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For comments or suggested additions, please contact Elena@kidsvscancer.org and NancyGoodman@kidsvscancer.org.
LEGISLATIVE ACCOMPLISHMENTS


2012: Congress includes in the Department of Defense Medical Research PRCP eligibility categories for: 1) neuroblastoma, 2) pediatric and adult brain cancers, and 3) childhood cancers and adolescent and young adult cancers, resulting in an additional funding for pediatric cancer research each year and $15.4 million in 2019.

2014: Congress passes the Gabriella Miller Kids First Research Act, resulting in $126 million allocation over 10 years for the NIH Gabriella Miller Kids First Research Program.

2017: Congress passes the RACE for Children Act requiring all cancer drugs to be studied in children with cancer.

2018: Congress passes the Childhood Cancer STAR Act, providing greater opportunities for childhood cancer research, improved efforts to identify and track childhood cancer incidences, and enhanced research into the quality of life for childhood cancer survivors.

2018: Congress passes the Deferment for Active Cancer Treatment Act, enabling students undergoing cancer treatment to defer student loans without accrual of interest.

2019: The 2019 President Trump’s State of the Union Budget of the U.S. Government includes a request for an additional $500 million over 10 years for childhood cancer research, resulting in the establishment of the Childhood Cancer Data Initiative. Congress directs NCI to fund $50 million to the CCDI for 2020.
LEGISLATIVE AGENDA FOR 2021

REAUTHORIZATION OF CURRENT LAW


FUNDING OF PAST ALLOCATIONS

2. Continued funding by NCI of $50 million to the childhood cancer data initiative as part of President Trump’s 2020 budget of $500 million over 10-years for pediatric cancer research.

3. Continued funding by NCI of $30 million for biospecimens, tracking of childhood cancer incidence, and survivorship research pursuant to the Childhood Cancer STAR Act

4. Appropriations to the Department of Defense CDMRP Pediatric Program.

5. Appropriation of $12.6 million to the NIH Gabriella Miller Kids First Research Program pursuant to the Gabriella Miller Kids First Research Act

PASSAGE OF NEW LAWS

6. Passage of the Global Hope Act, H.R. 5338

7. Passage of Kids First Research Act 2.0, H.R. 6556

8. Passage of Fairness to Kids with Cancer Act of 2019, H.R.4429

9. Passage of MEDS Act, S. 2723

10. Passage of the Clinical Treatment Act, H.R. 913

11. Passage of Jonny Wade Pediatric Cancer Research Act, H.R. 2234

12. Passage of Accelerating Kids’ Access to Care Act, H.R. 5900, S. 4717

13. Passage of Palliative Care and Hospice Education and Training Act, H.R. 647

14. Passage of House Resolution for DIPG (H.Res 114)
THE CREATING HOPE REAUTHORIZATION ACT
PEDIATRIC PRIORITY REVIEW VOUCHER (21 U.S.C. 360ff)

What is the problem/opportunity:

There have been an inadequate number of drugs developed for children with cancer.

In 2012, Congress passed the Creating Hope Act to establish the Rare Pediatric Priority Review Voucher Program. The Creating Hope Act is not permanent and has been reauthorized several times, with the latest sunset in September 2020. The four-year reauthorization of the Creating Hope Act was passed by the House of Representatives in September 2020.

Accomplishments:

In 2012, Congress passed the Creating Hope Act Pediatric Priority Review Voucher program to create a financial incentive for companies to develop drugs expressly for kids with rare diseases, including pediatric cancers.

Pursuant to the Creating Hope Act, a company that develops a drug for a pediatric rare disease – and receives FDA approval – also receives a voucher. The voucher comes with rights to faster FDA approval of any future drug, enabling the voucher holder to receive an FDA “priority review” instead of a “standard review.” The voucher is transferable.

Pediatric vouchers have been sold for as much as $350 million and are now trading at $100 million. Over $2 billion of vouchers have been traded. Since the enactment of the Creating Hope Act, the FDA has approved 24 drugs expressly for pediatric rare diseases, two of which are pediatric cancer drugs.

Congress originally passed the Creating Hope Act with a sunset provision, but has extended the program several times. The House of Representatives passed a four-year reauthorization in September 2020. The program expires on December 12, 2020.

Next steps:

Advocates will ask Senate to pass the Creating Hope Reauthorization Act of 2019.

