
 14 and

15 (B) sites located in different geographic  
 16 areas.

17 (c) ACTIVITIES UNDER DEMONSTRATION

18 PROJECT.—The activities conducted under the demonstra-  
 19 tion project under subsection (a) may, in addition to any  
 20 other activity specified by the Secretary, include activities  
 21 that seek to develop different models of care coordination,  
 22 including transitions of care, follow-up care, monitoring,  
 23 and other survivorship related programs that utilize a  
 24 multidisciplinary, team based approach to care, including  
 25 any of the following activities:

1           (1) Coordination of care and transitions of care  
2           between cancer care providers, primary care physi-  
3           cians, mental health professionals and any other rel-  
4           evant providers.

5           (2) Dissemination of information to, and train-  
6           ing of, health care providers about linguistically and  
7           culturally competent follow-up care specific to cancer  
8           survivors.

9           (3) Development of monitoring programs for  
10          cancer survivors and their families.

11          (4) Incorporation of peer support and men-  
12          toring programs to improve the quality of life of can-  
13          cer survivors.

14          (5) Designing systems and models for the effec-  
15          tive transfer of treatment information and care sum-  
16          maries from cancer care providers to other health  
17          care providers (including risk factors and a care  
18          plan).

19          (6) Evaluation of functional status and incorpo-  
20          ration of specific functional needs into the care plan-  
21          ning process.

22          (7) Dissemination of the information on activi-  
23          ties and programs conducted under this section to  
24          other health care providers (including primary care

1 physicians) and to cancer survivors and their fami-  
 2 lies, where appropriate.

3 (8) Other items determined by the Secretary.

4 (d) MEASURES.—The Secretary may use the fol-  
 5 lowing measures to assess the performance of each site:

6 (1) Patient care and patient/family satisfaction  
 7 measures.

8 (2) Resource utilization measures.

9 (3) Adult survivorship measures, as appro-  
 10 priate.

11 (e) GAO REPORT.—The Comptroller General of the  
 12 United States shall submit a report to Congress evaluating  
 13 the success of the demonstration project. Such report shall  
 14 include an assessment of the impact of the project upon  
 15 the quality and cost-efficiency of services furnished to indi-  
 16 viduals under this title, including an assessment of the sat-  
 17 isfaction of such individuals with respect to such services  
 18 that were furnished under such project. Such report shall  
 19 include recommendations regarding the possible expansion  
 20 of the demonstration project.

## 21 **Subtitle B—Coverage and Payment** 22 **of High Quality Care**

### 23 **SEC. 211. REPORT BY THE COMPTROLLER GENERAL.**

24 (a) IN GENERAL.—The Comptroller General of the  
 25 United States shall conduct a review and submit rec-

1 ommendations to Congress on existing barriers to obtain-  
2 ing and paying for adequate medical care for survivors of  
3 childhood cancer.

4 (b) CONSIDERATIONS.—In carrying out the review  
5 and formulating recommendations under subsection (a),  
6 the Comptroller General shall—

7 (1) identify existing barriers to the availability  
8 of complete and coordinated survivorship care for  
9 survivors of childhood cancer and to the availability  
10 of expert pediatric palliative care, including consider-  
11 ation of—

12 (A) understanding and education among  
13 patients, health care providers, regulators, and  
14 third-party payors;

15 (B) adequacy of payment codes to cover  
16 necessary survivorship services;

17 (C) access to necessary medical and other  
18 services for such survivors, including the serv-  
19 ices described in subsection (c); and

20 (D) lack of pediatric palliative care across  
21 all stages of illness and hospice services for pa-  
22 tients approaching the end of life; and

23 (2) make recommendations to provide improved  
24 access and payment plans for childhood cancer sur-

1 survivorship programs and palliative care, including  
2 psychosocial services and coverage of such services.

3 (c) SERVICES DESCRIBED.—The services described in  
4 this subsection are the following:

5 (1) Coordinated multidisciplinary long-term fol-  
6 low-up care with access to appropriate pediatric sub-  
7 specialists and adult subspecialists with specific ex-  
8 pertise in survivorship, including subspecialists with  
9 expertise in oncology, radiation oncology, surgery,  
10 cardiology, psychiatry or psychology, endocrinology,  
11 pulmonology, nephrology, dermatology, gynecology,  
12 and urology.

13 (2) Appropriate organ function testing (particu-  
14 larly screening for potential problems at much  
15 younger ages than usually indicated in the general  
16 population) and treatment, including—

17 (A) neuropsychological testing and mental  
18 health services;

19 (B) fertility testing and treatment;

20 (C) evaluation and treatment for endocrine  
21 disorders including growth hormone and testos-  
22 terone replacement;

23 (D) diagnostic imaging to screen for late  
24 effects of treatment (including subsequent can-  
25 cers), such as mammograms and magnetic reso-

1 nance imaging testing to screen for possible  
2 breast cancer;

3 (E) screening for cardiac problems, such  
4 as echocardiograms;

5 (F) screening for osteoporosis with bone  
6 densitometry, including dual x-ray absorptiometry and monitoring 25-hydroxyvitamin D levels;  
8

9 (G) dental coverage and necessary dental  
10 implants;

11 (H) hearing aids and other prosthetic devices; and  
12

13 (I) screening for lung problems, such as  
14 pulmonary function testing.

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