

111TH CONGRESS
1ST SESSION

H. R. 2109

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

IN THE HOUSE OF REPRESENTATIVES

APRIL 27, 2009

Ms. SPEIER (for herself, Mrs. BONO MACK, Mrs. CAPPS, Mr. MORAN of Virginia, Ms. KILROY, Ms. SCHAKOWSKY, and Mr. SESTAK) introduced the following bill; which was referred to the Committee on Energy and Commerce

A BILL

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

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

3 **SECTION 1. SHORT TITLE.**

4 This Act may be cited as the “Childhood Cancer Sur-
5 vivorship Research and Quality of Life Act of 2009”.

6 **SEC. 2. FINDINGS.**

7 The Congress finds as follows:

1 (1) There are almost 11,000,000 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
9 300,000 individuals of all ages as of 2007.

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) The 5-year survival rate for children with
15 cancer improved from 56 percent for those diag-
16 nosed between 1974 and 1976 to 79 percent for
17 those diagnosed between 1995 and 2000.

18 (6) According to the Intercultural Cancer Coun-
19 cil, because of disparities in health care delivery
20 throughout the cancer care continuum—from pre-
21 vention, screening, and diagnosis through cancer
22 treatment, follow-up, and end-of-life care—minority,
23 poor, and other medically underserved communities
24 are more likely to be diagnosed with late stage dis-
25 ease, experience poorer treatment outcomes, have

1 shorter survival time with less quality of life, and ex-
2 perience a substantially greater likelihood of cancer
3 death.

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

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

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

22 (10) Some late effects are identified early in
23 follow-up and are easily resolved, while others may
24 become chronic problems in adulthood and may have
25 serious consequences.

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

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

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

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

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

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 317T the following:

5 **“SEC. 317U. 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 childhood
22 cancer survivors.

23 “(2) RELIANCE ON GUIDELINES.—In carrying
24 out this subsection, the Secretary shall rely, where

1 appropriate, on existing guidelines for care of child-
2 hood cancer survivors.”.

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

4 (a) TECHNICAL AMENDMENT.—

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

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

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

19 **“SEC. 417G. EXPANSION OF CANCER SURVIVORSHIP ACTIVI-**
20 **TIES.**

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

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

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

9 “(A) development of a system for patient
10 tracking and analysis;

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

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

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

19 “(3) Identification of predictors of neu-
20 rocognitive and psychosocial outcomes, including
21 quality of life, in cancer survivors and identification
22 of quality of life and other outcomes in family mem-
23 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) childhood 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 childhood
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 psychosocial needs
9 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 linguis-
6 tically and culturally competent follow-up care to
7 childhood cancer survivors; and

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

9 **“SEC. 417G-1. IMPROVING THE QUALITY OF FOLLOW-UP**
10 **CARE FOR SURVIVORS OF CHILDHOOD CAN-**
11 **CERS AND THEIR FAMILIES.**

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

17 “(1) to improve the quality of immediate and
18 long-term follow-up care for survivors of childhood
19 cancers and their families; and

20 “(2) to ensure that such care is linguistically
21 and culturally competent.

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

24 “(1) a medical school;

25 “(2) a children’s hospital;

1 “(3) a cancer center;

2 “(4) a hospital with one or more residency pro-
3 grams that serve a significant number of childhood
4 cancer patients;

5 “(5) a graduate training program for health
6 professionals described in subsection (a) who will
7 treat survivors of childhood cancers; or

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

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

13 “(d) AUTHORIZATION OF APPROPRIATIONS.—To
14 carry out this section, there is authorized to be appro-
15 priated \$5,000,000 for each of fiscal years 2010 through
16 2014.

17 **“SEC. 417G-2. STUDY OF PILOT PROGRAMS TO EXPLORE**
18 **MODEL SYSTEMS OF CARE.**

19 “(a) IN GENERAL.—The Director of NIH, in con-
20 sultation with the Administrator of the Health Resources
21 and Services Administration, shall make grants to eligible
22 entities to establish pilot programs to develop, study, or
23 evaluate model systems for monitoring and caring for
24 childhood cancer survivors.

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 can-
8 cers.

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 is authorized to be appro-
18 priated \$10,000,000 for each of fiscal years 2010 through
19 2014.”.

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 317U the following:

1 **“SEC. 317V. 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 survivors of childhood can-
16 cers.

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 childhood cancer survivors;

9 “(4) providing linguistically and culturally com-
10 petent information to childhood cancer survivors and
11 their families; 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 \$15,000,000 for each of fiscal years 2010 through
18 2014.”.

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 317V the following:

1 **“SEC. 317W. 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 is authorized to be appro-
6 priated \$10,000,000 for each of fiscal years 2010 through
7 2014.”.

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