

number continues to grow with more than 300 million shipped in the United States annually.

The PASS Act would also allow for the Department of Energy to classify external power supplies connected to security or safety systems differently than other types. By design, external power supplies associated with a safety or security device are always in an active mode and simply do not have a no-load or inactive mode, which is why the distinction is needed.

This bill provides necessary regulatory relief while the Department of Energy develops standards for these products.

I urge my colleagues to support this bill.

Mr. OLSON. Mr. Speaker, I will close by saying that H.R. 6375 ensures that these important and potentially life-saving devices work when needed. This is a great bill. I urge all my colleagues to vote for this bill.

I yield back the balance of my time.

Mr. PALLONE. Mr. Speaker, I rise in support of H.R. 6375, the Power and Security Systems, or PASS Act. This bill will provide an important technical exemption to certain security and life safety products from energy efficiency standards set forth in the Energy Independence and Security Act of 2007. A provision in the law increased the energy efficiency requirements for battery chargers and external power supplies—and I strongly supported that change. However, the provision also mistakenly included security and life safety products, and required that they be manufactured with a standby mode, despite being products that are inherently always on.

Without providing this correction, the security industry will need to spend millions of dollars to comply with an energy standard that will yield no energy savings and could cost jobs, which was never the initial intent of the law.

Six years ago, I stood on the House floor in support of legislation I authored that provided this exemption through July 2017. I'm pleased that Representative Welch, along with Representative Pompeo, has taken up this important issue and introduced this bill to extend the exemption I originally authored through 2023. And, the language in the bill before us today will also allow the Department of Energy to extend this exemption or reclassify these products into a separate class if they deem it appropriate.

Mr. Speaker, this is a commonsense and consensus fix to a simple problem: the language was developed by both industry and efficiency advocates, with technical assistance from the Department of Energy. So it should come as no surprise that this bill enjoys broad support from the security industry and energy efficiency advocates. I urge all of my colleagues to support it.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Texas (Mr. OLSON) that the House suspend the rules and pass the bill, H.R. 6375.

The question was taken; and (two-thirds being in the affirmative) the rules were suspended and the bill was passed.

A motion to reconsider was laid on the table.

## CHILDHOOD CANCER SURVIVORSHIP, TREATMENT, ACCESS, AND RESEARCH ACT OF 2016

Mr. BURGESS. Mr. Speaker, I move to suspend the rules and pass the bill (H.R. 3381) to maximize discovery, and accelerate development and availability, of promising childhood cancer treatments, and for other purposes, as amended.

The Clerk read the title of the bill.

The text of the bill is as follows:

H.R. 3381

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

### SECTION 1. SHORT TITLE; TABLE OF CONTENTS.

(a) SHORT TITLE.—This Act may be cited as the “Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2016” or the “Childhood Cancer STAR Act”.

(b) TABLE OF CONTENTS.—The table of contents for this Act is as follows:

Sec. 1. Short title; table of contents.  
Sec. 2. Findings.

### TITLE I—MAXIMIZING RESEARCH THROUGH DISCOVERY

Subtitle A—Caroline Pryce Walker Conquer Childhood Cancer Research Authorization Act

Sec. 101. Children's cancer biorepositories and biospecimen research.

Sec. 102. Improving Childhood Cancer Surveillance.

Subtitle B—Pediatric Expertise at NIH

Sec. 111. Inclusion of at least one pediatric oncologist on the National Cancer Advisory Board.

Sec. 112. Sense of Congress regarding pediatric expertise at the National Cancer Institute.

Subtitle C—NIH Report on Childhood Cancer Activities

Sec. 121. Reporting on childhood cancer research projects.

### TITLE II—MAXIMIZING DELIVERY: CARE, QUALITY OF LIFE, SURVIVORSHIP, AND CAREGIVER SUPPORT

Subtitle A—Childhood Cancer Survivors' Quality of Life Act

Sec. 201. Cancer survivorship programs.

Sec. 202. Grants to improve care for pediatric cancer survivors.

Sec. 203. Comprehensive long-term follow-up services for pediatric cancer survivors.

Sec. 204. Survivorship demonstration project.

Subtitle B—Coverage and Payment of High Quality Care

Sec. 211. Report by the Comptroller General.

### SEC. 2. FINDINGS.

Congress makes the following findings:

(1) Each year in the United States there are an estimated 15,780 children between birth and the age of 19 diagnosed with cancer. Approximately 1 in 285 children in the United States will be diagnosed with cancer before their 20th birthday.

(2) In 1960, only 4 percent of children with cancer survived more than 5 years, but today, cure rates have increased to over 80 percent for children and adolescents under age 20.

(3) While the cure rates for some childhood cancers are now over 80 percent, the survival rates for many types of cancers in children remain extremely low.

(4) According to the Centers for Disease Control and Prevention, cancer continues to be the leading cause of death by disease in children and adolescents under the age of 14.

(5) By 2020, the population of childhood cancers survivors is expected to be 500,000 individuals.

(6) 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. Common late effects of childhood cancer are neurocognitive, psychological, cardiopulmonary, endocrine, and musculoskeletal effects, secondary malignancies, and early death.

(7) As a result of disparities in the delivery of cancer care, minority, low-income, and other medically underserved children 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.

