

110TH CONGRESS
1ST SESSION

H. R. 4450

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

IN THE HOUSE OF REPRESENTATIVES

DECEMBER 11, 2007

Ms. SOLIS (for herself and Mrs. BONO) introduced the following bill; which
was referred to the Committee on Energy and Commerce

A BILL

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

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Pediatric, Adolescent,
5 and Young Adult Cancer Survivorship Research and Qual-
6 ity of Life Act of 2007.”

7 **SEC. 2. FINDINGS.**

8 The Congress finds as follows:

1 (1) There are almost 10,000,000 cancer sur-
2 vivors (those living with, through, and beyond can-
3 cer) in the United States.

4 (2) Three out of every four American families
5 will have at least one family member diagnosed with
6 cancer.

7 (3) The size of the population of survivors of
8 childhood cancers has grown dramatically, to
9 270,000 individuals of all ages as of 1997.

10 (4) In 1960, only 4 percent of children with
11 cancer survived more than 5 years, but treatment
12 advances have changed the outlook for many chil-
13 dren diagnosed with cancer.

14 (5) According to the Intercultural Cancer Coun-
15 cil, because of disparities in health care delivery
16 throughout the cancer care continuum—from pre-
17 vention, screening, and diagnosis through cancer
18 treatment, follow-up, and end-of-life care—minority,
19 poor, and other medically underserved communities
20 are more likely to be diagnosed with late stage dis-
21 ease, experience poorer treatment outcomes, have
22 shorter survival time with less quality of life, and ex-
23 perience a substantially greater likelihood of cancer
24 death.

1 (6) The Institute of Medicine, in its report enti-
2 tled “From Cancer Patient to Cancer Survivor: Lost
3 in Transition”, states that there are disparities in
4 cancer survivorship. For instance, African Ameri-
5 cans are underrepresented in the cancer survivor
6 population—they made up approximately 13 percent
7 of the United States population in 2000, but only 8
8 percent of the survivor population.

9 (7) The 5-year survival rate for children with
10 cancer improved from 56 percent for those diag-
11 nosed between 1974 and 1976 to 79 percent for
12 those diagnosed between 1995 and 2000.

13 (8) One in 640 adults from age 20 to 39 has
14 a history of cancer.

15 (9) As many as two-thirds of childhood cancer
16 survivors are likely to experience at least one late ef-
17 fect of treatment, with as many as one-fourth expe-
18 riencing a late effect that is serious or life-threat-
19 ening. The most common late effects of childhood
20 cancer are neurocognitive and psychological,
21 cardiopulmonary, endocrine and musculoskeletal,
22 and second malignancies.

23 (10) Some late effects are identified early in
24 follow-up and are easily resolved, while others may

1 become chronic problems in adulthood and may have
2 serious consequences.

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

7 (12) The Institute of Medicine, in its reports on
8 cancer survivorship entitled “Childhood Cancer Sur-
9 vivorship: Improving Care and Quality of Life” and
10 “From Cancer Patient to Cancer Survivor: Lost in
11 Transition”, has offered a number of recommenda-
12 tions for improving monitoring and follow-up care
13 for cancer survivors and enhancing the cancer survi-
14 vorship research agenda.

15 (13) The Institute of Medicine has also noted
16 the significant health insurance problems that may
17 be experienced by survivors of childhood cancer as
18 well as adult cancer survivors and has recommended
19 that policy makers take action to ensure access to
20 care, including appropriate follow-up care, by all
21 cancer survivors.

22 (14) The annual cost of cancer in the United
23 States is almost \$190,000,000,000 in direct and in-
24 direct costs.

1 (15) In fiscal year 2001, the National Institutes
2 of Health invested \$38,000,000 in survivorship, or
3 less than \$4.25 per survivor.

4 **SEC. 3. CDC CANCER CONTROL PROGRAMS.**

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 317S the following:

8 **“SEC. 317T. CANCER CONTROL PROGRAMS.**

9 “(a) IN GENERAL.—The Secretary, acting through
10 the Director of the Centers for Disease Control and Pre-
11 vention, shall expand and intensify the cancer control pro-
12 grams of the Centers, including programs for conducting
13 surveillance activities or supporting State comprehensive
14 cancer control plans.

