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115TH CONGRESS
2D SESSION

S. 292

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

IN THE SENATE OF THE UNITED STATES

FEBRUARY 2, 2017

Mr. REED (for himself, Mrs. CAPITO, Mr. VAN HOLLEN, Mr. ISAKSON, Mr. BLUNT, Mrs. SHAHEEN, Mr. RUBIO, Mrs. GILLIBRAND, Mr. BOOKER, Ms. COLLINS, Mr. KING, Mr. COONS, Mr. PERDUE, Mr. GRASSLEY, Ms. STABENOW, Mr. KENNEDY, Mr. WHITEHOUSE, Mr. CASSIDY, Mr. BLUMENTHAL, Mr. YOUNG, Mr. CASEY, Mr. MANCHIN, Mrs. ERNST, Mr. NELSON, Mr. PORTMAN, Mrs. FISCHER, Mr. FRANKEN, Mr. BROWN, Mr. HATCH, Mr. PETERS, Ms. MURKOWSKI, Ms. DUCKWORTH, Mr. MARKEY, Mr. HELLER, Ms. KLOBUCHAR, Mr. WICKER, Mr. MERKLEY, Mr. DONNELLY, Mrs. FEINSTEIN, Mr. SCHUMER, Mr. BENNET, Mr. LEAHY, Mr. KAINE, Ms. SMITH, Mr. TILLIS, Ms. CORTEZ MASTO, Mr. SANDERS, Mr. CARDIN, and Ms. BALDWIN) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

MARCH 12, 2018

Reported by Mr. ALEXANDER, with an amendment

[Strike out all after the enacting clause and insert the part printed in *italic*]

A BILL

To maximize discovery, and accelerate development and availability, 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 Can-
 cer 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 sur-
 vivors.
 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
10 rates have increased to over 80 percent for children
11 and adolescents under age 20.

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

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

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

22 (6) As many as two-thirds of childhood cancer
23 survivors are likely to experience at least one late ef-
24 fect of treatment, with as many as one-fourth experi-
25 encing a late effect that is serious or life-threat-
26 ening. Common late effects of childhood cancer are

1 neurocognitive, psychological, cardiopulmonary, en-
2 docrine, and musculoskeletal effects, secondary ma-
3 lignancies, and early death.

4 (7) As a result of disparities in the delivery of
5 cancer care, minority, low-income, and other medi-
6 cally underserved children are more likely to be diag-
7 nosed with late stage disease, experience poorer
8 treatment outcomes, have shorter survival time with
9 less quality of life, and experience a substantially
10 greater likelihood of cancer death.

11 (8) Collection of biospecimens, along with clin-
12 ical and outcome data, on children and adolescents
13 with cancer in the United States is necessary to im-
14 prove childhood and adolescent cancer treatments
15 and cures. Currently biospecimens, and clinical and
16 outcome data, are collected for less than half of chil-
17 dren in the United States with cancer.

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

22 (10) Despite the intense stress caused by child-
23 hood cancer, there is a lack of standardized and co-
24 ordinated psychosocial care for the children and

1 their families, from the date of diagnosis through
2 treatment and survivorship.

3 (11) The National Academy of Medicine, in its
4 report on cancer survivorship entitled “Childhood
5 Cancer Survivorship: Improving Care and Quality of
6 Life”, states that an organized system of care and
7 a method of care for pediatric cancer survivors is
8 needed.

9 (12) Focused and well-designed research and
10 pilot health delivery programs can answer questions
11 about the optimal ways to provide health care, fol-
12 low-up monitoring services, and survivorship care to
13 those diagnosed with childhood cancer and con-
14 tribute to improvements in the quality of care and
15 quality of life of those individuals through adult-
16 hood.

17 (13) The National Institutes of Health, includ-
18 ing the National Cancer Institute, invest approxi-
19 mately half of their annual appropriations to support
20 basic research that serves as the foundation for
21 translational and clinical research for all diseases
22 and conditions, with the potential to lead to break-
23 throughs for children with cancer. Virtually all
24 progress against cancer—in both children and

adults—has been founded in basic research, often in areas not directly related to the disease.

(14) The National Cancer Institute supports a number of key research programs specifically to advance childhood cancer care, including precision medicine clinical trials for children with cancer; the Children’s Oncology Group (part of the National Clinical Trials Network of the National Cancer Institute); the Pediatric Preclinical Testing Consortium; 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).

1 **TITLE I—MAXIMIZING RE-**
 2 **SEARCH THROUGH DIS-**
 3 **COVERY**

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

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

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

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

13 “(a) CHILDREN’S CANCER BIOREPOSITORIES.—

14 “(1) AWARD.—The Secretary, acting through
 15 the Director of NIH, may make awards to an entity
 16 or entities described in paragraph (4) to build upon
 17 existing initiatives to collect biospecimens and clin-
 18 ical and demographic information with a goal of col-
 19 lection for the vast majority of all children, adoles-
 20 cents, and young adults with selected cancer
 21 subtypes (and their recurrences) for which current
 22 treatments are least effective, through one or more
 23 biospecimen research efforts designed to achieve a
 24 better understanding of the cause of such cancers

(and their recurrences) and the effects of treatments for such cancers.

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

~~“(A) Acquire, preserve, and store high-quality, donated biospecimens and associated clinical and demographic information on children, adolescents, and young adults diagnosed with cancer in the United States, focusing on children and adolescents enrolled in clinical trials for whom current treatments are least effective. Activities under this subparagraph may include storage of biospecimens and associated clinical and demographic data at biorepositories supported by the National Cancer Institute, such as the Children’s Oncology Group Biorepository and the Pediatric Cooperative Human Tissue Network as well as through biorepositories established as appropriate to support the scientific needs of future research efforts.~~

~~“(B) Make such information publicly available, including the repositories described in subparagraph (A).~~

1 “(C) Maintain a secure searchable data-
 2 base on stored biospecimens and associated
 3 clinical and demographic data from children,
 4 adolescents, and young adults with cancer for
 5 the conduct of research by scientists and quali-
 6 fied health care professionals.

7 “(D) Establish procedures for evaluating
 8 applications for access to such biospecimens
 9 and clinical and demographic data from re-
 10 searchers and other qualified health care pro-
 11 fessionals.

12 “(E) Make available and distribute bio-
 13 specimens and clinical and demographic data
 14 from children, adolescents, and young adults
 15 with cancer to researchers and qualified health
 16 care professionals for peer-reviewed research at
 17 a minimal cost.