(8) Collection of biospecimens, along with clinical and outcome data, on children and adolescents with cancer in the United States is necessary to improve childhood and adolescent cancer treatments and cures. Currently biospecimens, and clinical and outcome data, are collected for less than half of children in the United States with cancer.

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

(10) Despite the intense stress 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.

(11) 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.

(12) 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 through adulthood.

(13) The National Institutes of Health, including the National Cancer Institute, invest approximately half of their annual appropriations to support basic research that serves as the foundation for translational and clinical research for all diseases and conditions, with the potential to lead to breakthroughs for children with cancer. Virtually all progress against cancer—in both children and adults—has been founded in basic research, often in areas not directly related to the disease.

(14) The National Cancer Institute supports a number of key research programs specifically to advance childhood cancer care, including precision medicine clinical trials for children with cancer, the Children's Oncology Group (part of the National Clinical Trials Network of the National Cancer Institute), the Pediatric Preclinical Testing Consortium, the Pediatric Brain Tumor Consortium, the Childhood Cancer Survivor Study, the Therapeutically Applicable Research to Generate Effective Treatments program and related pediatric cancer genomics research (including the Pediatric MATCH Precision Medicine trial), and the Pediatric Oncology Branch (part of the intramural program of the National Cancer Institute, whose mission is to develop new treatments for pediatric cancer).

# TITLE I—MAXIMIZING RESEARCH THROUGH DISCOVERY

## Subtitle A—Caroline Pryce Walker Conquer Childhood Cancer Reauthorization Act

### SEC. 101. CHILDREN'S CANCER BIOREPOSITORIES AND BIOSPECIMEN RESEARCH.

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

(1) by striking subsection (a) and inserting the following:

“(a) CHILDREN'S CANCER BIOREPOSITORIES.—

“(1) AWARD.—The Secretary, acting through the Director of NIH, may make awards to an entity or entities described in paragraph (4) to build upon existing initiatives to collect biospecimens and clinical and demographic information with a goal of collection for the vast majority of all children, adolescents, and young adults with selected cancer subtypes (and their recurrences) for which current treatments are least effective, through one or more biospecimen research efforts designed to achieve a better understanding of the cause of such cancers (and their recurrences) and the effects of treatments for such cancers.

“(2) USE OF FUNDS.—Amounts received under an award under paragraph (1) may be used to carry out the following:

“(A) Acquire, preserve, and store high-quality, donated biospecimens and associated clinical and demographic information on children, adolescents, and young adults diagnosed with cancer in the United States, focusing on children and adolescents enrolled in clinical trials for whom current treatments are least effective. Activities under this subparagraph may include storage of biospecimens and associated clinical and demographic data at biorepositories supported by the National Cancer Institute, such as the Children's Oncology Group Biorepository and the Pediatric Cooperative Human Tissue Network as well as through biorepositories established as appropriate to support the scientific needs of future research efforts.

“(B) Make such information publicly available, including the repositories described in subparagraph (A).

“(C) Maintain a secure searchable database on stored biospecimens and associated clinical and demographic data from children, adolescents, and young adults with cancer for the conduct of research by scientists and qualified health care professionals.

“(D) Establish procedures for evaluating applications for access to such biospecimens and clinical and demographic data from researchers and other qualified health care professionals.

“(E) Make available and distribute biospecimens and clinical and demographic data from children, adolescents, and young adults with cancer to researchers and qualified health care professionals for peer-reviewed research at a minimal cost.

“(3) NO REQUIREMENT.—No child, adolescent, or young adult with cancer shall be required under this subsection to contribute a specimen to a biorepository or share clinical or demographic data.

“(4) APPLICATION; CONSIDERATIONS.—

“(A) APPLICATION.—To be eligible to receive an award under paragraph (1) an entity shall submit an application to the Secretary at such a time, in such manner, and containing such information as the Secretary may reasonably require.

“(B) CONSIDERATIONS.—In evaluating the applications in subparagraph (A), the Secretary shall consider the existing infrastructure of the entity that would allow for the timely capture of biospecimens and related clinical and demographic information for children, adolescents, and young adults with cancer.

“(5) PRIVACY PROTECTIONS; CONSENT.—

“(A) IN GENERAL.—The Secretary may not make an award under paragraph (1) to an entity unless the Secretary ensures that such entity—

“(i) collects biospecimens and associated clinical and demographic information from children and adolescents with appropriate permission from parents or legal guardians in accordance with Federal and State law; and

“(ii) adheres to strict confidentiality to protect the identity and privacy of patients in accordance with Federal and State law.

“(B) CONSENT.—The Secretary shall establish an appropriate process for achieving consent from the patient, parent, or legal guardian.

“(6) SINGLE POINT OF ACCESS; STANDARD DATA; GUIDELINES AND OVERSIGHT.—

“(A) SINGLE POINT OF ACCESS.—The Secretary shall ensure that each biorepository supported under paragraph (1) has electronically searchable data for use by researchers and other qualified health care professionals in the manner and to the extent defined by the Secretary.

“(B) STANDARD DATA.—The Secretary shall require all recipients of an award under this section to make available a standard dataset for the purposes of subparagraph (A) in a standard electronic format that enables researchers and qualified health care professionals to search.