15 “(b) CERTAIN ACTIVITIES.—In carrying out sub-
16 section (a), the Secretary shall—

17 “(1) in collaboration with the Director of the
18 National Cancer Institute, provide guidance to
19 States on projects and interventions that may be in-
20 corporated into State comprehensive cancer control
21 programs to improve the long-term health status of
22 childhood cancer survivors, including childhood can-
23 cer survivors in minority and other medically under-
24 served populations;

1 “(2) encourage States to incorporate strategies
2 for improving systems of care for childhood cancer
3 survivors and their families into State comprehensive
4 cancer plans; and

5 “(3) collaborate with the Director of the Na-
6 tional Cancer Institute to improve existing surveil-
7 lance systems or develop appropriate new systems
8 for tracking cancer survivors and assessing their
9 health status and risk for other chronic and dis-
10 abling conditions.

11 “(c) CHILDHOOD CANCER SURVIVORSHIP.—

12 “(1) FOCUS ON CHILDHOOD CANCER SURVIVOR-
13 SHIP.—In conducting or supporting national, State,
14 and local comprehensive cancer control programs
15 through the Centers for Disease Control and Preven-
16 tion, the Secretary shall enhance such programs—

17 “(A) to include a focus on childhood cancer
18 survivorship, including survivorship in minority
19 and other medically underserved populations;
20 and

21 “(B) to include childhood cancer survivor-
22 ship initiatives for improving—

23 “(i) the monitoring of survivors of all
24 forms of cancer; and

25 “(ii) follow-up treatment for survivors.

1 “(2) RELIANCE ON GUIDELINES.—In carrying
2 out this subsection, the Secretary shall rely, where
3 appropriate, on existing guidelines for care of child-
4 hood cancer survivors.”.

5 **SEC. 4. NIH CANCER SURVIVORSHIP PROGRAMS.**

6 (a) TECHNICAL AMENDMENT.—

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

12 (2) EFFECTIVE DATE.—The amendment made
13 by paragraph (1) shall take effect as if included in
14 section 3 of the Hematological Cancer Research In-
15 vestment and Education Act of 2002 (Public Law
16 107–172; 116 Stat. 541).

17 (b) CANCER SURVIVORSHIP PROGRAMS.—Subpart 1
18 of part C of title IV of the Public Health Service Act (42
19 U.S.C. 285 et seq.), as amended by subsection (a), is
20 amended by adding at the end the following:

21 **“SEC. 417E. EXPANSION OF CANCER SURVIVORSHIP ACTIVI-**
22 **TIES.**

23 “(a) EXPANSION OF ACTIVITIES.—The Director of
24 the Institute shall coordinate the activities of the National

1 Institutes of Health with respect to cancer survivorship,
2 including childhood cancer survivorship.

3 “(b) PRIORITY AREAS.—In carrying out subsection
4 (a), the Director of the Institute shall give priority to the
5 following:

6 “(1) Comprehensive assessment of the preva-
7 lence and etiology of late effects of cancer and its
8 treatment, including physical, neurocognitive, and
9 psychosocial late effects. Such assessment shall in-
10 clude—

11 “(A) development of a system for patient
12 tracking and analysis;

13 “(B) establishment of a system of tissue
14 collection, banking, and analysis for childhood
15 cancers, using guidelines from the Office of
16 Biorepositories and Biospecimen Research; and

17 “(C) coordination of, and resources for, as-
18 sessment and data collection.

19 “(2) Identification of risk and protective factors
20 related to the development of late effects of cancer.

21 “(3) Identification of predictors of
22 neurocognitive and psychosocial outcomes, including
23 quality of life, in cancer survivors and identification
24 of quality of life and other outcomes in family mem-
25 bers.

1 “(4) Development and implementation of inter-
2 vention studies for patients and families, including
3 studies focusing on—

4 “(A) preventive interventions during treat-
5 ment;

6 “(B) interventions to lessen the impact of
7 late effects;

8 “(C) rehabilitative or remediative interven-
9 tions;

10 “(D) interventions to promote health be-
11 haviors in long-term survivors; and

12 “(E) interventions to improve health care
13 utilization and access to linguistically and cul-
14 turally competent long-term follow-up care for
15 childhood cancer survivors in minority and
16 other medically underserved populations.

17 “(c) GRANTS FOR RESEARCH ON CAUSES OF
18 HEALTH DISPARITIES IN CHILDHOOD CANCER SURVI-
19 VORSHIP.—

20 “(1) GRANTS.—The Director of NIH, acting
21 through the Director of the Institute, shall make
22 grants to entities to conduct research relating to—

23 “(A) pediatric cancer survivors within mi-
24 nority populations; and

1 “(B) health disparities in cancer survivor-
2 ship outcomes within minority or other medi-
3 cally underserved populations.

