

[Childhood Cancer STAR Act of 2018 \(S 292, 115th Congress\)](#)

Amends a series of sections throughout the Public Health Service Act to improve the treatment and understanding of pediatric cancers and late effects for survivors and their families.

Updated last **April 4, 2018**
for the 03/26/2018 version of S 292.

WHAT IT DOES

[S 292](#), the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act of 2018, addresses the maximization of 1) childhood cancer research and 2) the delivery of care for childhood cancer survivors. Here, “childhood cancer” includes cancer in children, adolescents, and young adults.

Portions of this act amend sections of the [Public Health Service Act](#) to improve childhood cancer research and [survivorship](#) by awarding grants for [surveillance](#) and collection of childhood cancer [biospecimens](#), awarding grants for survivor monitoring and assistance programs, and facilitating the development of expertise in clinical and administrative positions. This act has the following amendments and stipulations:

Section 101 — Children’s Cancer Biorepositories and Biospecimen Research

This section amends section 417E of the Public Health Service Act ([42 U.S.C. 285a-11](#)), establishing and funding Department of Health and Human Services (HHS) and National Institute of Health (NIH) efforts to facilitate and expand opportunities for research regarding the treatment and prevention of childhood cancers, with respect to the following:

- Awards, Use of Funds, and Criteria for Applicants – Provide \$30 million annually (fiscal years 2019 through 2023) in funding and an application process to support:
 - Collection and secured storage of biospecimens, clinical data, and demographic data voluntarily provided by patients diagnosed with the country’s hardest to treat childhood cancers; and
 - Integration of the biospecimens and data into a publicly available and searchable database to be used by researchers and physicians for research regarding the cause of these cancers, why relapse occurs, and the effects of known cancer treatments.
- Guidelines and Oversight – HHS will determine responsible development, maintenance, and oversight of awarded biorepositories.
- Reports – mandates the HHS to submit a report to Congress within four years regarding:
 - Number of data collected and requested resulting from the Childhood Cancer STAR Act;
 - Barriers and complications in the collection or access of data; and
 - Recommendations for the improvement of provisions under the Childhood Cancer STAR Act.

Section 102 — Improving Childhood Cancer Surveillance

Section 102 of this act amends section 399E-1 of the Public Health Service Act ([42 U.S.C. 280e-3a](#)), to provide funding for State cancer registries for the identification of and collection of information regarding childhood cancers, which would eventually be incorporated into a national registry. Such funding may be used for:

- Identification, recruitment, and training of patient data sources (e.g., medical facilities);
- Procedures and infrastructure for quick and easy inclusion of data in State cancer registries by electronic reporting; and/or
- The submission of anonymized biospecimen, clinical, and demographic data to the Center for Disease Control’s (CDC) [national registry](#).

Section 111 — Inclusion of at Least One Pediatric Oncologist on the [National Cancer Advisory Board](#)

This section amends clause (iii) of section 406(h)(2)(A) of the Public Health Service Act ([42 U.S.C. 284a\(h\)\(2\)\(A\)](#)), which determines the establishment; membership; compensation; and terms of office for advisors to the national research institutes, to ensure at least one member of the National Cancer Advisory Board of that National Cancer Institute (NCI) has professional experience in pediatric oncology.

Section 112 — Sense of Congress Regarding Pediatric Expertise at the National Cancer Institute

This section broadly recommends that the NCI should include pediatric oncologists in “all applicable study sections, committees, advisory groups, and panels”.

Section 121 — Reporting on Childhood Cancer Research Projects

This section requires that childhood cancer research projects conducted or supported by the NIH are included in any appropriate reports to Congress.

Section 201 — Cancer Survivorship Programs

This section enables HHS to give grants for pilot programs to develop, study, and evaluate systems for lifelong monitoring and care of childhood cancer survivors to provide them with more holistic care beyond cancer treatment. This section also requires HHS to review and report on HHS activities related to workforce development for healthcare providers specializing in the treatment of pediatric cancer patients and survivors. This review must assess the effectiveness of psychosocial care services for these individuals and must yield recommendations for improving the provision of such care.

Section 202 — Grants to Improve Care for Pediatric Cancer Survivors

This section amends section 417E of the Public Health Service Act ([42 U.S.C. 285a-11](#)), which establishes and funds NIH research on the treatment and prevention of pediatric cancers. Specifically, the section authorizes the NIH to continue funding or supporting research on childhood cancer survivorship to examine aspects like treatment outcomes; barriers to care; the impacts of familial, socioeconomic, and environmental factors; and late effects of cancer treatment and the development of targeted interventions to limit those effects.

Section 203 — Best Practices for Long-Term Follow-Up Services for Pediatric Cancer Survivors

This section allows HHS to identify best practices for pediatric cancer survivorship care and to consult with a variety of medical professionals with expertise in the late effects of pediatric cancer disease and treatment.