For more information, please contact:

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RACE FOR CHILDREN ACT OF 2017 (21 U.S.C. 355c)

What is the problem/opportunity:

There are thousands of drugs in the adult cancer pipeline but few of them have been studied for children with cancer. While the Pediatric Research Equity Act (PREA) requires companies to develop their adult drugs for children as well, PREA has not been applied to cancer because kids often have cancers that arise in different organs than adult cancers.

Accomplishments:

The RACE for Children Act was passed into law as Title V of the FDA Reauthorization Act to amend the Pediatric Research Equity Act (PREA) (21 U.S.C. 355c) in 2017.

The RACE for Children Act updates the Pediatric Research Equity Act by requiring companies developing targeted cancer drugs for adults to also develop those drugs for children. In addition, the RACE for Children Act ends an exemption from PREA requirements for cancer drugs that have orphan status.

Pursuant to requirements of the RACE for Children Act, in 2018, the FDA held two public meetings to provide input on development of a guidance. Additionally, FDA published lists of molecular targets to guide submissions for pediatric study plans.

In 2019, the FDA published a draft Guidance on RACE for Children Act.

In August 2020, the requirements of the RACE for Children Act took effect.

Next steps:

The FDA will publish a final Guidance on the RACE for Children Act.

For more information, please contact:

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CHILDHOOD CANCER STAR ACT (PUBLIC LAW 115-180)

Accomplishments:

On June 5, 2018, the Childhood Cancer STAR Act (Public law 115-180) was signed into law. Congress fully funded the STAR Act at $30 million per year for FY19.

The Childhood Cancer STAR Act will support: NCI collection of biospecimens; tracking of childhood cancer incidence; survivorship research; and NCI focus on pediatric cancer.

The Childhood Cancer STAR Act authorizes the National Cancer Institute (NCI) to expand existing efforts to collect biospecimens for childhood cancer patients.

The STAR Act authorizes grants to state cancer registries to track incidence of pediatric and young adult cancers.

The STAR Act establishes a pilot program for innovative models of care for survivors.

The STAR Act directs NIH childhood health reporting requirements to include pediatric cancer.

Next steps:

Advocates will ask for full appropriation of the STAR Act every year for the next three years.

For more information, please contact:

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Dana Richter (Sen. Shelley Moore Capito, R-WV), Dana_Richter@capito.senate.gov
CHILDHOOD CANCER DATA INITIATIVE

What is the problem/opportunity:

There are a lack of efficient ways to collect, share, and integrate data from individual hospitals where children with cancer are treated. This limits the potential for researchers to collaborate.

In 2019 in his State of the Union address, President Trump asked for an additional $500 million over the next 10 years for childhood cancer research as part of the Budget of the U.S. Government.

Accomplishments:

The establishment of the Childhood Cancer Data Initiative (CCDI) to enhance data sharing, collection, analysis, and access for ongoing and planned childhood and AYA cancer and survivorship research throughout the Institute, to be funded at $50 million per year.

In 2020, NCI has started the following tasks in alignment with CCDI’s goals: Conduct a landscape analysis of existing childhood and AYA cancer data, tools and repositories that can be connected under the CCDI, develop the National Childhood Cancer Registry (NCCR), support ongoing research to develop a preclinical data commons for childhood cancers, establish a framework, or technical infrastructure, that will allow various types of childhood cancer and clinical care data and tools, including the NCCR and preclinical data commons, to be connected to one another, expand comprehensive data collection to involve more institutions engaged in childhood cancer and survivorship research, and other initiatives.

Next steps:

Advocates will ask Congress' budget for FY2022 to include language funding CCDI at $50 million.

For more information, please contact:

The National Cancer Institute,
DEPARTMENT OF DEFENSE MEDICAL RESEARCH PROGRAM

What is the problem/opportunity:

The Department of Defense (DoD) has an approximately $1.5 billion medical research program through the Congressionally Directed Medical Research Program (CDMRP). Additionally, under the CDMRP, there is a Peer Reviewed Cancer Research Program (PRCRP) which identifies cancers eligible for research funding. The advocates’ goal is to include funding for young adult and pediatric cancer research.

Accomplishments:

Over the past few years, the pediatric cancer community created and secured the continued inclusion of three pediatric cancer eligibility categories in the Department of Defense Medical Research Programs through the Peer-Reviewed Cancer Research Program (PRCRP).

The three pediatric cancer eligibility categories are: 1) neuroblastoma, 2) pediatric brain tumors, 3) cancers in children, adolescents and young adult cancer (AYA).