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

22 “(4) APPLICATION; CONSIDERATIONS.—

23 “(A) APPLICATION.—To be eligible to re-
 24 ceive an award under paragraph (1) an entity
 25 shall submit an application to the Secretary at

1 such a time, in such manner, and containing
2 such information as the Secretary may reason-
3 ably require.

4 “(B) CONSIDERATIONS.—In evaluating the
5 applications in subparagraph (A), the Secretary
6 shall consider the existing infrastructure of the
7 entity that would allow for the timely capture of
8 biospecimens and related clinical and demo-
9 graphic information for children, adolescents,
10 and young adults with cancer.

11 “(5) PRIVACY PROTECTIONS; CONSENT.—

12 “(A) IN GENERAL.—The Secretary may
13 not make an award under paragraph (1) to an
14 entity unless the Secretary ensures that such
15 entity—

16 “(i) collects biospecimens and associ-
17 ated clinical and demographic information
18 from children and adolescents with appro-
19 priate permission from parents or legal
20 guardians in accordance with Federal and
21 State law; and

22 “(ii) adheres to strict confidentiality
23 to protect the identity and privacy of pa-
24 tients in accordance with Federal and
25 State law.

1 “(B) CONSENT.—The Secretary shall es-
2 tablish an appropriate process for achieving
3 consent from the patient, parent, or legal
4 guardian.

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

7 “(A) SINGLE POINT OF ACCESS.—The Sec-
8 retary shall ensure that each biorepository sup-
9 ported under paragraph (1) has electronically
10 searchable data for use by researchers and
11 other qualified health care professionals in the
12 manner and to the extent defined by the Sec-
13 retary.

14 “(B) STANDARD DATA.—The Secretary
15 shall require all recipients of an award under
16 paragraph (1) to make available a standard
17 dataset for the purposes of subparagraph (A) in
18 a standard electronic format that enables re-
19 searchers and qualified health care professionals
20 to search.

21 “(C) GUIDELINES AND OVERSIGHT.—The
22 Secretary shall develop and disseminate appro-
23 priate guidelines for the development and main-
24 tenance of the biorepositories supported under
25 this subsection, including appropriate oversight.

1 ~~“(7) COORDINATION.—The Secretary shall en-~~
 2 ~~sure that clinical and demographic information col-~~
 3 ~~lected in accordance with this subsection is collected~~
 4 ~~in coordination with the information collected under~~
 5 ~~section 399E–1.~~

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

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

16 ~~“(A) the number of biospecimens and cor-~~
 17 ~~responding clinical demographic data collected~~
 18 ~~through the biospecimen research efforts sup-~~
 19 ~~ported under paragraph (1);~~

20 ~~“(B) the number of biospecimens and cor-~~
 21 ~~responding clinical demographic data requested~~
 22 ~~for use by researchers;~~

23 ~~“(C) any barriers to the collection of bio-~~
 24 ~~specimens and corresponding clinical demo-~~
 25 ~~graphic data;~~

1 “(D) any barriers experienced by research-
 2 ers or health care professionals in accessing the
 3 biospecimens and corresponding clinical demo-
 4 graphic data necessary for use in research; and

5 “(E) any recommendations with respect to
 6 improving the biospecimen and biorepository re-
 7 search efforts under this subsection.

8 “(10) DEFINITIONS.—For purposes of this sub-
 9 section:

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

13 “(B) BIOSPECIMEN.—The term ‘biospeci-
 14 men’ includes—

15 “(i) solid tumor tissue or bone mar-
 16 row;

17 “(ii) normal or control tissue;

18 “(iii) blood and plasma;

19 “(iv) DNA and RNA extractions;

20 “(v) familial DNA; and

21 “(vi) any other sample required by the
 22 Secretary.

23 “(C) CLINICAL AND DEMOGRAPHIC INFOR-
 24 MATION.—The term ‘clinical and demographic
 25 information’ includes—

- 1 “(i) date of diagnosis;
- 2 “(ii) age at diagnosis;
- 3 “(iii) the patient’s gender, race, eth-
- 4 nicity, and environmental exposures;
- 5 “(iv) extent of disease at enrollment;
- 6 “(v) site of metastases;
- 7 “(vi) location of primary tumor coded;
- 8 “(vii) histologic diagnosis;
- 9 “(viii) tumor marker data when avail-
- 10 able;
- 11 “(ix) treatment and outcome data;
- 12 “(x) information related to specimen
- 13 quality; and
- 14 “(xi) any other information required
- 15 by the Secretary.”; and
- 16 (2) in subsection (d)—
- 17 (A) by striking “and section 399E–1” and
- 18 inserting “and sections 317U, 399E–1, 417H,
- 19 and 417H–1”;
- 20 (B) by striking “2009 through 2013” and
- 21 inserting “2018 through 2022”; and
- 22 (C) by striking “such purpose” and insert-
- 23 ing “such purposes”.

1 **SEC. 102. IMPROVING CHILDHOOD CANCER SURVEIL-**
2 **LANCE.**

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

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

7 (2) by striking subsection (a) and inserting the
8 following:

9 “(a) **IN GENERAL.**—The Secretary, acting through
10 the Director of the Centers for Disease Control and Pre-
11 vention, may make awards to State cancer registries to
12 enhance and expand infrastructure to track the epidemi-
13 ology of cancer in children, adolescents, and young adults.
14 Such registries may be updated to include each occurrence
15 of such cancers within a period of time designated by the
16 Secretary.

17 “(b) **ACTIVITIES.**—The grants described in sub-
18 section (a) may be used for—

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

22 “(2) developing procedures to implement early
23 inclusion of childhood, adolescent, and young adult
24 cancer cases on State cancer registries through the
25 use of electronic reporting;

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

8 “~~(5) tracking the late effects of childhood, ado-~~
9 lescent, and young adult cancers.

10 “(c) COORDINATION.—The Secretary shall ensure
11 that information collected through State cancer registries
12 under this section is collected in coordination with clinical
13 and demographic information collected under section
14 417E(a), as appropriate.”.

17 SEC. 111. INCLUSION OF AT LEAST ONE PEDIATRIC
18 ONCOLOGIST ON THE NATIONAL CANCER AD-
19 VISORY BOARD.

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

23 “~~(iii)~~ of the members appointed to the Board—

24 “(I) not less than 5 members shall be indi-
25 viduals knowledgeable in environmental carcino-

genesis (including carcinogenesis involving occupational and dietary factors); and

“(H) not less than one member shall be an individual knowledgeable in pediatric oncology.”.