RELEVANT SCIENCE

Biospecimen Collection and Storage

Sections 101 and 102 of this bill call for the funding of biospecimen collection for the purpose of studying the causes and treatment of childhood cancers. Biospecimens are voluntarily collected samples of [DNA](#), [cells](#), [tissues](#) (e.g., a [tumor](#)), blood, [gametes](#), and/or waste emissions (including sweat, hair, and shed skin cells.) Biospecimens [enable scientists](#) to study the molecular and cellular characteristics of different types of cancer. For instance, by sequencing the DNA of a tumor and comparing it to normal tissue, researchers can begin to identify cancer-promoting genetic changes. The methods and techniques of biospecimen collection and storage can greatly affect the quality of research derived. Here, quality is a function of how little the biospecimen is altered at a molecular and cellular level by the collection and storage processes. While this bill allocates funding for the improvement of biospecimen collection, the NCI has published [best practices](#) for biospecimen collection, storage, and research to ensure quality

research as well as the privacy and autonomy of the patients whose biospecimens are collected.

Late effects of Childhood Cancers

Health complications experienced by cancer survivors as a result of the cancer or its treatment are known as late effects. According to [research](#) from St. Jude Children's Research Hospital, more than 95% of childhood cancer survivors will have a significant health-related issue by the time they are 45 years of age in the form of a late effect. Late effects, sometimes fatal, can affect [a wide variety of bodily functions](#).

According to the [NCI](#), childhood cancer late effects are often caused by the treatment that the patient receives, which can have unintended effects on other parts of the body besides the cancer:

- [Chemotherapy](#) - can cause cancer cells (and normal cells) to stop growing and/or die through a variety of mechanisms, but often works by damaging DNA;
- [Radiation therapy](#) - damages DNA in cancer (and normal) cells, causing the cells to stop dividing and/or die;
- Surgery - surgery goals are balanced between removing as much of the tumor as possible and limiting damage to the surrounding normal tissue; and
- [Stem cell transplant](#) - replenishes blood stem cells wiped out by high doses of radiation or chemotherapy, but can cause [side effects](#).

The [late effects of childhood cancers](#) can be especially damaging due to their effect on the development of the child or adolescent. [Areas of particular concern](#) for childhood and adolescent cancer survivors include:

- [Secondary cancers](#) - new cancers that can arise months or years after treatment, often as a result of DNA damage to normal tissue caused by treatment.
- Growth and Fitness - endocrine defects, sometimes caused by treatment or the tumor itself, can stunt bone and muscle growth, organ fitness, metabolism, and strength.
- Sexual Development - in addition to affecting a patient's reproductive health, chemo and radiation therapies, as well as cancers of the reproductive organs, can also delay or severely impair puberty.
- Brain Development and Behavioral Maturity - brain and blood cancers, and their treatment, tend to have the greatest effect on the survivor's brain development and behavioral maturity. Nevertheless, radiation treatments of all cancers have a great effect on children's brains as they are vulnerable during early development. Negative effects on survivors' brain development and behavior maturity can include:
 - learning disabilities;
 - problems with memory and attention;
 - poor eye-hand coordination;
 - delayed development; and
 - delayed schooling.

[Psychosocial Effects of Childhood Cancer](#)

Provisions under sections 201 and 202 stipulate programs and research to address the psychosocial effects of childhood cancer experienced by patients and their families. While the stress of childhood cancer can have negative effects on a patient's adherence to their treatment regimen by impairing cognition and weakening motivation, stress can also present problems for patients and families. Families of children with cancer have shown signs of post-traumatic stress disorder and psychological problems (such as depression and anxiety) are often accompanied by physical problems like loss of appetite, sleeplessness, and fatigue.

ENDORSEMENTS & OPPOSITION

Endorsements

- [Representative Michael McCaul](#) (R-TX), [press release](#), February 6, 2017: “[T]his tragedy [of childhood cancer] continues to be a far too frequent occurrence for children across the nation. That is why we need to move legislation like the STAR Act through Congress this year, and prevent the worst outcomes from becoming a reality.”
- [Senator Jack Reed](#) (D-RI), [press release](#), February 2, 2017: “The Childhood Cancer STAR Act will bring needed assistance to children with cancer and their families by expanding opportunities for research on childhood cancer and providing new strategies to help survivors overcome late health effects, such as secondary cancers.”
- [Alliance for Childhood Cancer](#), [press release](#), February 3, 2017: “Children with cancer are our most vulnerable patients and more must be done to advance research that will help unlock new therapeutic strategies that will save lives as well as improve the quality of life and survivability for pediatric cancer patients. We firmly believe that the Childhood Cancer STAR Act puts a number of policies in place that will accomplish our collective goal of accelerating the pace of progress against childhood cancer.”