“(C) GUIDELINES AND OVERSIGHT.—The Secretary shall develop and disseminate appropriate guidelines for the development and maintenance of the biorepositories supported under this section, including appropriate oversight.

“(7) COORDINATION.—The Secretary shall ensure that clinical and demographic information collected in accordance with this section is collected in coordination with the information collected under section 399E-1.

“(8) PROHIBITION ON USE OF FUNDS.—Funds made available to carry out this subsection shall not be used to acquire, preserve, or maintain a biospecimen collected from a patient if such activity is already covered by funds available from the National Cancer Institute for such purpose.

“(9) REPORT.—Not later than 4 years after the date of enactment of the Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2016, the Secretary shall submit to Congress a report on—

“(A) the number of biospecimens and corresponding clinical demographic data collected through the biospecimen research efforts supported under paragraph (1);

“(B) the number of biospecimens and corresponding clinical demographic data requested for use by researchers;

“(C) any barriers to the collection of biospecimens and corresponding clinical demographic data;

“(D) any barriers experienced by researchers or health care professionals in accessing the biospecimens and corresponding clinical demographic data necessary for use in research; and

“(E) any recommendations with respect to improving the biospecimen and biorepository research efforts under this subsection.

“(10) DEFINITIONS.—For purposes of this subsection:

“(A) AWARD.—The term ‘award’ includes a grant, contract, cooperative agreement, or other transaction determined by the Secretary.

“(B) BIOSPECIMEN.—The term ‘biospecimen’ includes—

“(i) solid tumor tissue or bone marrow;

“(ii) normal or control tissue;

“(iii) blood and plasma;

“(iv) DNA and RNA extractions;

“(v) familial DNA; and

“(vi) any other sample required by the Secretary.

“(C) CLINICAL AND DEMOGRAPHIC INFORMATION.—The term ‘clinical and demographic information’ includes—

“(i) date of diagnosis;

“(ii) age at diagnosis;

“(iii) the patient's gender, race, ethnicity, and environmental exposures;

“(iv) extent of disease at enrollment;

“(v) site of metastases;

“(vi) location of primary tumor coded;

“(vii) histologic diagnosis;

“(viii) tumor marker data when available;

“(ix) treatment and outcome data;

“(x) information related to specimen quality; and

“(xi) any other information required by the Secretary.”; and

(2) in subsection (d)—

(A) by striking “and section 399E-1” and inserting “and sections 317U, 399E-1, 417H, and 417H-1”; and

(B) by striking “2009 through 2013” and inserting “2017 through 2021”; and

(C) by striking “such purpose” and inserting “such purposes”.

### SEC. 102. IMPROVING CHILDHOOD CANCER SURVEILLANCE.

Section 399E-1 of the Public Health Service Act (42 U.S.C. 280e-3a) is amended—

(1) by redesignating subsection (b) as subsection (d); and

(2) by striking subsection (a) and inserting the following:

“(a) IN GENERAL.—The Secretary, acting through the Director of the Centers for Disease Control and Prevention, may make awards to State cancer registries to enhance and expand infrastructure to track the epidemiology of cancer in children, adolescents, and young adults. Such registries may be updated to include each occurrence of such cancers within a period of time designated by the Secretary.

“(b) ACTIVITIES.—The grants described in subsection (a) may be used for—

“(1) identifying, recruiting, and training all potential sources for reporting childhood, adolescent, and young adult cancer cases;

“(2) developing procedures to implement early inclusion of childhood, adolescent, and young adult cancer cases on State cancer registries through the use of electronic reporting;

“(3) purchasing infrastructure to support the early inclusion of childhood, adolescent, and young adult cancer cases on such registries;

“(4) submitting deidentified data to the Centers for Disease Control and Prevention for inclusion in a national database of childhood, adolescent, and young adult cancers; and

“(5) tracking the late effects of childhood, adolescent, and young adult cancers.

“(c) COORDINATION.—The Secretary shall ensure that information collected through State cancer registries under this section is collected in coordination with clinical and demographic information collected under section 417E(a) as appropriate.”.

### Subtitle B—Pediatric Expertise at NIH

### SEC. 111. INCLUSION OF AT LEAST ONE PEDIATRIC ONCOLOGIST ON THE NATIONAL CANCER ADVISORY BOARD.

Clause (iii) of section 406(h)(2)(A) of the Public Health and Service Act (42 U.S.C. 284a(h)(2)(A)) is amended to read as follows:

“(iii) of the members appointed to the Board—

“(I) not less than 5 members shall be individuals knowledgeable in environmental carcinogenesis (including carcinogenesis involving occupational and dietary factors); and

“(II) not less than one member shall be an individual knowledgeable in pediatric oncology.”.

**SEC. 112. SENSE OF CONGRESS REGARDING PEDIATRIC EXPERTISE AT THE NATIONAL CANCER INSTITUTE.**

It is the sense of Congress that the Director of the National Cancer Institute should ensure that all applicable study sections, committees, advisory groups, and panels at the National Cancer Institute include one or more qualified pediatric oncologists, as appropriate.

**Subtitle C—NIH Report on Childhood Cancer Activities**

**SEC. 121. REPORTING ON CHILDHOOD CANCER RESEARCH PROJECTS.**

Section 409D(c)(3) of the Public Health Service Act (42 U.S.C. 284h(c)(3)) is amended by—

(1) striking “public on” and inserting “public on—

“(A)”;

(2) striking the period at the end and inserting “; and”;

(3) inserting at the end the following:

“(B) childhood cancer research projects conducted or supported by the National Institutes of Health.”.