SEC. 112. SENSE OF CONGRESS REGARDING PEDIATRIC EXPERTISE AT THE NATIONAL CANCER INSTITUTE.

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

Subtitle C—NIH Report on Childhood Cancer Activities

SEC. 121. REPORTING ON CHILDHOOD CANCER RESEARCH PROJECTS.

Section 409D(e)(3) of the Public Health Service Act (42 U.S.C. 284h(e)(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:

1 “(B) childhood cancer research projects
2 conducted or supported by the National Insti-
3 tutes of Health.”.

4 **TITLE H—MAXIMIZING DELIV-**
5 **ERY: CARE, QUALITY OF LIFE,**
6 **SURVIVORSHIP, AND CARE-**
7 **GIVER SUPPORT**
8 **Subtitle A—Childhood Cancer**
9 **Survivors’ Quality of Life Act**

10 **SEC. 201. CANCER SURVIVORSHIP PROGRAMS.**

11 (a) CANCER SURVIVORSHIP PROGRAMS.—The Public
12 Health Service Act is amended by inserting after section
13 399N of such Act (42 U.S.C. 280g–2) the following:

14 **“SEC. 399N–1. PILOT PROGRAMS TO EXPLORE MODEL SYS-**
15 **TEMS OF CARE FOR PEDIATRIC CANCER SUR-**
16 **VIVORS.**

17 “(a) IN GENERAL.—Not later than 1 year after the
18 date of enactment of the Childhood Cancer Survivorship,
19 Treatment, Access, and Research Act of 2017, the Sec-
20 retary may make awards to eligible entities to establish
21 pilot programs to develop, study, or evaluate model sys-
22 tems for monitoring and caring for childhood cancer sur-
23 vivors throughout their lifespan, including evaluation of
24 shared care and medical home and clinic based models for
25 transition to adult care.

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

3 “(1) a medical school;

4 “(2) a children’s hospital;

5 “(3) a cancer center;

6 “(4) a community-based medical facility; or

7 “(5) any other entity with significant experience
8 and expertise in treating survivors of childhood can-
9 cers.

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

13 “(1) to use the award to establish a pilot pro-
14 gram to develop, study, or evaluate one or more
15 model systems for monitoring and caring for cancer
16 survivors; and

17 “(2) in developing, studying, and evaluating
18 such systems; to give special emphasis to—

19 “(A) design of protocols for different mod-
20 els of follow-up care, monitoring, and other sur-
21 vivorship programs (including peer support and
22 mentoring programs);

23 “(B) development of various models for
24 providing multidisciplinary care;

1 “(C) dissemination of information and the
 2 provision of training to health care providers
 3 about how to provide linguistically and cul-
 4 turally competent follow-up care and monitoring
 5 to cancer survivors and their families;

6 “(D) development of psychosocial interven-
 7 tions and support programs to improve the
 8 quality of life of cancer survivors and their fam-
 9 ilies;

10 “(E) design of systems for the effective
 11 transfer of treatment information and care
 12 summaries from cancer care providers to other
 13 health care providers (including risk factors and
 14 a plan for recommended follow-up care);

15 “(F) dissemination of the information and
 16 programs described in subparagraphs (A)
 17 through (E) to other health care providers (in-
 18 cluding primary care physicians and internists)
 19 and to cancer survivors and their families;
 20 where appropriate; and

21 “(G) development of initiatives that pro-
 22 mote the coordination and effective transition of
 23 care between cancer care providers, primary
 24 care physicians, and mental health profes-
 25 sionals.

1 **“SEC. 399N-2. WORKFORCE DEVELOPMENT COLLABO-**
 2 **RATIVE ON MEDICAL AND PSYCHOSOCIAL**
 3 **CARE FOR CHILDHOOD CANCER SURVIVORS.**

4 “(a) IN GENERAL.—The Secretary shall, not later
 5 than 1 year after the date of enactment of the Childhood
 6 Cancer Survivorship, Treatment, Access, and Research
 7 Act of 2017, convene a Workforce Development Collabo-
 8 rative on Medical and Psychosocial Care for Pediatric
 9 Cancer Survivors (referred to in this section as the ‘Col-
 10 laborative’). The Collaborative shall be a cross-specialty,
 11 multidisciplinary group composed of educators, consumer
 12 and family advocates, and providers of psychosocial and
 13 biomedical health services.

14 “(b) GOALS AND REPORTS.—The Collaborative shall
 15 submit to the Secretary a report establishing a plan to
 16 meet the following objectives for medical and psychosocial
 17 care workforce development:

18 “(1) Identifying, refining, and broadly dissemi-
 19 nating to health care educators information about
 20 workforce competencies, models, and curricula rel-
 21 evant to providing medical and psychosocial services
 22 to persons surviving pediatric cancers.

23 “(2) Adapting curricula for continuing edu-
 24 cation of the existing workforce using efficient work-
 25 place-based learning approaches.

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

4 “(4) Strengthening the emphasis on psycho-
5 social health care in educational accreditation stand-
6 ards and professional licensing and certification
7 exams by recommending revisions to the relevant
8 oversight organizations.

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

11 “(6) Evaluating the effectiveness of peer sup-
12 port programs in the psychosocial care of pediatric
13 cancer patients and survivors.”.

14 (b) TECHNICAL AMENDMENT.—

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

20 (2) EFFECTIVE DATE.—The amendment made
21 by paragraph (1) shall take effect as if included in
22 section 3 of the Hematological Cancer Research In-
23 vestment and Education Act of 2002 (Public Law
24 107–172; 116 Stat. 541).

1 **SEC. 202. GRANTS TO IMPROVE CARE FOR PEDIATRIC CAN-**
 2 **CER SURVIVORS.**

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

6 (1) in the section heading, by striking “**RE-**
 7 **SEARCH AND AWARENESS**” and inserting “**RE-**
 8 **SEARCH, AWARENESS, AND SURVIVORSHIP**”;
 9 and

10 (2) by striking subsection (b) and inserting the
 11 following:

12 “(b) IMPROVING CARE FOR PEDIATRIC CANCER SUR-
 13 VIVORS.—

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

16 “(A) RESEARCH AWARDS.—The Director
 17 of NIH, in coordination with ongoing research
 18 activities, may conduct or support pediatric
 19 cancer survivorship research including in any of
 20 the following areas:

21 “(i) Needs and outcomes of pediatric
 22 cancer survivors within minority or other
 23 medically underserved populations.