Opposition

- At present, there has not been any publicly reported endorsement of or opposition to this bill.

STATUS

S 292 was introduced in the Senate on February 2, 2017, and passed the Senate by unanimous consent on March 22, 2018. The bill was then introduced in the House on March 26, 2018, where it was referred to the [Committee on Energy and Commerce](#).

RELATED POLICIES

The Hematological Cancer Research Investment and Education Act

The Hematological Cancer Research Investment and Education Act of 2002 ([42 U.S. Code § 285a-10](#)), referenced in [section 201](#) of this bill, amended the Public Health Service Act to fund NCI research and education programs focused on blood cancers.

National Cancer Moonshot Initiative and Task Force

In January of 2016, under President Obama, the [National Cancer Moonshot Initiative](#) ([SciPol brief Available](#)) was created to direct over \$1 billion provided by the [21st Century Cures Act](#) ([SciPol brief Available](#)) to identify new ways to prevent, diagnose, and treat cancer. Within this new initiative, funding for the study of new childhood cancer treatments was stipulated.

Proclamation of National Childhood Cancer Awareness Month

On September 1st, 2016, the Executive Office of the President under Barack Obama issued a [proclamation](#) stipulating September as National Childhood Cancer Awareness Month to bring attention to the stories of childhood cancer patients, survivors, and their families.

[HR 1121](#), 115th Congress - Pre-Existing Conditions Protection Act of 2017 and

[HR 628](#), 115th Congress - Guaranteed Health Coverage for Pre-Existing Conditions Act of 2017

These related bills, introduced in February and January of 2017, would prevent the exclusion and discrimination of individuals with pre-existing health conditions from obtaining insurance, in the event the Patient Protection and Affordable Care Act is repealed ([SciPol brief Available](#)).

[S 463](#) and [HR 1834](#), 115th Congress - Cancer Care Payment Reform Act of 2017

These identical bills introduced at the end of February 2017 in the House and Senate amends [title XVIII](#) of the Social Security Act, which deals with the provision of Medicare. This amendment provides funding to the Centers for Medicare and Medicaid Services to establish an Oncology Medical Home Demonstration Project, which would fund and monitors efforts to coordinate patient oncology care.

[S 456](#) and [HR 1231](#), 115th Congress – RACE for Children Act

These identical bills, introduced at the end of February 2017 in the House and Senate amends the [Federal Food, Drug, and Cosmetic Act](#) to fund, monitor, and incentivize the development of new and timely drug treatments for childhood cancers.

[HR 2008](#), 115th Congress – Kids First Research Act 2.0

This bill, introduced in April of 2017 in the House proposes to increase funding for the treatment of childhood diseases, by amending the [Internal Revenue Code](#) to eliminate taxpayer financing of presidential election campaigns and reallocate the funds to the NIH's Pediatric Research Fund.

White House Press Release Regarding Patients with Preexisting Conditions

On May 2, 2017, the White House Office of the Press Secretary provided a statement for immediate release that directed attention to [a Wall Street Journal editorial](#) written by the newspaper's Editorial Board explaining how the House's Patient Protection and Affordable Care Act replacement, the American Health Care Act, would better serve patients with preexisting conditions, including survivors of childhood cancers facing late effects.

POLICY HISTORY

S 292 was originally introduced in the Senate on February 2, 2017 ([SciPol brief available](#)) but underwent significant amendments before it passed the Senate. A textually identical bill to the original version, [HR 820](#), was also introduced on February 2, 2017, but presumably has been discarded in favor of the Senate-passed version now present before the House.

Similar versions of this bill ([HR 3381](#) and [S 1883](#), 114th Congress) were introduced in July 2015. Akin to the current bill, the House of Representatives passed and sent an [amended version](#) of HR 3381 to the Senate in December of 2016. The amended version was identical to the 115th's HR 820. The 114th Senate was [unable to act](#) on the bill before the end of the legislative session.

SPONSORS

Sponsor: [Senator Jack Reed](#) (D-RI)

Cosponsors:

- [Senator Shelley Moore Capito](#) (R-WV)
- [Senator Chris Van Hollen](#) (D-MD)
- [Senator Johnny Isakson](#) (R-GA)

PRIMARY AUTHOR

Scott "Esko" Brummel, MA Candidate

EDITOR(S)

Jacqueline Robinson-Hamm, PhD Candidate; Alex Robeson, PhD; Andrew Pericak, MEM

RECOMMENDED CITATION

Duke SciPol, "Childhood Cancer STAR Act of 2018 (S 292, 115th Congress)" available at <http://scipol.duke.edu/content/childhood-cancer-star-act-hr-820-s-292-115th-congress> (04/04/2018).