113TH CONGRESS
1ST SESSION

S. 1247

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

IN THE SENATE OF THE UNITED STATES

JUNE 27, 2013

Mr. REED introduced the following bill; which was read twice and referred to the Committee on Health, Education, Labor, and Pensions

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A BILL

To improve and enhance research and programs on childhood 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 2013''.

SEC. 2. FINDINGS.

Congress finds as follows:

(1) An estimated 13,500 children and adolescents under age 20 are diagnosed with cancer each year.

(2) In 1960, only 4 percent of children with cancer survived more than 5 years, but by 2011, cure rates have increased to 78 percent for children and adolescents under age 20.

(3) As of June 2013, there are more than 360,000 childhood cancer survivors living in the United States.

(4) As many as ⅔ of childhood cancer survivors are likely to experience at least one late effect of treatment, with as many as ¼ experiencing a late effect that is serious or life-threatening. The most common late effects of childhood cancer are neurocognitive, psychological, cardiopulmonary, endocrine, and musculoskeletal effects and secondary malignancies.

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

(6) The Institute of Medicine, in its report on cancer survivorship entitled ''Childhood Cancer Survivorship: Improving Care and Quality of Life'',

states that an organized system of care and a method of care for pediatric cancer survivors is needed.

SEC. 3. CANCER SURVIVORSHIP PROGRAMS.

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

"SEC. 417H. PILOT PROGRAMS TO EXPLORE MODEL SYSTEMS OF CARE FOR PEDIATRIC CANCER SURVIVORS.

''(a) IN GENERAL.—The Secretary may make grants to eligible entities to establish pilot programs to develop, study, or evaluate model systems for monitoring and caring for childhood 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 cancers.

''(c) USE OF FUNDS.—The Secretary 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—

''(A) the design of protocols for different models of follow-up care, monitoring, and other survivorship programs (including peer support and mentoring programs);

''(B) the development of various models for providing multidisciplinary care;

''(C) the dissemination of information and the provision of training to health care providers about how to provide linguistically and culturally competent follow-up care and monitoring to cancer survivors and their families;

''(D) the development of support programs to improve the quality of life of cancer survivors;

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

''(F) the dissemination of the information and programs described in subparagraphs (A) through (E) to other health care providers (including primary care physicians and internists) to cancer survivors and their families, where appropriate; and

''(G) the development of initiatives that promote the coordination and effective transition of care between cancer care providers, primary care physicians, and mental health professionals.

''(d) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section $15,000,000 for each of fiscal years 2014 through 2018.

''SEC. 417H–1. WORKFORCE DEVELOPMENT COLLABORATIVE ON MEDICAL AND PSYCHOSOCIAL CARE FOR CHILDHOOD CANCER SURVIVORS.

''(a) IN GENERAL.—Not later than 1 year after the date of enactment of the Pediatric, Adolescent, and Young Adult Cancer Survivorship Research and Quality of Life Act of 2013, the Secretary may convene a Workforce Development Collaborative on Medical and Psychosocial Care for Pediatric Cancer Survivors (referred to in this section as the 'Collaborative'). The Collaborative shall be a cross-specialty, multidisciplinary group composed of educators,

consumer and family advocates, and providers of psychosocial and biomedical health services.

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

''(1) Identifying, refining, and broadly disseminating to healthcare educators information about workforce competencies, models, and preservices curricula relevant to providing medical and psychosocial services to individuals with pediatric cancers.

''(2) Adapting curricula for continuing education of the existing workforce using efficient workplace-based learning approaches.

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

''(4) Strengthening the emphasis on psychosocial healthcare in educational accreditation standards and professional licensing and certification exams by recommending revisions to the relevant oversight organizations.

''(5) Evaluating the effectiveness of patient navigators in pediatric cancer survivorship care.

''(6) Evaluating the effectiveness of peer support programs in the psychosocial care of pediatric cancer patients and survivors.

''(c) AUTHORIZATION OF APPROPRIATIONS.—There are authorized to be appropriated to carry out this section $5,000,000 for each of fiscal years 2014 through 2018.''.

(b) 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).

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