24 “(ii) Health disparities in pediatric
 25 cancer survivorship outcomes within minor-

ity or other medically underserved populations.

“(iii) Barriers that pediatric cancer survivors within minority or other medically underserved populations face in receiving follow-up care.

“(iv) Familial, socioeconomic, and other environmental factors and the impact of such factors on treatment outcomes and survivorship.

“(B) BALANCED APPROACH.—In conducting or supporting research under subparagraph (A)(i) on pediatric cancer survivors within minority or other medically underserved populations, the Director of NIH shall ensure that such research addresses both the physical and the psychological needs of such survivors, as appropriate.

“(2) RESEARCH ON LATE EFFECTS AND FOLLOW-UP CARE FOR PEDIATRIC CANCER SURVIVORS.—The Director of NIH, in coordination with ongoing research activities, may conduct or support research on follow-up care for pediatric cancer survivors, including in any of the following areas:

1 “(A) The development of indicators used
2 for long-term patient tracking and analysis of
3 the late effects of cancer treatment for pediatric
4 cancer survivors.

5 “(B) The identification of risk factors as-
6 sociated with the late effects of cancer treat-
7 ment.

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

10 “(D) The identification of the molecular
11 underpinnings of long-term complications.

12 “(E) The development of risk prediction
13 models to identify those at highest risk of long-
14 term complications.

15 “(F) Initiatives to protect cancer survivors
16 from the late effects of cancer treatment, by de-
17 veloping targeted interventions to reduce the
18 burden of morbidity borne by cancer survivors.

19 “(G) Transitions in care for pediatric can-
20 cer survivors.

21 “(H) Training of professionals to provide
22 linguistically and culturally competent follow-up
23 care to pediatric cancer survivors.

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

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

3 **SEC. 203. COMPREHENSIVE LONG-TERM FOLLOW-UP SERV-**
4 **ICES FOR PEDIATRIC CANCER SURVIVORS.**

5 Part B of title III of the Public Health Service Act
6 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
7 tion 317T the following:

8 **“SEC. 317U. STANDARDS FOR COMPREHENSIVE LONG-TERM**
9 **CARE FOR PEDIATRIC CANCER SURVIVORS**
10 **THROUGH THE LIFESPAN.**

11 “The Secretary may establish a task force to develop
12 and test standards, outcomes, and metrics for high-quality
13 childhood cancer survivorship care in consultation with a
14 full spectrum of representation of experts in late effects
15 of disease and treatment of childhood cancers, including—

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

18 “(2) oncologists who treat adults;

19 “(3) primary care providers engaged in survi-
20 vorship care;

21 “(4) survivors of childhood cancer;

22 “(5) parents of children who have been diag-
23 nosed with and treated for cancer and parents of
24 long-term survivors;

1 “(6) professionals who are engaged in the devel-
 2 opment of clinical practice guidelines;
 3 “(7) nurses and social workers;
 4 “(8) mental health professionals;
 5 “(9) allied health professionals, including phys-
 6 ical therapists and occupational therapists;
 7 “(10) experts in health care quality measure-
 8 ment and improvement; and
 9 “(11) others, as the Secretary determines ap-
 10 propriate.”.

11 **SEC. 204. SURVIVORSHIP DEMONSTRATION PROJECT.**

12 (a) ~~IN GENERAL.~~—Not later than 1 year after the
 13 date of the enactment of this Act, the Secretary of Health
 14 and Human Services (referred to in this section as the
 15 “Secretary”) may carry out a demonstration project over
 16 a ~~3~~-year period, designed to improve the quality and effi-
 17 ciency of care provided to childhood cancer survivors
 18 throughout their lifespan, through improved care coordi-
 19 nation as survivors transitions to adult care.

20 (b) ~~SELECTION OF DEMONSTRATION SITES.~~—

21 (1) ~~MAXIMUM NUMBER OF SITES.~~—The max-
 22 imum number of sites at which the demonstration
 23 project under subsection (a) is carried out may not
 24 exceed ~~10~~.

1 (2) DIVERSITY OF SITES.—In selecting entities
2 to participate in the demonstration project, the Sec-
3 retary may, to the extent practicable, include in such
4 selection—

5 (A) small-, medium-, and large-sized sites;
6 and

7 (B) sites located in different geographic
8 areas.

9 (c) ACTIVITIES UNDER DEMONSTRATION
10 PROJECT.—The activities conducted under the demonstra-
11 tion project under subsection (a) may, in addition to any
12 other activity specified by the Secretary, include activities
13 that seek to develop different models of care coordination,
14 including transitions of care, follow-up care, monitoring,
15 and other survivorship related programs that utilize a
16 multidisciplinary, team based approach to care, including
17 any of the following activities:

18 (1) Coordination of care and transitions of care
19 between cancer care providers, primary care physi-
20 cians, mental health professionals and any other rel-
21 evant providers.

22 (2) Dissemination of information to, and train-
23 ing of, health care providers about linguistically and
24 culturally competent follow-up care specific to cancer
25 survivors.

1 (3) Development of monitoring programs for
2 cancer survivors and their families.

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

6 (5) Designing systems and models for the effec-
7 tive transfer of treatment information and care sum-
8 maries from cancer care providers to other health
9 care providers (including risk factors and a care
10 plan).

11 (6) Evaluation of functional status and incorpo-
12 ration of specific functional needs into the care plan-
13 ning process.

14 (7) Dissemination of the information on activi-
15 ties and programs conducted under this section to
16 other health care providers (including primary care
17 physicians) and to cancer survivors and their fami-
18 lies, where appropriate.

19 (8) Other items determined by the Secretary.

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

22 (1) Patient care and patient/family satisfaction
23 measures.

24 (2) Resource utilization measures.

1 ~~(2)~~ Adult survivorship measures, as appropriate.
 2 ~~priate.~~

3 ~~(c) GAO REPORT.~~—The Comptroller General of the
 4 United States shall submit a report to Congress evaluating
 5 the success of the demonstration project. Such report shall
 6 include an assessment of the impact of the project upon
 7 the quality and cost-efficiency of services furnished to indi-
 8 viduals under this title, including an assessment of the sat-
 9 isfaction of such individuals with respect to such services
 10 that were furnished under such project. Such report shall
 11 include recommendations regarding the possible expansion
 12 of the demonstration project.