**TITLE II—MAXIMIZING DELIVERY: CARE, QUALITY OF LIFE, SURVIVORSHIP, AND CAREGIVER SUPPORT**

**Subtitle A—Childhood Cancer Survivors' Quality of Life Act**

**SEC. 201. CANCER SURVIVORSHIP PROGRAMS.**

(a) **CANCER SURVIVORSHIP PROGRAMS.**—The Public Health Service Act is amended by inserting after section 399N of such Act (42 U.S.C. 280g–2) the following:

**“SEC. 399N–1. PILOT PROGRAMS TO EXPLORE MODEL SYSTEMS OF CARE FOR PEDIATRIC CANCER SURVIVORS.**

“(a) **IN GENERAL.**—Not later than 1 year after the date of enactment of this section, the Secretary may make awards to eligible entities to establish pilot programs to develop, study, or evaluate model systems for monitoring and caring for childhood cancer survivors throughout their lifespan, including evaluation of shared care and medical home and clinic based models for transition to adult care.

“(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 community-based medical facility;

or

“(5) any other entity with significant experience and expertise in treating survivors of childhood cancers.

“(c) **USE OF FUNDS.**—The Secretary may make an award under this section to an eligible entity only if the entity agrees—

“(1) to use the award 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 psychosocial interventions and support programs to improve the quality of life of cancer survivors and their families.

“(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.

**“SEC. 399N–2. 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 curricula relevant to providing medical and psychosocial services to persons surviving 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.”.

**(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. 202. GRANTS TO IMPROVE CARE FOR PEDIATRIC CANCER SURVIVORS.**

(a) **IN GENERAL.**—Section 417E of the Public Health Service Act (42 U.S.C. 285a–11), as amended by section 101, is further amended—

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

(2) by striking subsection (b) and inserting the following:

“(b) **IMPROVING CARE FOR PEDIATRIC CANCER SURVIVORS.—**

“(1) **RESEARCH ON CAUSES OF HEALTH DISPARITIES IN PEDIATRIC CANCER SURVIVORSHIP.—**

“(A) **RESEARCH AWARDS.**—The Director of NIH, in coordination with ongoing research activities, may conduct or support pediatric

cancer survivorship research including any of the following areas:

“(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.

“(iv) Familial, socioeconomic, and other environmental factors and the impact of such factors on treatment outcomes and survivorship.

“(B) **BALANCED APPROACH.**—In supporting 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 psychological needs of such survivors, as appropriate.

“(2) **RESEARCH ON LATE EFFECTS AND FOLLOW-UP CARE FOR PEDIATRIC CANCER SURVIVORS.**—The Director of NIH, in coordination with ongoing research activities, may conduct or support research on follow-up care for pediatric cancer survivors, including any of the following areas:

“(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 associated with the late effects of cancer treatment.

“(C) The identification of predictors of adverse neurocognitive and psychosocial outcomes.

“(D) The identification of the molecular underpinnings of long-term complications.

“(E) The development of risk prediction models to identify those at highest risk of long-term complications.

“(F) Initiatives to protect cancer survivors from the late effects of cancer treatment, by developing targeted interventions to reduce the burden of morbidity borne by cancer survivors.

“(G) Transitions in care for pediatric cancer survivors.

“(H) Training of professionals to provide linguistically and culturally competent follow-up care to pediatric cancer survivors.

“(I) Different models of follow-up care.

“(J) Examining the cost-effectiveness of the different models of follow-up care.”.

**SEC. 203. 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. STANDARDS FOR COMPREHENSIVE LONG-TERM CARE FOR PEDIATRIC CANCER SURVIVORS THROUGH THE LIFESPAN.**

“The Secretary may establish a task force to develop and test standards, outcomes, and metrics for high-quality childhood cancer survivorship care in consultation with a full spectrum of representation of experts in late effects of disease and treatment of childhood cancers, including—

“(1) oncologists who treat children and adolescents;

“(2) oncologists who treat adults;

“(3) primary care providers engaged in survivorship care;

“(4) survivors of childhood cancer;

“(5) parents of children who have been diagnosed with and treated for cancer and parents of long-term survivors;

“(6) professionals who are engaged in the development of clinical practice guidelines;

“(7) nurses and social workers;

“(8) mental health professionals;  
 “(9) allied health professionals, including physical therapists and occupational therapists;  
 “(10) experts in health care quality measurement and improvement; and  
 “(11) others, as the Secretary determines appropriate.”

**SEC. 204. SURVIVORSHIP DEMONSTRATION PROJECT.**

(a) IN GENERAL.—Not later than one year after the date of the enactment of this Act, the Secretary of Health and Human Services (referred to in this section as the “Secretary”) may carry out a demonstration project over a 3-year period, designed to improve the quality and efficiency of care provided to childhood cancer survivors throughout their lifespan, through improved care coordination as survivors transition to adult care.

(b) SELECTION OF DEMONSTRATION SITES.—

(1) MAXIMUM NUMBER OF SITES.—The maximum number of sites at which the demonstration project under subsection (a) is carried out may not exceed 10.

