I

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

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A BILL

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

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled,

SECTION 1. SHORT TITLE.

This Act may be cited as the ''Pediatric, Adolescent, and Young Adult Cancer Survivorship Research and Quality of Life Act of 2007.''

SEC. 2. FINDINGS.

The Congress finds as follows:

(1) There are almost 10,000,000 cancer survivors (those living with, through, and beyond cancer) in the United States.

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

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

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

(5) According to the Intercultural Cancer Council, because of disparities in health care delivery throughout the cancer care continuum—from prevention, screening, and diagnosis through cancer treatment, follow-up, and end-of-life care—minority, poor, and other medically underserved communities are more likely to be diagnosed with late stage disease, experience poorer treatment outcomes, have shorter survival time with less quality of life, and experience a substantially greater likelihood of cancer death.

(6) The Institute of Medicine, in its report entitled ''From Cancer Patient to Cancer Survivor: Lost in Transition'', states that there are disparities in cancer survivorship. For instance, African Americans are underrepresented in the cancer survivor population—they made up approximately 13 percent of the United States population in 2000, but only 8 percent of the survivor population.

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

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

(9) As many as two-thirds of childhood cancer survivors are likely to experience at least one late effect of treatment, with as many as one-fourth experiencing a late effect that is serious or life-threatening. The most common late effects of childhood cancer are neurocognitive and psychological, cardiopulmonary, endocrine and musculoskeletal, and second malignancies.

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

become chronic problems in adulthood and may have serious consequences.

(11) The late effects of treatment may change as treatments evolve, which means that the monitoring and treatment of late effects may need to be modified on a routine basis.

(12) The Institute of Medicine, in its reports on cancer survivorship entitled ''Childhood Cancer Survivorship: Improving Care and Quality of Life'' and ''From Cancer Patient to Cancer Survivor: Lost in Transition'', has offered a number of recommendations for improving monitoring and follow-up care for cancer survivors and enhancing the cancer survivorship research agenda.

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

(14) The annual cost of cancer in the United States is almost $190,000,000,000 in direct and indirect costs.

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

SEC. 3. CDC CANCER CONTROL PROGRAMS.

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

"SEC. 317T. CANCER CONTROL PROGRAMS.

"(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, shall expand and intensify the cancer control programs of the Centers, including programs for conducting surveillance activities or supporting State comprehensive cancer control plans.

"(b) CERTAIN ACTIVITIES.—In carrying out subsection (a), the Secretary shall—

"(1) in collaboration with the Director of the National Cancer Institute, provide guidance to States on projects and interventions that may be incorporated into State comprehensive cancer control programs to improve the long-term health status of childhood cancer survivors, including childhood cancer survivors in minority and other medically underserved populations;

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

''(3) collaborate with the Director of the National Cancer Institute to improve existing surveillance systems or develop appropriate new systems for tracking cancer survivors and assessing their health status and risk for other chronic and disabling conditions.

''(c) CHILDHOOD CANCER SURVIVORSHIP.—

''(1) FOCUS ON CHILDHOOD CANCER SURVIVORSHIP.—In conducting or supporting national, State, and local comprehensive cancer control programs through the Centers for Disease Control and Prevention, the Secretary shall enhance such programs—

''(A) to include a focus on childhood cancer survivorship, including survivorship in minority and other medically underserved populations; and

''(B) to include childhood cancer survivorship initiatives for improving—

''(i) the monitoring of survivors of all forms of cancer; and

''(ii) follow-up treatment for survivors.

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

SEC. 4. NIH CANCER SURVIVORSHIP PROGRAMS.

(a) TECHNICAL AMENDMENT.—

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

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

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

“SEC. 417E. EXPANSION OF CANCER SURVIVORSHIP ACTIVITIES.

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

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

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

''(1) Comprehensive assessment of the prevalence and etiology of late effects of cancer and its treatment, including physical, neurocognitive, and psychosocial late effects. Such assessment shall include—

''(A) development of a system for patient tracking and analysis;

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

''(C) coordination of, and resources for, assessment and data collection.

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

''(3) Identification of predictors of neurocognitive and psychosocial outcomes, including quality of life, in cancer survivors and identification of qualify of life and other outcomes in family members.

“(4) Development and implementation of intervention studies for patients and families, including studies focusing on—

“(A) preventive interventions during treatment;

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

“(C) rehabilitative or remediative interventions;

“(D) interventions to promote health behaviors in long-term survivors; and

“(E) interventions to improve health care utilization and access to linguistically and culturally competent long-term follow-up care for childhood cancer survivors in minority and other medically underserved populations.

“(c) GRANTS FOR RESEARCH ON CAUSES OF HEALTH DISPARITIES IN CHILDHOOD CANCER SURVIVORSHIP.—

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

“(A) pediatric cancer survivors within minority populations; and

“(B) health disparities in cancer survivorship outcomes within minority or other medically underserved populations.

“(2) Balanced approach.—In making grants for research under paragraph (1)(A) on pediatric cancer survivors within minority populations, the Director of NIH shall ensure that such research addresses both the physical and the psychological needs of such survivors.