13 **Subtitle B—Coverage and Payment** 14 **of High Quality Care**

15 **SEC. 211. REPORT BY THE COMPTROLLER GENERAL.**

16 ~~(a) IN GENERAL.~~—The Comptroller General of the
 17 United States shall conduct a review and submit rec-
 18 ommendations to Congress on existing barriers to obtain-
 19 ing and paying for adequate medical care for survivors of
 20 childhood cancer.

21 ~~(b) CONSIDERATIONS.~~—In carrying out the review
 22 and formulating recommendations under subsection (a),
 23 the Comptroller General shall—

24 ~~(1)~~ identify existing barriers to the availability
 25 of complete and coordinated survivorship care for

1 survivors of childhood cancer and to the availability
 2 of expert pediatric palliative care, including consider-
 3 ation of—

4 (A) understanding and education among
 5 patients, health care providers, regulators, and
 6 third-party payors;

7 (B) adequacy of payment codes to cover
 8 necessary survivorship services;

9 (C) access to necessary medical and other
 10 services for such survivors, including the serv-
 11 ices described in subsection (e); and

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

15 (2) make recommendations to provide improved
 16 access and payment plans for childhood cancer sur-
 17 vivorship programs and palliative care, including
 18 psychosocial services and coverage of such services.

19 (e) SERVICES DESCRIBED.—The services described in
 20 this subsection are the following:

21 (1) Coordinated multidisciplinary long-term fol-
 22 low-up care with access to appropriate pediatric sub-
 23 specialists and adult subspecialists with specific ex-
 24 pertise in survivorship, including subspecialists with
 25 expertise in oncology, radiation oncology, surgery,

1 cardiology, psychiatry or psychology, endocrinology,
 2 pulmonology, nephrology, dermatology, gynecology,
 3 and urology.

4 (2) Appropriate organ function testing (particu-
 5 larly screening for potential problems at much
 6 younger ages than usually indicated in the general
 7 population) and treatment, including—

8 (A) neuropsychological testing and mental
 9 health services;

10 (B) fertility testing and treatment;

11 (C) evaluation and treatment for endocrine
 12 disorders including growth hormone and testos-
 13 terone replacement;

14 (D) diagnostic imaging to screen for late
 15 effects of treatment (including subsequent can-
 16 cers), such as mammograms and magnetic reso-
 17 nance imaging testing to screen for possible
 18 breast cancer;

19 (E) screening for cardiac problems, such
 20 as echocardiograms;

21 (F) screening for osteoporosis with bone
 22 densitometry, including dual x-ray absorptiom-
 23 etry and monitoring 25-hydroxyvitamin D lev-
 24 els;

- 1 (G) dental coverage and necessary dental
 2 implants;
 3 (H) hearing aids and other prosthetic de-
 4 vices; and
 5 (I) screening for lung problems, such as
 6 pulmonary function testing.

7 **SECTION 1. SHORT TITLE; TABLE OF CONTENTS.**

8 (a) *SHORT TITLE.*—*This Act may be cited as the*
 9 *“Childhood Cancer Survivorship, Treatment, Access, and*
 10 *Research Act of 2018” or the “Childhood Cancer STAR*
 11 *Act”.*

12 (b) *TABLE OF CONTENTS.*—*The table of contents for*
 13 *this Act is as follows:*

Sec. 1. Short title; table of contents.

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 Reporting on Childhood Cancer Activities

Sec. 121. Reporting on childhood cancer research projects.

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

Sec. 201. Cancer survivorship programs.

Sec. 202. Grants to improve care for pediatric cancer survivors.

Sec. 203. Best practices for long-term follow-up services for pediatric cancer survivors.

Sec. 204. Technical amendment.

1 ***TITLE I—MAXIMIZING RESEARCH***
 2 ***THROUGH DISCOVERY***
 3 ***Subtitle A—Caroline Pryce Walker***
 4 ***Conquer Childhood Cancer Re-***
 5 ***authorization Act***

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

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

10 *(1) in the section heading, by striking “RE-*
 11 ***SEARCH AND AWARENESS”*** *and inserting “RE-*
 12 ***SEARCH, AWARENESS, AND SURVIVORSHIP”;***

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

15 *“(a) CHILDREN’S CANCER BIOREPOSITORIES.—*

16 *“(1) AWARD.—The Secretary, acting through the*
 17 *Director of NIH, may make awards to an entity or*
 18 *entities described in paragraph (4) to build upon ex-*
 19 *isting research efforts to collect biospecimens and clin-*
 20 *ical and demographic information of children, adoles-*
 21 *cents, and young adults with selected cancer subtypes*
 22 *(and their recurrences) for which current treatments*
 23 *are least effective, in order to achieve a better under-*
 24 *standing of the causes of such cancer subtypes (and*

1 *their recurrences), and the effects and outcomes of*
2 *treatments for such cancers.*

3 *“(2) USE OF FUNDS.—Amounts received under*
4 *an award under paragraph (1) may be used to carry*
5 *out the following:*

6 *“(A) Collect and store high-quality, donated*
7 *biospecimens and associated clinical and demo-*
8 *graphic information on children, adolescents,*
9 *and young adults diagnosed with cancer in the*
10 *United States, focusing on children, adolescents,*
11 *and young adults with cancer enrolled in clin-*
12 *ical trials for whom current treatments are least*
13 *effective. Activities under this subparagraph may*
14 *include storage of biospecimens and associated*
15 *clinical and demographic data at existing bio-*
16 *repositories supported by the National Cancer*
17 *Institute.*

18 *“(B) Maintain an interoperable, secure, and*
19 *searchable database on stored biospecimens and*
20 *associated clinical and demographic data from*
21 *children, adolescents, and young adults with can-*
22 *cer for the purposes of research by scientists and*
23 *qualified health care professionals.*

24 *“(C) Establish and implement procedures*
25 *for evaluating applications for access to such bio-*

1 *specimens and clinical and demographic data*
 2 *from researchers and other qualified health care*
 3 *professionals.*

4 *“(D) Provide access to biospecimens and*
 5 *clinical and demographic data from children,*
 6 *adolescents, and young adults with cancer to re-*
 7 *searchers and qualified health care professionals*
 8 *for peer-reviewed research—*