4 “(2) BALANCED APPROACH.—In making grants
5 for research under paragraph (1)(A) on pediatric
6 cancer survivors within minority populations, the Di-
7 rector of NIH shall ensure that such research ad-
8 dresses both the physical and the psychological
9 needs of such survivors.

10 “(3) HEALTH DISPARITIES.—In making grants
11 for research under paragraph (1)(B) on health dis-
12 parities in cancer survivorship outcomes within mi-
13 nority populations, the Director of NIH shall ensure
14 that such research examines each of the following:

15 “(A) Key adverse events after childhood
16 cancer.

17 “(B) Assessment of health and quality of
18 life in childhood cancer survivors.

19 “(C) Barriers to follow-up care to child-
20 hood cancer survivors.

21 “(d) RESEARCH TO EVALUATE FOLLOW-UP CARE
22 FOR CHILDHOOD CANCER SURVIVORS.—The Director of
23 NIH shall conduct or support research to evaluate systems
24 of follow-up care for childhood cancer survivors, with spe-
25 cial emphasis given to—

1 “(1) transitions in care for childhood cancer
2 survivors;

3 “(2) those professionals who should be part of
4 care teams for childhood cancer survivors;

5 “(3) training of professionals to provide linguistically
6 tically and culturally competent follow-up care to
7 childhood cancer survivors; and

8 “(4) different models of follow-up care.

9 **“SEC. 417E-1. IMPROVING THE QUALITY OF FOLLOW-UP**
10 **CARE FOR SURVIVORS OF CHILDHOOD, ADO-**
11 **LESCENT, AND YOUNG ADULT CANCERS AND**
12 **THEIR FAMILIES.**

13 “(a) IN GENERAL.—The Secretary, in consultation
14 with the Director of NIH, shall make grants to eligible
15 entities to establish or improve training programs for
16 health care professionals (including physicians, nurses,
17 physician assistants, and mental health professionals)—

18 “(1) to improve the quality of immediate and
19 long-term follow-up care for survivors of childhood,
20 adolescent, and young adult cancers and their fami-
21 lies; and

22 “(2) to ensure that such care is linguistically
23 and culturally competent.

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

1 “(1) a medical school;

2 “(2) a children’s hospital;

3 “(3) a cancer center;

4 “(4) a hospital with one or more residency pro-
5 grams that serve a significant number of pediatric
6 cancer patients;

7 “(5) a graduate training program for health
8 professionals described in subsection (a) who will
9 treat survivors of childhood, adolescent, and young
10 adult cancers; or

11 “(6) any other entity with significant experience
12 and expertise in treating survivors of childhood, ado-
13 lescent, and young adult cancers.

14 “(c) DURATION.—Each grant under this section shall
15 be for a period of 2 years.

16 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
17 carry out this section, there are authorized to be appro-
18 priated \$5,000,000 for each of fiscal years 2009 through
19 2013.

20 **“SEC. 417E-2. STUDY OF PILOT PROGRAMS TO EXPLORE**
21 **MODEL SYSTEMS OF CARE.**

22 “(a) IN GENERAL.—The Director of NIH, in con-
23 sultation with the Administrator of the Health Resources
24 and Services Administration, shall make grants to eligible
25 entities to establish pilot programs to develop, study, or

1 evaluate model systems for monitoring and caring for can-
2 cer survivors.

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

5 “(1) a medical school;

6 “(2) a children’s hospital;

7 “(3) a cancer center; or

8 “(4) any other entity with significant experience
9 and expertise in treating survivors of childhood, ado-
10 lescent, and young adult cancers.

11 “(c) USE OF FUNDS.—The Director of NIH may
12 make a grant under this section to an eligible entity only
13 if the entity agrees—

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

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

21 “(A) Design of protocols for follow-up
22 care, monitoring, and other survivorship pro-
23 grams (including peer support and mentoring
24 programs).

1 “(B) Dissemination of information to
2 health care providers about how to provide lin-
3 guistically and culturally competent follow-up
4 care and monitoring to cancer survivors and
5 their families.

6 “(C) Dissemination of other information,
7 as appropriate, to health care providers and to
8 cancer survivors and their families.

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

11 “(E) Design of systems for the effective
12 transfer of treatment information from cancer
13 care providers to other health care providers
14 (including family practice physicians and inter-
15 nists) and to cancer survivors and their fami-
16 lies, where appropriate.