(2) DIVERSITY OF SITES.—In selecting entities to participate in the demonstration project, the Secretary may, to the extent practicable, include in such selection—

(A) small-, medium-, and large-sized sites; and

(B) sites located in different geographic areas.

(c) ACTIVITIES UNDER DEMONSTRATION PROJECT.—The activities conducted under the demonstration project under subsection (a) may, in addition to any other activity specified by the Secretary, include activities that seek to develop different models of care coordination, including transitions of care, follow-up care, monitoring, and other survivorship related programs that utilize a multidisciplinary, team based approach to care, including any of the following activities:

(1) Coordination of care and transitions of care between cancer care providers, primary care physicians, mental health professionals and any other relevant providers.

(2) Dissemination of information to, and training of, health care providers about linguistically and culturally competent follow-up care specific to cancer survivors.

(3) Development of monitoring programs for cancer survivors and their families.

(4) Incorporation of peer support and mentoring programs to improve the quality of life of cancer survivors.

(5) Designing systems and models for the effective transfer of treatment information and care summaries from cancer care providers to other health care providers (including risk factors and a care plan).

(6) Evaluation of functional status and incorporation of specific functional needs into the care planning process.

(7) Dissemination of the information on activities and programs conducted under this section to other health care providers (including primary care physicians) and to cancer survivors and their families, where appropriate.

(8) Other items determined by the Secretary.

(d) MEASURES.—The Secretary may use the following measures to assess the performance of each site:

(1) Patient care and patient/family satisfaction measures.

(2) Resource utilization measures.

(3) Adult survivorship measures, as appropriate.

(e) GAO REPORT.—The Comptroller General of the United States shall submit a report to Congress evaluating the success of the demonstration project. Such report shall include an assessment of the impact of the project upon the quality and cost-efficiency

of services furnished to individuals under this title, including an assessment of the satisfaction of such individuals with respect to such services that were furnished under such project. Such report shall include recommendations regarding the possible expansion of the demonstration project.

**Subtitle B—Coverage and Payment of High Quality Care**

**SEC. 211. REPORT BY THE COMPTROLLER GENERAL.**

(a) IN GENERAL.—The Comptroller General of the United States shall conduct a review and submit recommendations to Congress on existing barriers to obtaining and paying for adequate medical care for survivors of childhood cancer.

(b) CONSIDERATIONS.—In carrying out the review and formulating recommendations under subsection (a), the Comptroller General shall—

(1) identify existing barriers to the availability of complete and coordinated survivorship care for survivors of childhood cancer and to the availability of expert pediatric palliative care, including consideration of—

(A) understanding and education among patients, health care providers, regulators, and third-party payors;

(B) adequacy of payment codes to cover necessary survivorship services;

(C) access to necessary medical and other services for such survivors, including the services described in subsection (c); and

(D) lack of pediatric palliative care across all stages of illness and hospice services for patients approaching the end of life; and

(2) make recommendations to provide improved access and payment plans for childhood cancer survivorship programs and palliative care, including psychosocial services and coverage of such services.

(c) SERVICES DESCRIBED.—The services described in this subsection are the following:

(1) Coordinated multidisciplinary long-term follow-up care with access to appropriate pediatric subspecialists and adult subspecialists with specific expertise in survivorship, including subspecialists with expertise in oncology, radiation oncology, surgery, cardiology, psychiatry or psychology, endocrinology, pulmonology, nephrology, dermatology, gynecology, and urology.

(2) Appropriate organ function testing (particularly screening for potential problems at much younger ages than usually indicated in the general population) and treatment, including—

(A) neuropsychological testing and mental health services;

(B) fertility testing and treatment;

(C) evaluation and treatment for endocrine disorders including growth hormone and testosterone replacement;

(D) diagnostic imaging to screen for late effects of treatment (including subsequent cancers), such as mammograms and magnetic resonance imaging testing to screen for possible breast cancer;

(E) screening for cardiac problems, such as echocardiograms;

(F) screening for osteoporosis with bone densitometry, including dual x-ray absorptiometry and monitoring 25 hydroxyvitamin D levels;

(G) dental coverage and necessary dental implants;

(H) hearing aids and other prosthetic devices; and

(I) screening for lung problems, such as pulmonary function testing.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from Texas (Mr. BURGESS) and the gentlewoman from California (Ms. MATSUI) each will control 20 minutes.

The Chair recognizes the gentleman from Texas.

**GENERAL LEAVE**

Mr. BURGESS. Mr. Speaker, I ask unanimous consent that all Members may have 5 legislative days in which to revise and extend their remarks and insert extraneous materials into the RECORD on the bill.

The SPEAKER pro tempore. Is there objection to the request of the gentleman from Texas?

There was no objection.

Mr. BURGESS. Mr. Speaker, I yield myself such time as I may consume.

I rise today in support of H.R. 3381, the Childhood Cancer Survivorship, Treatment, Access, and Research Act of 2016, also known as the Childhood Cancer STAR Act. This bill was introduced by my Texas colleague, Representative MIKE MCCAUL; Representative CHRIS VAN HOLLEN; and Representative JACKIE SPEIER.

The legislation we are considering today is important for many young Americans, as it is intended to help the most vulnerable among us: children who have been diagnosed with cancer.