9 *“(i) consistent with the procedures es-*
 10 *tablished pursuant to subparagraph (C);*

11 *“(ii) only to the extent permitted by*
 12 *applicable Federal and State law; and*

13 *“(iii) in a manner that protects per-*
 14 *sonal privacy to the extent required by ap-*
 15 *plicable Federal and State privacy law, at*
 16 *minimum.*

17 *“(3) NO REQUIREMENT.—No child, adolescent, or*
 18 *young adult with cancer shall be required under this*
 19 *subsection to contribute a specimen to a biorepository*
 20 *or share clinical or demographic data.*

21 *“(4) APPLICATION; CONSIDERATIONS.—*

22 *“(A) APPLICATION.—To be eligible to re-*
 23 *ceive an award under paragraph (1) an entity*
 24 *shall submit an application to the Secretary at*
 25 *such a time, in such manner, and containing*

1 *such information as the Secretary may reason-*
 2 *ably require.*

3 “(B) *CONSIDERATIONS.*—*In evaluating ap-*
 4 *plications submitted under subparagraph (A),*
 5 *the Secretary shall consider the existing infra-*
 6 *structure of the entity that would allow for the*
 7 *timely capture of biospecimens and related clin-*
 8 *ical and demographic information for children,*
 9 *adolescents, and young adults with cancer for*
 10 *whom current treatments are least effective.*

11 “(5) *PRIVACY PROTECTIONS AND INFORMED CON-*
 12 *SENT.*—

13 “(A) *IN GENERAL.*—*The Secretary may not*
 14 *make an award under paragraph (1) to an enti-*
 15 *ty unless the Secretary ensures that such enti-*
 16 *ty—*

17 “(i) *collects biospecimens and associ-*
 18 *ated clinical and demographic information*
 19 *only from participants who have given their*
 20 *informed consent in accordance with Fed-*
 21 *eral and State law; and*

22 “(ii) *protects personal privacy to the*
 23 *extent required by applicable Federal and*
 24 *State law, at minimum.*

1 “(B) *INFORMED CONSENT.*—*The Secretary*
 2 *shall ensure biospecimens and associated clinical*
 3 *and demographic information are collected with*
 4 *informed consent, as described in subparagraph*
 5 *(A)(i).*

6 “(6) *GUIDELINES AND OVERSIGHT.*—*The Sec-*
 7 *retary shall develop and disseminate appropriate*
 8 *guidelines for the development and maintenance of the*
 9 *biorepositories supported under this subsection, in-*
 10 *cluding appropriate oversight, to facilitate further re-*
 11 *search on select cancer subtypes (and their*
 12 *recurrences) in children, adolescents, and young*
 13 *adults with such cancers (and their recurrences).*

14 “(7) *COORDINATION.*—*To encourage the greatest*
 15 *possible efficiency and effectiveness of federally sup-*
 16 *ported efforts with respect to the activities described*
 17 *in this subsection, the Secretary shall ensure the ap-*
 18 *propriate coordination of programs supported under*
 19 *this section with existing federally supported cancer*
 20 *registry programs and the activities under section*
 21 *399E–1, as appropriate.*

22 “(8) *SUPPLEMENT NOT SUPPLANT.*—*Funds pro-*
 23 *vided under this subsection shall be used to supple-*
 24 *ment, and not supplant, Federal and non-Federal*

1 *funds available for carrying out the activities de-*
 2 *scribed in this subsection.*

3 “(9) *REPORT.*—*Not later than 4 years after the*
 4 *date of enactment of the Childhood Cancer Survivor-*
 5 *ship, Treatment, Access, and Research Act of 2018,*
 6 *the Secretary shall submit to Congress a report on—*

7 “(A) *the number of biospecimens and cor-*
 8 *responding clinical demographic data collected*
 9 *through the biospecimen research efforts sup-*
 10 *ported under paragraph (1);*

11 “(B) *the number of biospecimens and cor-*
 12 *responding clinical demographic data requested*
 13 *for use by researchers;*

14 “(C) *barriers to the collection of biospeci-*
 15 *mens and corresponding clinical demographic*
 16 *data;*

17 “(D) *barriers experienced by researchers or*
 18 *health care professionals in accessing the bio-*
 19 *specimens and corresponding clinical demo-*
 20 *graphic data necessary for use in research; and*

21 “(E) *recommendations with respect to im-*
 22 *proving the biospecimen and biorepository re-*
 23 *search efforts under this subsection.*

24 “(10) *DEFINITIONS.*—*For purposes of this sub-*
 25 *section:*

1 “(A) *AWARD*.—The term ‘award’ includes a
2 grant, contract, or cooperative agreement deter-
3 mined by the Secretary.

4 “(B) *BIOSPECIMEN*.—The term ‘biospeci-
5 men’ includes—

6 “(i) solid tumor tissue or bone marrow;

7 “(ii) normal or control tissue;

8 “(iii) blood and plasma;

9 “(iv) DNA and RNA extractions;

10 “(v) familial DNA; and

11 “(vi) any other sample relevant to can-
12 cer research, as required by the Secretary.

13 “(C) *CLINICAL AND DEMOGRAPHIC INFOR-*
14 *MATION*.—The term ‘clinical and demographic
15 information’ includes—

16 “(i) date of diagnosis;

17 “(ii) age at diagnosis;

18 “(iii) the patient’s sex, race, ethnicity,
19 and environmental exposures;

20 “(iv) extent of disease at enrollment;

21 “(v) site of metastases;

22 “(vi) location of primary tumor coded;

23 “(vii) histologic diagnosis;

24 “(viii) tumor marker data when avail-
25 able;

1 “(ix) treatment and outcome data;
 2 “(x) information related to specimen
 3 quality; and
 4 “(xi) any other applicable information
 5 required by the Secretary.”; and
 6 (3) in subsection (c), by striking “(42 U.S.C. 202
 7 note)”.