In 2019 these three categories were awarded $15.4 million:
- $7.4 million for cancers in children and AYA
- $4.8 million for neuroblastoma
- $3.2 million for pediatric brain tumors.

The 2017-2019 total for these categories is $36.2 million.

In 2020, Rep. Ann Kirkpatrick (D-AZ), a member of the DoD Subcommittee, worked closely with the Rally Foundation for Childhood Cancer Research and became a champion for a stand-alone program for cancers in children and AYAs, funded at $30 million for fiscal year 2021. Advocates reached out to subcommittee members asking for their support.

Next steps:

Retaining the report language for cancers in children and AYAs, neuroblastoma, pediatric brain cancer, blood cancer and colorectal cancer, the House of Representatives added sarcomas, germ cell, thyroid and lymphoma to the $110 million Peer-Review Cancer Research program. The advocates will be asking the Senate for its support of the House report language.

In addition, the community will continue to advocate for the inclusion of neuroblastoma and pediatric brain tumors within the PRCRP and continued funding of the PRCRP.
For more information, please contact:

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GABRIELLA MILLER KIDS FIRST RESEARCH ACT OF 2014 (PL 113-94)

What is the problem/opportunity:

Pediatric cancer receives inadequate funding by the National Institutes of Health (NIH).

Gabriella Miller was a girl who died of cancer on October 26, 2013 at the age of 10. Then House Majority Leader Eric Cantor named the bill in her honor.

Accomplishments:

In 2014, The Gabriella Miller Kids First Research Act was signed into law, authorizing through the NIH a pediatric research fund, Gabriella Miller Kids First Research Program, of $126 million over 10 years.

Congress appropriated $12.6 million per year for each of the first five years of the Gabriella Miller Kids First Research Act.

Next steps:

Advocates will again ask Congress to fully fund The Gabriella Miller Kids First Research Act.

In addition, advocates are working with the NIH to ensure that the research funds from the Gabriella Miller Kids First Act are dedicated specifically to pediatric cancer.

For more information, please contact:

Ellyn Miller, Smashing Walnuts Foundation, ellyn@smashingwalnuts.org
https://commonfund.nih.gov/kidsfirst
GABRIELLA MILLER KIDS FIRST RESEARCH ACT 2.0, H.R. 6556

What is the problem/opportunity:

The Kids First Research Act 2.0 is a continuation of the Gabriella Miller Kids First Research Act. It would redirect penalties levied against pharmaceutical manufacturers by the U.S. Securities and Exchange Commission for violating the Foreign Corrupt Practice Act towards the Kids First Pediatric Research Program at the National Institutes of Health.

The funds would be used to develop a comprehensive shared data resource for scientists researching pediatric cancers and structural birth defects and would support the development of computational tools to analyze these large, complex genomic and clinical datasets.

Accomplishments:

The Kids First Research Act 2.0 was introduced in the House in April 2017 by Rep. Jeff Denham (R-CA) and Rep. Fred Upton (R-MI) as H.R. 2008. The bill expired in December 2018 with the end of the 115th Congress. In April 2020, it has been introduced in the House of Representatives by Congresswoman Jennifer Wexton (D-VA-10), Representatives Tom Cole (R-OK-04), Peter Welch (D-VT-At Large) and Gus Bilirakis (R-FL-12).

Next steps:

Advocates will ask for the bill to be introduced in the Senate and will ask Congress to pass the Kids First Research Act 2.0

For more information, please contact:

Ellyn Miller, Smashing Walnuts Foundation, ellyn@smashingwalnuts.org
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Mike Gillette, The Truth 365, mike@thetruth365.org
Joe Baber, The Nicholas Conor Institute, jwbaber3@gmail.com.
GLOBAL HOPE ACT OF 2019, H.R. 5338

What is the problem/opportunity:

While the survival rate for childhood cancers in the U.S is about 80%, in developing countries it is only about 20% as children in developing countries lack access to the care and medicines they need. The Global Hope Act will facilitate partnerships between the federal government, the private sector, research institutions, and non-governmental organizations to address this resource gap and decrease pediatric cancer mortality globally. This will include supporting efforts to train medical personnel and develop the capabilities of other existing healthcare infrastructure to diagnose, treat, and care for childhood cancer; improving access to affordable and essential medicines and technologies that treat childhood cancer; pursuing research partnerships with international institutions and international health ministries and pharmaceutical companies to facilitate efforts for broader, global clinical trials for medicines to treat or care for childhood cancer in the United States and globally.

Accomplishments:

This bill, introduced by Rep. Michael McCaul, (R-TX), and Eliot Engel (D-NY), passed the House in January 2020.