We have made progress in combating childhood cancer. In 1960, only 4 percent of children with cancer survived more than 5 years. Today, 80 percent of children with cancer survive, but there is work left to do.

H.R. 3381 will expand the opportunities for childhood cancer research, improve childhood cancer surveillance, help improve the quality of life for childhood cancer survivors, and help ensure that there is proper pediatric cancer research within the National Institutes of Health.

This legislation enjoys broad bipartisan support. It has 270 cosponsors, representing over 60 percent of the House of Representatives.

Mr. Speaker, I urge my colleagues to vote “yes” on H.R. 3381.

I reserve the balance of my time.

Ms. MATSUI. Mr. Speaker, I yield myself such time as I may consume.

I rise today in support of H.R. 3381, the Childhood Cancer Survivorship, Treatment, Access, and Research Act.

Nearly 16,000 children are diagnosed with cancer in the United States each year. These children bravely battle disease and carry burdens that no one their age should. The Childhood Cancer STAR Act gives those children and their families hope by encouraging improved research, development of treatments, and survivorship programs for children with cancer.

This legislation urges the National Institutes of Health to find new opportunities to expand research into pediatric cancer and survivorship, including research on the causes of health disparities in pediatric cancer survivors.

This legislation would also allow the Centers for Disease Control and Prevention to award funding to help States better track pediatric cancer. Improved information about childhood cancer will help guide public health decisions and strategies as well as research.

Expanding research that leads to treatments and cures is only part of the solution for children diagnosed with cancer. This bill recognizes that these children often require different care for the remainder of their lives.

As many as two-thirds of pediatric cancer survivors suffer from the effects of their disease and treatments long term, including secondary cancers and organ damage.

To help children after they have beat pediatric cancer, this bill would create a pilot program to explore model systems of care for pediatric cancer survivors and to study barriers to adequate medical care for survivors of childhood cancer.

I urge my colleagues to support this bill.

Mr. Speaker, I reserve the balance of my time.

□ 1245

Mr. BURGESS. Mr. Speaker, I yield such time as he may consume to the gentleman from Texas (Mr. MCCAUL), the chairman of the Committee on Homeland Security, a true champion for all things pediatric.

Mr. MCCAUL. Mr. Speaker, I want to also thank the gentleman from Texas (Mr. BURGESS) for his work on this effort as well. I chair the Committee on Homeland Security, but I also chair the Congressional Childhood Cancer Caucus. It is one of the biggest threats to our children. It is the number one killer of our children.

Therefore, I rise in support of H.R. 3381, the Childhood Cancer STAR Act, because it will address four major concerns facing the pediatric cancer community: survivorship, treatment, access, and research. I introduced this bill with my colleagues on the other side of the aisle, CHRIS VAN HOLLEN of Maryland and Ms. JACKIE SPEIER of California, to be the most comprehensive childhood cancer bill ever considered before this House.

I cofounded, as I said, the Congressional Childhood Cancer Caucus 7 years ago as a platform to give children a voice, children who don't have lobbyists, children who are dying, who have been impacted by this life-altering diagnosis.

To better fight childhood cancer, we must know more about it, and that is what the STAR Act does. It authorizes NIH to expand their efforts to collect data on childhood cancer so we can better understand its causes and the effects of treatment. It also builds on previous work from cancer research groups to provide doctors with the resources necessary to identify children who may be at risk for developing cancer, preventing the worst outcomes from becoming a reality.

Finally, we must address the needs of two-thirds of childhood cancer survivors facing serious lifelong medical conditions. Our bill will improve collaboration among providers so doctors are better able to care for survivors as they age.

I am pleased this bill has the strong support of the patient advocacy community. I especially want to thank the St. Baldrick's Foundation for their continued support and help and work on this important bill. Their CEO, Kathleen Ruddy, as well as Kevin Mathis and Danielle Leach, have been relentless advocates of this bill to make a difference in kids' lives. I look forward to working with them in the future as we look to further address the needs of the childhood cancer community.

Mr. Speaker, I close by stating that we are also very excited that the Cures Act bill passed the House of Representatives, a very important bill about curing not just childhood cancer, but all diseases. We urge the Senate to pass that legislation as well. In that bill was the Advancing Hope Act, which will make a difference in the number of drugs that can be developed to cure childhood cancer.

In fact, it reauthorizes a bill that I introduced to the year 2020, a bill that has already produced a childhood cancer drug, the first since the 1980s, to cure neuroblastoma in children. When I went to meet with Rex Ryan at Dell Children's Medical Center in Austin, Texas, in this clinical trial, the idea, Mr. Speaker, that you can actually pass a bill in this Congress and see that tangible result, a bill passed in this great body that transforms into saving the life of a child, is truly a tremendous and extraordinary experience.

Ms. MATSUI. Mr. Speaker, I yield 5 minutes to the gentlewoman from California (Ms. SPEIER).

Ms. SPEIER. Mr. Speaker, let me first say what a joy it has been to work with my colleague MIKE MCCAUL on this issue, and with CHRIS VAN HOLLEN as well. Their passion, compassion, and commitment to this issue is one that I have not seen replicated many times.