8 **SEC. 102. IMPROVING CHILDHOOD CANCER SURVEILLANCE.**

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

11 (1) in subsection (a)—

12 (A) by striking “shall award a grant” and
 13 inserting “may make awards to State cancer
 14 registries”; and

15 (B) by striking “track the epidemiology of
 16 pediatric cancer into a comprehensive nation-
 17 wide registry of actual occurrences of pediatric
 18 cancer” and inserting “collect information to
 19 better understand the epidemiology of cancer in
 20 children, adolescents, and young adults”; and

21 (C) by striking the second sentence and in-
 22 serting “Such registries may be updated to in-
 23 clude each occurrence of such cancers within a
 24 period of time designated by the Secretary.”;

1 (2) by redesignating subsection (b) as subsection
2 (d);

3 (3) by inserting after subsection (a) the fol-
4 lowing:

5 “(b) *ACTIVITIES.*—The grants described in subsection
6 (a) may be used for—

7 “(1) identifying, recruiting, and training poten-
8 tial sources for reporting childhood, adolescent, and
9 young adult cancer cases;

10 “(2) developing practices to ensure early inclu-
11 sion of childhood, adolescent, and young adult cancer
12 cases in State cancer registries through the use of elec-
13 tronic reporting;

14 “(3) collecting and submitting deidentified data
15 to the Centers for Disease Control and Prevention for
16 inclusion in a national database that includes infor-
17 mation on childhood, adolescent, and young adult
18 cancers; and

19 “(4) improving State cancer registries and the
20 database described in paragraph (3), as appropriate,
21 including to support the early inclusion of childhood,
22 adolescent, and young adult cancer cases.

23 “(c) *COORDINATION.*—To encourage the greatest pos-
24 sible efficiency and effectiveness of federally supported ef-
25 forts with respect to the activities described in this section,

1 *the Secretary shall ensure the appropriate coordination of*
 2 *programs supported under this section with other federally*
 3 *supported cancer registry programs and the activities under*
 4 *section 417E(a), as appropriate.”; and*

5 *(4) in subsection (d), as so redesignated, by*
 6 *striking “registry established pursuant to subsection*
 7 *(a)” and inserting “activities described in this sec-*
 8 *tion”.*

9 *(b) AUTHORIZATION OF APPROPRIATIONS.—Section*
 10 *417E(d) of the Public Health Service Act (42 U.S.C. 285a–*
 11 *11(d)) is amended—*

12 *(1) by striking “2009 through 2013” and insert-*
 13 *ing “2019 through 2023”; and*

14 *(2) by striking the second sentence.*

15 ***Subtitle B—Pediatric Expertise at***
 16 ***NIH***

17 ***SEC. 111. INCLUSION OF AT LEAST ONE PEDIATRIC***
 18 ***ONCOLOGIST ON THE NATIONAL CANCER AD-***
 19 ***VISORY BOARD.***

20 *Clause (iii) of section 406(h)(2)(A) of the Public*
 21 *Health Service Act (42 U.S.C. 284a(h)(2)(A)) is amended—*

22 *(1) by striking “Board not less than five” and*
 23 *inserting “Board—*

24 *“(I) not less than 5”;*

25 *(2) by inserting “and” after the semicolon; and*

1 (3) *by adding at the end the following:*

2 “(II) *not less than one member shall be an*
3 *individual knowledgeable in pediatric oncology;*”.

4 **SEC. 112. SENSE OF CONGRESS REGARDING PEDIATRIC EX-**
5 **PERTISE AT THE NATIONAL CANCER INSTI-**
6 **TUTE.**

7 *It is the sense of Congress that the Director of the Na-*
8 *tional Cancer Institute should ensure that all applicable*
9 *study sections, committees, advisory groups, and panels at*
10 *the National Cancer Institute include one or more qualified*
11 *pediatric oncologists, as appropriate.*

12 ***Subtitle C—NIH Reporting on***
13 ***Childhood Cancer Activities***

14 **SEC. 121. REPORTING ON CHILDHOOD CANCER RESEARCH**
15 **PROJECTS.**

16 *The Director of the National Institutes of Health shall*
17 *ensure that childhood cancer research projects conducted or*
18 *supported by the National Institutes of Health are included*
19 *in appropriate reports to Congress, which may include the*
20 *Pediatric Research Initiative report.*

1 **TITLE II—MAXIMIZING DELIV-**
 2 **ERY: CARE, QUALITY OF LIFE,**
 3 **SURVIVORSHIP, AND CARE-**
 4 **GIVER SUPPORT**

5 **SEC. 201. CANCER SURVIVORSHIP PROGRAMS.**

6 (a) *PILOT PROGRAMS TO EXPLORE MODEL SYSTEMS*
 7 *OF CARE FOR PEDIATRIC CANCER SURVIVORS.*—

8 (1) *IN GENERAL.*—*The Secretary of Health and*
 9 *Human Services (referred to in this section as the*
 10 *“Secretary”)* may make awards to eligible entities to
 11 establish pilot programs to develop, study, or evaluate
 12 model systems for monitoring and caring for child-
 13 hood cancer survivors throughout their lifespan, in-
 14 cluding evaluation of models for transition to adult
 15 care and care coordination.

16 (2) *AWARDS.*—

17 (A) *TYPES OF ENTITIES.*—*In making*
 18 *awards under this subsection, the Secretary*
 19 *shall, to the extent practicable, include—*

20 (i) *small, medium, and large-sized eli-*
 21 *gible entities; and*

22 (ii) *sites located in different geographic*
 23 *areas, including rural and urban areas.*

24 (B) *ELIGIBLE ENTITIES.*—*In this sub-*
 25 *section, the term “eligible entity” means—*

- 1 (i) a medical school;
- 2 (ii) a children's hospital;
- 3 (iii) a cancer center;
- 4 (iv) a community-based medical facil-
- 5 ity; or
- 6 (v) any other entity with significant
- 7 experience and expertise in treating sur-
- 8 vivors of childhood cancers.

9 (3) *USE OF FUNDS.*—Funds awarded under this
 10 subsection may be used—

11 (A) to develop, study, or evaluate one or
 12 more models for monitoring and caring for can-
 13 cer survivors; and

14 (B) in developing, studying, and evaluating
 15 such models, to give special emphasis to—

16 (i) design of models of follow-up care,
 17 monitoring, and other survivorship pro-
 18 grams (including peer support and men-
 19 toring programs);

20 (ii) development of models for pro-
 21 viding multidisciplinary care;

22 (iii) dissemination of information to
 23 health care providers about culturally and
 24 linguistically appropriate follow-up care for

1 *cancer survivors and their families, as ap-*
 2 *propriate and practicable;*

3 *(iv) development of psychosocial and*
 4 *support programs to improve the quality of*
 5 *life of cancer survivors and their families,*
 6 *which may include peer support and men-*
 7 *toring programs;*

8 *(v) design of systems for the effective*
 9 *transfer of treatment information and care*
 10 *summaries from cancer care providers to*
 11 *other health care providers (including risk*
 12 *factors and a plan for recommended follow-*
 13 *up care);*

14 *(vi) dissemination of the information*
 15 *and programs described in clauses (i)*
 16 *through (v) to other health care providers*
 17 *(including primary care physicians and in-*
 18 *ternists) and to cancer survivors and their*
 19 *families, where appropriate and in accord-*
 20 *ance with Federal and State law; and*

21 *(vii) development of initiatives that*
 22 *promote the coordination and effective tran-*
 23 *sition of care between cancer care providers,*
 24 *primary care physicians, mental health*
 25 *professionals, and other health care profes-*

1 sionals, as appropriate, including models
 2 that use a team-based or multi-disciplinary
 3 approach to care.

