H. R. 3015

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

IN THE HOUSE OF REPRESENTATIVES

SEPTEMBER 22, 2011

Ms. Speier (for herself, Mr. Latham, Mr. McCaul, Mr. Van Hollen, Mr. Moran, Mr. King of New York, Ms. Bordallo, Ms. Woolsey, and Ms. Fudge) 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 “Pediatric, Adolescent, 
5 and Young Adult Cancer Survivorship Research and Qual-
6 ity of Life Act of 2011”.

7 SEC. 2. FINDINGS.

8 Congress finds the following:
(1) An estimated 12,400 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 today, cure rates have increased to 78 percent for children and adolescents under age 20.

(3) The population of survivors of childhood cancers has grown dramatically, to over 300,000 individuals of all ages as of 2007.

(4) Whereas 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, psychological, cardiopulmonary, endocrine, and musculoskeletal effects and secondary malignancies.

(5) According to the Intercultural Cancer Council, because of disparities in health care delivery throughout the cancer care continuum, 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 ex-
perience a substantially greater likelihood of cancer death.

(6) 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.

(7) Despite the trauma caused by childhood cancer, there is a lack of standardized and coordinated psychosocial care for the children and their families, from the date of diagnosis through treatment and survivorship.

(8) The Institute of Medicine, in its reports 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.

(9) Focused and well-designed research and pilot health delivery programs can answer questions about the optimal ways to provide health care, follow-up monitoring services, and survivorship care to those diagnosed with childhood cancer and contribute to improvements in the quality of care and quality of life of those individuals.
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. 417G. PILOT PROGRAMS TO EXPLORE MODEL SYSTEMS OF CARE FOR PEDIATRIC CANCER SURVIVORS.

(a) IN GENERAL.—The Secretary shall 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 the following:

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

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

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

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

""(G) 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.—To carry out this section, there is authorized to be appropriated $15,000,000 for each of fiscal years 2013 through 2017.

""SEC. 417G-1. WORKFORCE DEVELOPMENT COLLABORATIVE ON MEDICAL AND PSYCHOSOCIAL CARE FOR CHILDHOOD CANCER SURVIVORS.

""(a) In General.—The Secretary shall, not later than 1 year after the date of enactment of this Act, convene a Workforce Development Collaborative on Medical and Psychosocial Care for Pediatric Cancer Survivors (referred to in this paragraph 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 health care educators information about workforce competencies, models, and preservices curricula relevant to providing medical and psychosocial services to persons 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 health care 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.—To carry out this section, there is authorized to be appropriated $5,000,000 for each of fiscal years 2013 through 2017.”.

(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).

SEC. 4. GRANTS TO IMPROVE CARE FOR PEDIATRIC CANCER SURVIVORS.

Section 417E of the Public Health Service Act (42 U.S.C. 285a–11) is amended—

(1) in the heading, by striking “RESEARCH AND AWARENESS” and inserting “RESEARCH, AWARENESS, AND SURVIVORSHIP”;

(2) in subsection (a)—

(A) by redesignating paragraph (2) as paragraph (4); and
(B) by inserting after paragraph (1) the following:

"(2) RESEARCH ON CAUSES OF HEALTH DISPARITIES IN PEDIATRIC CANCER SURVIVORSHIP.—

"(A) GRANTS.—The Director of NIH, acting through the Director of the Institute, in coordination with ongoing research activities, shall make grants to entities to conduct research relating to—

"(i) needs and outcomes of pediatric cancer survivors within minority or other medically underserved populations;

"(ii) health disparities in pediatric cancer survivorship outcomes within minority or other medically underserved populations;

"(iii) barriers that pediatric cancer survivors within minority or other medically underserved populations face in receiving follow-up care; and

"(iv) familial, socioeconomic, and other environmental factors and the impact of such factors on treatment outcomes and survivorship.
“(B) BALANCED APPROACH.—In making
grants for research under subparagraph (A)(i)
on pediatric cancer survivors within minority or
other medically underserved populations, the
Director of NIH shall ensure that such research
addresses both the physical and the psycho-
logical needs of such survivors.

“(3) RESEARCH ON LATE EFFECTS AND FOL-
LOW-UP CARE FOR PEDIATRIC CANCER SUR-
VIVORS.—The Director of NIH, in coordination with
ongoing research activities, shall conduct or support
research on follow-up care for pediatric cancer sur-
vivors, with special emphasis given to—

“(A) the development of indicators used
for long-term patient tracking and analysis of
the late effects of cancer treatment for pediatric
cancer survivors;

“(B) the identification of risk factors asso-
iated with the late effects of cancer treatment;

“(C) the identification of predictors of
neurocognitive and psychosocial outcomes;

“(D) initiatives to protect cancer survivors
from the late effects of cancer treatment;

“(E) transitions in care for pediatric can-
cer survivors;
“(F) training of professionals to provide linguistically and culturally competent follow-up care to pediatric cancer survivors; and

“(G) different models of follow-up care.”;

and

(3) in subsection (d)—

(A) by striking “this section and” and inserting “subsection (a)(1), subsection (b), and”;

(B) by striking “2013” and inserting “2017”; and

(C) by inserting after the second sentence the following: “For purposes of carrying out subsections (a)(2) and (a)(3), there is authorized to be appropriated $10,000,000 for each of fiscal years 2013 through 2017.”.

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

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

“SEC. 317U. CLINICS FOR COMPREHENSIVE LONG-TERM FOLLOW-UP SERVICES FOR PEDIATRIC CANCER SURVIVORS.

“(a) IN GENERAL.—The Secretary shall make grants to eligible entities to establish and operate a clinic for com-
prehensive long-term follow-up services for pediatric 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 determined by the Secretary to have significant experience and expertise in—

"(A) treating pediatric, adolescent, and young adult cancers; or
"(B) integrating medical and psychosocial services for pediatric, adolescent, and young adult cancer survivors and their families.

"(c) 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 pediatric cancer survivors, which may include the costs of—

"(1) providing medical and psychosocial follow-up services, including coordination with the patient’s primary care provider and oncologist in order to ensure that the medical needs of survivors are ad-
dressed, and providing linguistically and culturally
competent information to survivors and families with
appropriate outreach to medically underserved popu-
lations;

"(2) the construction, expansion, and mod-
ernization of facilities;

"(3) acquiring and leasing facilities and equip-
ment (including paying the costs of amortizing the
principal of, and paying the interest on, loans for
such facilities and equipment) to support or further
the operation of the grantee; and

"(4) the construction and structural modifica-
tion (including equipment acquisition) of facilities to
permit the integrated delivery of ongoing medical
and psychosocial care to pediatric cancer survivors
and their families at a single service site.

"(d) AUTHORIZATION OF APPROPRIATIONS.—To
carry out this section, there is authorized to be appro-
priated $10,000,000 for each of fiscal years 2013 through
2017."