Let me comment by talking about the letter I received from Sylvia DeCoursey in my district. Her son Tyler has been battling stage 4 neuroblastoma for about a year. She had written to me the following: "As a parent of a pediatric cancer patient, I wanted to say thank you for introducing the Childhood Cancer STAR Act. This has the potential to make a huge difference for my son Tyler and his fellow warriors. In August we lost two little buddies to the neuroblastoma monster. To think that if this act was already in place, that may not have happened, and the heartaches of their families and friends could be prevented. I hope and pray that my son will beat this. Thank you again for sponsoring the STAR Act. . . ."

On Friday I received a follow-up email from Sylvia, and it still sends chills up and down my spine. Tyler has officially been in remission for 2 weeks. It is only fitting that today we are taking up the STAR Act.

The STAR Act would not have been possible without the perseverance of families like Sylvia and Tyler and of

the young people who are living with the cancers. There have been more than 50 organizations that have worked on this issue. Together they have managed to push even a gridlocked Congress into action.

I would like to take a moment to highlight the personal importance of the survivorship provisions of the STAR Act, which I have been working on since 2011. Fifty years ago, only 4 percent of children with cancer survived more than 5 years beyond their diagnosis. Today the cure rate has increased to over 80 percent. It is a remarkable accomplishment. Now we have some 500,000 young people who have survived childhood cancer.

But, as many families know, the fight against childhood cancer doesn't end with remission. As many as two-thirds of childhood cancer survivors experience secondary cancers, and that is why this particular provision of the bill is so important. It is imperative that the STAR Act has a strategy to improve their care and quality of life, and it would not have happened without the guidance of Susan Weiner and Sue Emmer of Children's Cause for Cancer Advocacy. I would also like to thank the staff of all of our offices who worked so hard on this measure: Thomas Rice, Jessica Nalepa, Austin Carson, Kelly Cotner, and Andy Taylor with Congressman MCCAUL; Ziky Ababiya and Erika Appel with Congressman VAN HOLLEN; Jill Brimmer with Senator REED; Dana Richter with Senator MOORE CAPITO; Adrianna Simonelli with Chairman UPTON; Waverly Gordon with Ranking Member PALLONE; Kelly Dixon with Majority Leader MCCARTHY; Charlene MacDonald with Democratic Whip HOYER; Holly Gibbons and her team at the NIH; and Molly Fishman on my staff as well.

I want to thank my colleagues for the time, the leadership, and for giving us an opportunity to do something to improve the lives of these children living with cancer and their parents who are advocating for them.

Mr. BURGESS. Mr. Speaker, I yield 2 minutes to the gentleman from Georgia (Mr. CARTER).

Mr. CARTER of Georgia. Mr. Speaker, I rise today in support of H.R. 3381, the Childhood Cancer STAR Act, which would allow the National Institutes of Health and the Department of Health and Human Services to expand their efforts to research treatments and care for childhood cancer patients.

Each year, thousands of children are diagnosed with cancer, and far too many children are lost to this horrible disease. Childhood cancer survivors and their families still face an uphill battle after remission, as the chances for recurrence can be higher for children.

Advances in treatment have greatly improved outcomes, but more must be done to support patients, survivors, and their families. The bill would help expand efforts to improve the lives of childhood cancer survivors, develop new treatments, increase access to

care, and accelerate lifesaving research for those impacted by childhood cancer.

Childhood cancer patients and survivors have unique needs, and this bill will ensure that those needs are addressed through continued child-focused research. We must continue the fight until no child is lost to cancer. I urge my colleagues to support childhood cancer patients, survivors, and families by supporting the Childhood Cancer STAR Act.

Ms. MATSUI. Mr. Speaker, I urge my colleagues to support the Childhood Cancer STAR Act.

I yield back the balance of my time.

Mr. BURGESS. Mr. Speaker, I urge all Members to vote in favor of H.R. 3381.

I yield back the balance of my time.

The SPEAKER pro tempore. The question is on the motion offered by the gentleman from Texas (Mr. BURGESS) that the House suspend the rules and pass the bill, H.R. 3381, as amended.

The question was taken; and (two-thirds being in the affirmative) the rules were suspended and the bill, as amended, was passed.

A motion to reconsider was laid on the table.

#### EXPANDING CAPACITY FOR HEALTH OUTCOMES ACT

Mr. BURGESS. Mr. Speaker, I move to suspend the rules and pass the bill (S. 2873) to require studies and reports examining the use of, and opportunities to use, technology-enabled collaborative learning and capacity building models to improve programs of the Department of Health and Human Services, and for other purposes.

The Clerk read the title of the bill.

The text of the bill is as follows:

S. 2873

*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 “Expanding Capacity for Health Outcomes Act” or the “ECHO Act”.

#### SEC. 2. DEFINITIONS.

In this Act:

(1) **HEALTH PROFESSIONAL SHORTAGE AREA.**—The term “health professional shortage area” means a health professional shortage area designated under section 332 of the Public Health Service Act (42 U.S.C. 254e).

(2) **INDIAN TRIBE.**—The term “Indian tribe” has the meaning given the term in section 4 of the Indian Self-Determination and Education Assistance Act (25 U.S.C. 5304).

(3) **MEDICALLY UNDERSERVED AREA.**—The term “medically underserved area” has the meaning given the term “medically underserved community” in section 799B of the Public Health Service Act (42 U.S.C. 295p).