4 (b) *WORKFORCE DEVELOPMENT FOR HEALTH CARE*
 5 *PROVIDERS ON MEDICAL AND PSYCHOSOCIAL CARE FOR*
 6 *CHILDHOOD CANCER SURVIVORS.*—

7 (1) *IN GENERAL.*—*The Secretary shall, not later*
 8 *than 1 year after the date of enactment of this Act,*
 9 *conduct a review of the activities of the Department*
 10 *of Health and Human Services related to workforce*
 11 *development for health care providers who treat pedi-*
 12 *atric cancer patients and survivors. Such review shall*
 13 *include—*

14 (A) *an assessment of the effectiveness of sup-*
 15 *portive psychosocial care services for pediatric*
 16 *cancer patients and survivors, including pedi-*
 17 *atric cancer survivorship care patient navigators*
 18 *and peer support programs;*

19 (B) *identification of existing models rel-*
 20 *evant to providing medical and psychosocial*
 21 *services to individuals surviving pediatric can-*
 22 *cers, and programs related to training for health*
 23 *professionals who provide such services to indi-*
 24 *viduals surviving pediatric cancers; and*

1 (C) *recommendations for improving the*
 2 *provision of psychosocial care for pediatric can-*
 3 *cer survivors and patients.*

4 (2) *REPORT.*—*Not later than 2 years after the*
 5 *date of enactment of this Act, the Secretary shall sub-*
 6 *mit to the Committee on Health, Education, Labor,*
 7 *and Pensions of the Senate and Committee on Energy*
 8 *and Commerce of the House of Representatives, a re-*
 9 *port concerning the findings and recommendations*
 10 *from the review conducted under paragraph (1).*

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

13 (a) *IN GENERAL.*—*Section 417E of the Public Health*
 14 *Service Act (42 U.S.C. 285a–11), as amended by section*
 15 *101, is further amended by striking subsection (b) and in-*
 16 *serting the following:*

17 “(b) *IMPROVING CARE FOR PEDIATRIC CANCER SUR-*
 18 *VIVORS.*—

19 “(1) *RESEARCH ON PEDIATRIC CANCER SURVI-*
 20 *VORSHIP.*—*The Director of NIH, in coordination*
 21 *with ongoing research activities, may continue to con-*
 22 *duct or support pediatric cancer survivorship research*
 23 *including in any of the following areas:*

24 “(A) *Outcomes of pediatric cancer sur-*
 25 *vivors, including within minority or other medi-*

1 *cally underserved populations and with respect*
 2 *to health disparities of such outcomes.*

3 *“(B) Barriers to follow-up care for pedi-*
 4 *atric cancer survivors, including within minor-*
 5 *ity or other medically underserved populations.*

6 *“(C) The impact of relevant factors, which*
 7 *may include familial, socioeconomic, and other*
 8 *environmental factors, on treatment outcomes*
 9 *and survivorship.*

10 *“(D) The development of indicators used for*
 11 *long-term follow-up and analysis of the late ef-*
 12 *fects of cancer treatment for pediatric cancer*
 13 *survivors.*

14 *“(E) The identification of, as applicable—*

15 *“(i) risk factors associated with the*
 16 *late effects of cancer treatment;*

17 *“(ii) predictors of adverse*
 18 *neurocognitive and psychosocial outcomes;*
 19 *and*

20 *“(iii) the molecular basis of long-term*
 21 *complications.*

22 *“(F) The development of targeted interven-*
 23 *tions to reduce the burden of morbidity borne by*
 24 *cancer survivors in order to protect such cancer*
 25 *survivors from the late effects of cancer.*

1 “(2) *BALANCED APPROACH.*—*In conducting or*
 2 *supporting research under paragraph (1)(A)(i) on pe-*
 3 *diatric cancer survivors within minority or other*
 4 *medically underserved populations, the Director of*
 5 *NIH shall ensure that such research addresses both the*
 6 *physical and the psychological needs of such sur-*
 7 *vivors, as appropriate.”.*

8 **SEC. 203. BEST PRACTICES FOR LONG-TERM FOLLOW-UP**
 9 **SERVICES FOR PEDIATRIC CANCER SUR-**
 10 **VIVORS.**

11 *The Secretary of Health and Human Services may fa-*
 12 *cilitate the identification of best practices for childhood and*
 13 *adolescent cancer survivorship care, and, as appropriate,*
 14 *may consult with individuals who have expertise in late*
 15 *effects of disease and treatment of childhood and adolescent*
 16 *cancers, which may include—*

17 (1) *oncologists, which may include pediatric*
 18 *oncologists;*

19 (2) *primary care providers engaged in survivor-*
 20 *ship care;*

21 (3) *survivors of childhood and adolescent cancer;*

22 (4) *parents of children and adolescents who have*
 23 *been diagnosed with and treated for cancer and par-*
 24 *ents of long-term survivors;*

25 (5) *nurses and social workers;*

- 1 (6) *mental health professionals;*
2 (7) *allied health professionals, including physical*
3 *therapists and occupational therapists; and*
4 (8) *others, as the Secretary determines appro-*
5 *priate.*

6 **SEC. 204. TECHNICAL AMENDMENT.**

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

11 (b) *EFFECTIVE DATE.*—The amendment made by sub-
12 section (a) shall take effect as if included in section 3 of
13 the *Hematological Cancer Research Investment and Edu-*
14 *cation Act of 2002 (Public Law 107–172; 116 Stat. 541).*

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2^D Session

S. 292

A BILL

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

MARCH 12, 2018

Reported with an amendment