Next steps:

Advocates will ask for the bill to be introduced in the Senate and will ask Congress to pass the Global Hope Act.

For more information, please contact:

Bri Mikeska (Rep. Michael McCaul, R-TX), Bri.Mikeska@mail.house.gov
FAIRNESS TO KIDS WITH CANCER ACT OF 2019, H.R.4429

What is the problem/opportunity:

Less than 4% of the total National Cancer Institute (NCI) research budget is presently directed specifically toward childhood cancer research. This bill requires the share of federal funds for cancer research that is allocated to pediatric cancer research to equal the percentage of the U.S. population that is under the age of 18.

Accomplishments:

In September 2019, the Fairness to Kids with Cancer Act was introduced in the House of Representatives by Representatives Brian Fitzpatrick (PA-01), Josh Gottheimer (NJ-05), Elise Stefanik (NY-21), Mike Kelly (PA-16), Brendan Boyle (PA-02), and Stephanie Murphy (FL-07). This bipartisan bill has 25 cosponsors.

Next steps:

Advocates will ask for the bill to be introduced in the Senate and will ask Congress to pass the Fairness to Kids with Cancer Act.

For more information, please contact:

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Emery Boylan, Emery.boylan@mail.house.gov
MITIGATING EMERGENCY DRUG SHORTAGES (MEDS) ACT, S. 2723

What is the problem/opportunity:

Drug shortages have been on the rise for several years, with an estimated 210 drugs currently at risk or not readily available for U.S. hospitals, with many shortages lasting multiple years. Drug shortages are a major driver of skyrocketing healthcare costs.

This legislation is a response to repeated alarming drug shortages, such as the vincristine shortage that impacted children with cancer.

The MEDS Act aims to provide additional authority to the FDA to develop market-based incentives to help ensure a stable supply of medications critical for patient care. Specifically, the MEDS Act creates a priority pathway for the review of drug shortage applications, seeks recommendations to incentivize manufacturers to enter the market for shortages, and requires manufacturers to report contingency plans to ensure ongoing supply.

Accomplishments:

The MEDS Act was introduced in the House of Representatives in October 2019 by Rep. Susan Collins (R-ME) and Tina Smith (D-MN). It currently has four cosponsors.

Next steps:

Advocates will ask for the bill to be introduced in the Senate and will ask Congress to pass the MEDS Act.

For more information, please contact:

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The office of Senator Tina Smith, Tel. (202) 224-5641
CLINICAL TREATMENT ACT, H.R. 913

What is the problem/opportunity:

Most children with cancer are treated in the context of clinical trials, and their routine care is covered by insurance while the research costs of a trial are covered by a sponsor (most often the NCI). The Clinical Treatment Act amends Title XIX of the Social Security Act to require Medicaid to cover routine costs for items and services furnished in connection with participation in qualifying clinical trials for those with life-threatening conditions. At least one-third of childhood cancer patients depend on Medicaid coverage for their care.

Today only about a dozen states view clinical trials as standard care. In those states that do not recognize clinical trials as routine standard medical care families of children with cancer are responsible for medical care expenses.

Accomplishments:

The bill was introduced by Rep. Ben Ray Lujan (NM-3) and Rep. Gus Bilirakis (FL-12) in 2019 and currently has 55 cosponsors.

Next steps:

Advocates will ask for the bill to be introduced in the Senate and will ask Congress to pass the Clinical Treatment Act.

For more information, please contact:

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The offices of Representatives Ben Ray Lujan, Tel: (202) 225-6190, and Gus Bilirakis, Tel. (202) 225-5755.
JONNY WADE PEDIATRIC CANCER RESEARCH ACT, H.R.2234

What is the problem/opportunity:

Through the Presidential Election Campaign Fund presidential candidates receive federal funds to pay for the qualified expenses of their political campaigns in primary and general elections. This fund has not been utilized since 2008 and has accumulated over $370 million. The Jonny Wade Pediatric Cancer Research Act terminates (1) the taxpayer election to designate $3 of income tax liability for financing of presidential election campaigns, (2) the Presidential Election Campaign Fund, and (3) the Presidential Primary Matching Payment Account, and transfers the funds remaining in the Presidential Election Campaign Fund to the 10-Year Pediatric Research Initiative Fund to help identify treatments for pediatric diseases.

Accomplishments:

The bill was introduced in the House of Representatives in April 2019 by Rep. Rodney Davis (R-IL-13). It has 7 cosponsors.