(4) **MEDICALLY UNDERSERVED POPULATION.**—The term “medically underserved population” has the meaning given the term in section 330(b) of the Public Health Service Act (42 U.S.C. 254b(b)).

(5) **NATIVE AMERICANS.**—The term “Native Americans” has the meaning given the term in section 736 of the Public Health Service

Act (42 U.S.C. 293) and includes Indian tribes and tribal organizations.

(6) **SECRETARY.**—The term “Secretary” means the Secretary of Health and Human Services.

(7) **TECHNOLOGY-ENABLED COLLABORATIVE LEARNING AND CAPACITY BUILDING MODEL.**—The term “technology-enabled collaborative learning and capacity building model” means a distance health education model that connects specialists with multiple other health care professionals through simultaneous interactive videoconferencing for the purpose of facilitating case-based learning, disseminating best practices, and evaluating outcomes.

(8) **TRIBAL ORGANIZATION.**—The term “tribal organization” has the meaning given the term in section 4 of the Indian Self-Determination and Education Assistance Act (25 U.S.C. 5304).

#### SEC. 3. EXAMINATION AND REPORT ON TECHNOLOGY-ENABLED COLLABORATIVE LEARNING AND CAPACITY BUILDING MODELS.

(a) **EXAMINATION.**—

(1) **IN GENERAL.**—The Secretary shall examine technology-enabled collaborative learning and capacity building models and their impact on—

(A) addressing mental and substance use disorders, chronic diseases and conditions, prenatal and maternal health, pediatric care, pain management, and palliative care;

(B) addressing health care workforce issues, such as specialty care shortages and primary care workforce recruitment, retention, and support for lifelong learning;

(C) the implementation of public health programs, including those related to disease prevention, infectious disease outbreaks, and public health surveillance;

(D) the delivery of health care services in rural areas, frontier areas, health professional shortage areas, and medically underserved areas, and to medically underserved populations and Native Americans; and

(E) addressing other issues the Secretary determines appropriate.

(2) **CONSULTATION.**—In the examination required under paragraph (1), the Secretary shall consult public and private stakeholders with expertise in using technology-enabled collaborative learning and capacity building models in health care settings.

(b) **REPORT.**—

(1) **IN GENERAL.**—Not later than 2 years after the date of enactment of this Act, the Secretary shall submit to the Committee on Health, Education, Labor, and Pensions of the Senate and the Committee on Energy and Commerce of the House of Representatives, and post on the appropriate website of the Department of Health and Human Services, a report based on the examination under subsection (a).

(2) **CONTENTS.**—The report required under paragraph (1) shall include findings from the examination under subsection (a) and each of the following:

(A) An analysis of—

(i) the use and integration of technology-enabled collaborative learning and capacity building models by health care providers;

(ii) the impact of such models on health care provider retention, including in health professional shortage areas in the States and communities in which such models have been adopted;

(iii) the impact of such models on the quality of, and access to, care for patients in the States and communities in which such models have been adopted;

(iv) the barriers faced by health care providers, States, and communities in adopting such models;

(v) the impact of such models on the ability of local health care providers and special-

ists to practice to the full extent of their education, training, and licensure, including the effects on patient wait times for specialty care; and

(vi) efficient and effective practices used by States and communities that have adopted such models, including potential cost-effectiveness of such models.

(B) A list of such models that have been funded by the Secretary in the 5 years immediately preceding such report, including the Federal programs that have provided funding for such models.

(C) Recommendations to reduce barriers for using and integrating such models, and opportunities to improve adoption of, and support for, such models as appropriate.

(D) Opportunities for increased adoption of such models into programs of the Department of Health and Human Services that are in existence as of the report.

(E) Recommendations regarding the role of such models in continuing medical education and lifelong learning, including the role of academic medical centers, provider organizations, and community providers in such education and lifelong learning.

The SPEAKER pro tempore. Pursuant to the rule, the gentleman from Texas (Mr. BURGESS) and the gentleman from California (Ms. MATSUI) each will control 20 minutes.

The Chair recognizes the gentleman from Texas.

#### GENERAL LEAVE

Mr. BURGESS. Mr. Speaker, I ask unanimous consent that all Members have 5 legislative days in which to revise and extend their remarks and insert extraneous materials into the RECORD on the bill.

The SPEAKER pro tempore. Is there objection to the request of the gentleman from Texas?

There was no objection.

Mr. BURGESS. Mr. Speaker, I yield myself such time as I may consume.

Mr. Speaker, I rise today in support of S. 2873, the Expanding Capacity for Health Outcomes Act, also known as the ECHO Act. This bipartisan legislation by Senators HATCH and SCHATZ passed the Senate 97-0 on November 29. House companion legislation has been introduced and championed by Representative MATSUI and me.

This legislation requires the Secretary of Health and Human Services to examine technology-enabled collaborative learning and capacity building models and their impact on the healthcare workforce, the implementation of public health programs, and the delivery of health services in rural and underserved areas to underserved populations. The bill would require the Secretary to consult with public and private stakeholders with expertise in these delivery models to evaluate their potential and larger adoption in States and within the Federal Government.

Within 2 years, the Secretary then would submit to Congress and publicly post a report that includes an analysis of these programs which utilize technology in a novel manner. One such method these programs may employ is using a hub-and-spoke approach to connecting specialty and primary care workers for health surveillance and