

110TH CONGRESS
2D SESSION

S. 2877

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

IN THE SENATE OF THE UNITED STATES

APRIL 17, 2008

Mr. REID (for Mrs. CLINTON) introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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 2008.”

7 **SEC. 2. FINDINGS.**

8 The Congress finds as follows:

1 (1) There are more than 10,000,000 cancer
2 survivors (those living with, through, and beyond
3 cancer) 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 more than \$190,000,000,000 in direct and
24 indirect costs.

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

2 Part B of title III of the Public Health Service Act
3 (42 U.S.C. 243 et seq.) is amended by inserting after sec-
4 tion 317S the following:

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

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

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

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

22 “(2) encourage States to incorporate strategies
23 for improving systems of care for childhood cancer
24 survivors and their families into State comprehensive
25 cancer plans; and

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

7 “(c) CHILDHOOD CANCER SURVIVORSHIP.—

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

13 “(A) to include a focus on childhood cancer
14 survivorship, including survivorship in minority
15 and other medically underserved populations;
16 and

17 “(B) to include childhood cancer survivor-
18 ship initiatives for improving—

19 “(i) the monitoring of survivors of all
20 forms of cancer; and

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

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

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

2 (a) TECHNICAL AMENDMENT.—

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

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

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

17 **“SEC. 417E. EXPANSION OF CANCER SURVIVORSHIP ACTIVI-**
18 **TIES.**

19 “(a) EXPANSION OF ACTIVITIES.—The Director of
20 the Institute shall coordinate the activities of the National
21 Institutes of Health with respect to cancer survivorship,
22 including childhood cancer survivorship.

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

1 “(1) Comprehensive assessment of the preva-
2 lence and etiology of late effects of cancer and its
3 treatment, including physical, neurocognitive, and
4 psychosocial late effects. Such assessment shall in-
5 clude—

6 “(A) development of a system for patient
7 tracking and analysis;

8 “(B) establishment of a system of tissue
9 collection, banking, and analysis for childhood
10 cancers, using guidelines from the Office of
11 Biorepositories and Biospecimen Research; and

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

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

16 “(3) Identification of predictors of
17 neurocognitive and psychosocial outcomes, including
18 quality of life, in cancer survivors and identification
19 of quality of life and other outcomes in family mem-
20 bers.

21 “(4) Development and implementation of inter-
22 vention studies for patients and families, including
23 studies focusing on—

24 “(A) preventive interventions during treat-
25 ment;

1 “(B) interventions to lessen the impact of
2 late effects;

3 “(C) rehabilitative or remediative interven-
4 tions;

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

7 “(E) interventions to improve health care
8 utilization and access to linguistically and cul-
9 turally competent long-term follow-up care for
10 childhood cancer survivors in minority and
11 other medically underserved populations.

12 “(c) GRANTS FOR RESEARCH ON CAUSES OF
13 HEALTH DISPARITIES IN CHILDHOOD CANCER SURVI-
14 VORSHIP.—

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

18 “(A) pediatric cancer survivors within mi-
19 nority populations; and

20 “(B) health disparities in cancer survivor-
21 ship outcomes within minority or other medi-
22 cally underserved populations.

23 “(2) BALANCED APPROACH.—In making grants
24 for research under paragraph (1)(A) on pediatric
25 cancer survivors within minority populations, the Di-

1 rector of NIH shall ensure that such research ad-
2 dresses both the physical and the psychological
3 needs of such survivors.

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

9 “(A) Key adverse events after childhood
10 cancer.

11 “(B) Assessment of health and quality of
12 life in childhood cancer survivors.

13 “(C) Barriers to follow-up care to child-
14 hood cancer survivors.

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

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

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

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

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

4 **“SEC. 417E-1. IMPROVING THE QUALITY OF FOLLOW-UP**
5 **CARE FOR SURVIVORS OF CHILDHOOD, ADO-**
6 **LESCENT, AND YOUNG ADULT CANCERS AND**
7 **THEIR FAMILIES.**

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

13 “(1) to improve the quality of immediate and
14 long-term follow-up care for survivors of childhood,
15 adolescent, and young adult cancers and their families;
16 and

17 “(2) to ensure that such care is linguistically
18 and culturally competent.

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

21 “(1) a medical school;

22 “(2) a children’s hospital;

23 “(3) a cancer center;

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; or

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

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

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

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

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

23 “(B) Dissemination of information to
24 health care providers about how to provide lin-
25 guistically and culturally competent follow-up

1 care and monitoring to cancer survivors and
2 their families.

3 “(C) Dissemination of other information,
4 as appropriate, to health care providers and to
5 cancer survivors and their families.

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

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

14 “(F) Development of various models for
15 providing multidisciplinary care.

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

20 **SEC. 5. CLINICS FOR COMPREHENSIVE LONG-TERM FOL-**
21 **LOW-UP SERVICES FOR CHILDHOOD CANCER**
22 **SURVIVORS.**

23 Part B of title III of the Public Health Service Act
24 (42 U.S.C. 243 et seq.), as amended by section 3, is
25 amended by inserting after section 317T the following:

1 **“SEC. 317U. CLINICS FOR COMPREHENSIVE LONG-TERM**
2 **FOLLOW-UP SERVICES FOR CHILDHOOD CAN-**
3 **CER SURVIVORS.**

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

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

11 “(1) a school of medicine;

12 “(2) a children’s hospital;

13 “(3) a cancer center; or

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

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

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

1 “(1) purchasing or leasing facilities;

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

7 “(3) conducting research to improve care for
8 cancer survivors;

9 “(4) providing linguistically and culturally com-
10 petent information to survivors and their families;
11 and

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

15 “(e) AUTHORIZATION OF APPROPRIATIONS.—To
16 carry out this section, there is authorized to be appro-
17 priated \$12,000,000 for each of fiscal years 2009 through
18 2013.”.

19 **SEC. 6. GRANTS TO IMPROVE ACCESS TO CARE FOR CHILD-**
20 **HOOD CANCER SURVIVORS.**

21 Part B of title III of the Public Health Service Act
22 (42 U.S.C. 243 et seq.), as amended by section 5, is
23 amended by inserting after section 317U the following:

1 **“SEC. 317V. GRANTS TO IMPROVE ACCESS TO CARE FOR**
2 **CHILDHOOD CANCER SURVIVORS.**

3 “(a) GRANTS.—The Secretary shall make grants to
4 recognized childhood cancer professional and advocacy or-
5 ganizations to improve physical and psychosocial care for
6 childhood cancer survivors, especially childhood cancer
7 survivors in minority or other medically underserved popu-
8 lations.

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

15 “(1) patient navigator programs;

16 “(2) peer support programs;

17 “(3) education and outreach for survivors and
18 their families, including developing bilingual mate-
19 rials;

20 “(4) follow-up care for uninsured and under-
21 insured survivors—

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

24 and

25 “(B) to screen for cancer recurrence; and

1 “(5) assistance with transportation necessary to
2 receive medical care for survivors and their families
3 who lack adequate transportation resources.

4 “(c) AUTHORIZATION OF APPROPRIATIONS.—To
5 carry out this section, there are authorized to be appro-
6 priated \$5,000,000 for each of fiscal years 2009 through
7 2013.”.

○