Next steps:

If the bill is not passed in the 116th Congress, advocates will ask for reintroduction and passage of the bill in the next Congress.

For more information, please contact:

Kimberly Wade, Kids Shouldn't Have Cancer Foundation, kwade@kshcf.org
Jimmy Ballard (Rep. Rodney Davis, D-IL), jimmy.ballard@mail.house.gov.
ACCELERATING KIDS’ ACCESS TO CARE ACT, H.R. 5900, S. 4717

What is the problem/opportunity:

When a child enrolled in Medicaid has clinical needs that cannot be met by providers in his or her home state, the State Medicaid Agency and/or Medicaid Managed Care Organization in concert with the child’s healthcare provider will determine that care needs to be delivered out-of-state. Under current law, the out-of-state providers need to be screened and subsequently enrolled in the Medicaid program of the child. However, there exists no process to facilitate a streamlined screening, meaning that more often than not providers expend significant amounts of time to address varying state requirements. When this happens, access to care is delayed and the child’s health situation may worsen.

This bipartisan legislation amends title XIX of the Social Security Act to streamline enrollment of certain Medicaid providers who serve children or adults whose condition initiated in childhood across state lines. This bill requires state Medicaid programs to establish a process through which qualifying out-of-state providers may enroll as participating providers without undergoing additional screening requirements.

Accomplishments:

The bill was introduced in the House in February 2020, where it has 5 cosponsors, and in the Senate in September 2020, with 6 cosponsors.

Next steps:

Advocates are asking Congress to enact Accelerating Kids’ Access to Care bill prior to the end of the current Congress.

For more information, please contact:

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PALLIATIVE CARE AND HOSPICE EDUCATION AND TRAINING ACT
(PCHETA), H.R 647, S.2080

What is the problem/opportunity:

The goal of pediatric palliative care is to optimize quality of life and well-being of children with life-threatening illnesses by anticipating, preventing, and treating suffering in all its forms, from the time of diagnosis and throughout treatment.

The Palliative Care and Hospice Education and Training Act (PCHETA) establishes palliative care and hospice education centers to improve the training of interdisciplinary health professionals in palliative care; develop and disseminate curricula relating to palliative care; support continuing education; provide students with clinical training in appropriate sites of care. It directs the NIH to use existing authorities and funds to expand palliative care research to advance clinical practice and improve care delivery for patients with serious or life-threatening illnesses.

Accomplishments:

In October 2019 PCHETA was passed in the House of Representatives; it now has 295 co-sponsors. In July 2019 PCHETA was introduced in the Senate, where it has 37 co-sponsors.

Next steps:

Advocates will be asking Congress to pass PCHETA.

For more information, please contact:

http://patientqualityoflife.org
HOUSE RESOLUTION FOR DIPG (H.Res. 114)

What is the problem/opportunity:

Diffuse intrinsic pontine glioma (DIPG), a children's brain cancer, has a terminal prognosis. There has been no significant change in standard treatments or prognosis in over 40 years.

The DIPG Awareness Resolution (H. Res. 114) asks the NIH to elevate the consideration of mortality rate and years of life lost in the grant decision-making process. The Resolution would also establish a national “DIPG Awareness Day” on May 17 to raise awareness of the disease.

In addition, the Michael Mosier Defeat DIPG Foundation's "Across the Map" project is petitioning for every state to issue a proclamation also designating May 17 as DIPG Awareness Day.

Accomplishments:

In 2017, the House introduced The DIPG Awareness Resolution. It expired in December 2018. It was re-introduced in the House in February 2019 by Rep. Jackie Speier and referred to House Energy and Commerce Committee. The number of cosponsors increased from 50 in 2019 to 183 today. By 2020, 47 States issued either a gubernatorial proclamation or a legislative resolution for DIPG Awareness Day May 17, with four state measures in perpetuity.

Senator Marco Rubio introduced the resolution in the U.S. Senate and it passed on March 23, 2019 as S. Res. 223: A resolution expressing support for the designation of May 17, 2019, as “DIPG Pediatric Brain Cancer Awareness Day” to raise awareness of and encourage research on diffuse intrinsic pontine glioma tumors and pediatric cancers in general.

Next steps:

Advocates will ask Congress to pass House Resolution for DIPG. They are asking House E&C Committee for an official referral or deferral of jurisdiction to House leadership to ultimately decide the fate of this Resolution, and an exception to the House rule restricting resolutions for commemorative days.

For more information, please contact:

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