17 “(F) Development of various models for
18 providing multidisciplinary care.

19 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
20 carry out this section, there are authorized to be appro-
21 priated \$8,000,000 for each of fiscal years 2009 through
22 2013.”.

1 **SEC. 5. CLINICS FOR COMPREHENSIVE LONG-TERM FOL-**
2 **LOW-UP SERVICES FOR CHILDHOOD CANCER**
3 **SURVIVORS.**

4 Part B of title III of the Public Health Service Act
5 (42 U.S.C. 243 et seq.), as amended by section 3, is
6 amended by inserting after section 317T the following:

7 **“SEC. 317U. CLINICS FOR COMPREHENSIVE LONG-TERM**
8 **FOLLOW-UP SERVICES FOR CHILDHOOD CAN-**
9 **CER SURVIVORS.**

10 “(a) **IN GENERAL.**—The Secretary shall make grants
11 to eligible entities to pay all or a portion of the costs in-
12 curred during the first 4 years of establishing and oper-
13 ating a clinic for comprehensive long-term follow-up serv-
14 ices for childhood cancer survivors.

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

17 “(1) a school of medicine;

18 “(2) a children’s hospital;

19 “(3) a cancer center; or

20 “(4) any other entity with significant experience
21 and expertise in treating surviving childhood, adoles-
22 cent, and young adult cancers.

23 “(c) **PRIORITY.**—In making grants under this sec-
24 tion, the Secretary shall give priority to any eligible entity
25 that demonstrates an expertise in improving access to care
26 for minority and other medically underserved populations.

1 “(d) USE OF FUNDS.—The Secretary may make a
2 grant under this section to an eligible entity only if the
3 entity agrees to use the grant to pay costs incurred during
4 the first 4 years of establishing and operating a clinic for
5 comprehensive long-term follow-up services for childhood
6 cancer survivors. Such costs may include the costs of—

7 “(1) purchasing or leasing facilities;

8 “(2) providing medical and psychosocial follow-
9 up services, including coordination with the patient’s
10 primary care provider and oncologist in order to en-
11 sure that the unique medical needs of survivors are
12 addressed;

13 “(3) conducting research to improve care for
14 cancer survivors;

15 “(4) providing linguistically and culturally com-
16 petent information to survivors and their families;
17 and

18 “(5) improving access by minority or other
19 medically underserved populations to the best prac-
20 tices and care for childhood cancer survivors.

21 “(e) AUTHORIZATION OF APPROPRIATIONS.—To
22 carry out this section, there is authorized to be appro-
23 priated \$12,000,000 for each of fiscal years 2009 through
24 2013.”.

1 **SEC. 6. GRANTS TO IMPROVE ACCESS TO CARE FOR CHILD-**
2 **HOOD CANCER SURVIVORS.**

3 Part B of title III of the Public Health Service Act
4 (42 U.S.C. 243 et seq.), as amended by section 5, is
5 amended by inserting after section 317U the following:

6 **“SEC. 317V. GRANTS TO IMPROVE ACCESS TO CARE FOR**
7 **CHILDHOOD CANCER SURVIVORS.**

8 “(a) GRANTS.—The Secretary shall make grants to
9 recognized childhood cancer professional and advocacy or-
10 ganizations to improve physical and psychosocial care for
11 childhood cancer survivors, especially childhood cancer
12 survivors in minority or other medically underserved popu-
13 lations.

14 “(b) USE OF FUNDS.—The Secretary may make a
15 grant under this section to an organization only if the or-
16 ganization agrees to use the grant to improve physical and
17 psychosocial care for childhood cancer survivors, especially
18 childhood cancer survivors in minority or other medically
19 underserved populations. Such care may include—

20 “(1) patient navigator programs;

21 “(2) peer support programs;

22 “(3) education and outreach for survivors and
23 their families, including developing bilingual mate-
24 rials;

25 “(4) follow-up care for uninsured and under-
26 insured survivors—

1 “(A) to identify, prevent, or control side ef-
2 fects associated with cancer and its treatment;
3 and

4 “(B) to screen for cancer recurrence; and
5 “(5) assistance with transportation necessary to
6 receive medical care for survivors and their families
7 who lack adequate transportation resources.

8 “(c) AUTHORIZATION OF APPROPRIATIONS.—To
9 carry out this section, there are authorized to be appro-
10 priated \$5,000,000 for each of fiscal years 2009 through
11 2013.”.

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