“(3) Health disparities.—In making grants for research under paragraph (1)(B) on health disparities in cancer survivorship outcomes within minority populations, the Director of NIH shall ensure that such research examines each of the following:

“(A) Key adverse events after childhood cancer.

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

“(C) Barriers to follow-up care to childhood cancer survivors.

“(d) Research To Evaluate Follow-up Care for Childhood Cancer Survivors.—The Director of NIH shall conduct or support research to evaluate systems of follow-up care for childhood cancer survivors, with special emphasis given to—

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

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

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

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

“SEC. 417E–1. IMPROVING THE QUALITY OF FOLLOW-UP CARE FOR SURVIVORS OF CHILDHOOD, ADOLESCENT, AND YOUNG ADULT CANCERS AND THEIR FAMILIES.

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

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

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

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

“(1) a medical school;

“(2) a children’s hospital;

“(3) a cancer center;

“(4) a hospital with one or more residency programs that serve a significant number of pediatric cancer patients;

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

“(6) any other entity with significant experience and expertise in treating survivors of childhood, adolescent, and young adult cancers.

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

“(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated $5,000,000 for each of fiscal years 2009 through 2013.

“SEC. 417E–2. STUDY OF PILOT PROGRAMS TO EXPLORE MODEL SYSTEMS OF CARE.

“(a) IN GENERAL.—The Director of NIH, in consultation with the Administrator of the Health Resources and Services Administration, shall make grants to eligible entities to establish pilot programs to develop, study, or evaluate model systems for monitoring and caring for cancer survivors.

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

‘‘(1) a medical school;

‘‘(2) a children’s hospital;

‘‘(3) a cancer center; or

‘‘(4) any other entity with significant experience and expertise in treating survivors of childhood, adolescent, and young adult cancers.

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

‘‘(1) to use the grant to establish a pilot program to develop, study, or evaluate one or more model systems for monitoring and caring for cancer survivors; and

‘‘(2) in developing, studying, and evaluating such systems, to give special emphasis to the following:

‘‘(A) Design of protocols for follow-up care, monitoring, and other survivorship programs (including peer support and mentoring programs).

“(B) Dissemination of information to health care providers about how to provide linguistically and culturally competent follow-up care and monitoring to cancer survivors and their families.

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

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

“(E) Design of systems for the effective transfer of treatment information from cancer care providers to other health care providers (including family practice physicians and internists) and to cancer survivors and their families, where appropriate.

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

“(d) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there are authorized to be appropriated $8,000,000 for each of fiscal years 2009 through 2013.”.

SEC. 5. CLINICS FOR COMPREHENSIVE LONG-TERM FOLLOW-UP SERVICES FOR CHILDHOOD CANCER SURVIVORS.

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

"SEC. 317U. CLINICS FOR COMPREHENSIVE LONG-TERM FOLLOW-UP SERVICES FOR CHILDHOOD CANCER SURVIVORS.

''(a) IN GENERAL.—The Secretary shall make grants to eligible entities to pay all or a portion of the costs incurred during the first 4 years of establishing and operating a clinic for comprehensive long-term follow-up services for childhood cancer survivors.

''(b) ELIGIBLE ENTITIES.—In this section, the term 'eligible entity' means—

''(1) a school of medicine;

''(2) a children's hospital;

''(3) a cancer center; or

''(4) any other entity with significant experience and expertise in treating surviving childhood, adolescent, and young adult cancers.

''(c) PRIORITY.—In making grants under this section, the Secretary shall give priority to any eligible entity that demonstrates an expertise in improving access to care for minority and other medically underserved populations.

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

"(1) purchasing or leasing facilities;

"(2) providing medical and psychosocial follow-up services, including coordination with the patient's primary care provider and oncologist in order to ensure that the unique medical needs of survivors are addressed;

"(3) conducting research to improve care for cancer survivors;

"(4) providing linguistically and culturally competent information to survivors and their families; and

"(5) improving access by minority or other medically underserved populations to the best practices and care for childhood cancer survivors.

"(e) AUTHORIZATION OF APPROPRIATIONS.—To carry out this section, there is authorized to be appropriated $12,000,000 for each of fiscal years 2009 through 2013.".

SEC. 6. GRANTS TO IMPROVE ACCESS TO CARE FOR CHILDHOOD CANCER SURVIVORS.

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

"SEC. 317V. GRANTS TO IMPROVE ACCESS TO CARE FOR CHILDHOOD CANCER SURVIVORS.

''(a) GRANTS.—The Secretary shall make grants to recognized childhood cancer professional and advocacy organizations to improve physical and psychosocial care for childhood cancer survivors, especially childhood cancer survivors in minority or other medically underserved populations.

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

''(1) patient navigator programs;

''(2) peer support programs;

''(3) education and outreach for survivors and their families, including developing bilingual materials;

''(4) follow-up care for uninsured and underinsured survivors—

“(A) to identify, prevent, or control side effects associated with cancer and its treatment; and

“(B) to screen for cancer recurrence; and

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

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

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