



January 9, 2025

The Honorable John Thune
Majority Leader
United States Senate
Washington, D.C. 20510

The Honorable Chuck Schumer
Democratic Leader
United States Senate
Washington, D.C. 20510

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, DC 20515

Dear Majority Leader Thune, Democratic Leader Schumer, Speaker Johnson, and Leader Jeffries:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, consisting of patient advocacy groups, healthcare professionals, and scientific organizations representing Americans who care deeply about childhood cancer. We are writing to urge you to prioritize the needs of children with cancer by making key investments in research and acting on critical legislation before the current continuing resolution expires on January 30th, 2026.

Approximately 1 in 264 children in the U.S. are diagnosed with cancer before their 20th birthday. Unfortunately, cancer remains the most common cause of death by disease among children in the United States. Unfortunately, 1 in 5 children diagnosed with cancer in the U.S. will not survive, and for the ones who do, the battle is never over. By the age of 50, more than 99% of survivors have a chronic health problem, and 96% have experienced a severe or life-threatening condition caused by the toxicity of the treatment that initially saved their life, including: brain damage, loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more. By the time a child in treatment for cancer today reaches the age of 50, we want these statistics to be far less grim.

Prioritizing the Needs of Children with Cancer

In the 118th Congress, the House of Representatives unanimously passed bills that would address many of the most critical needs of childhood cancer patients. Last December, each bill was included in a bipartisan negotiated health title of the end-of-year package. Unfortunately, the final version of the continuing resolution left out these bipartisan bills. Together, these bipartisan bills would have constituted the most influential childhood cancer legislation since the passing of the original The Childhood Cancer Survivorship, Treatment, Access, Research (STAR) Act.

These two critical policies, the Accelerating Kids' Access to Care Act (H.R. 1509/S. 752) and the Mikaela Naylor Give Kids a Chance Act (H.R. 1262) would address some of the most pressing needs of children and families with cancer, including extending vital research incentives, ensuring children with cancer continue to have access to the newest cures, and removing bureaucratic red tape that impacts access to specialty care and clinical trials.

Further, both bills passed the House of Representatives this year. The Accelerating Kids' Access to Care Act was included in the House-passed version of H.R. 1, the One Big Beautiful Bill Act and the Mikaela Naylor Give Kids a Chance Act unanimously passed the House on December 1st. **As Congress considers a spending package before the current continuing resolution expires on January 30th, 2026, it is more important than ever that Congress uses this opportunity to move these two critical childhood cancer research and access-to-care bills over the finish line.**

Accelerating Kids' Access to Care Act (AKACA) (H.R. 1509/S. 752) – Children with complex medical needs such as cancer are routinely required to travel out of state to receive care or participate in a clinical trial. More than half of children in the United States rely on Medicaid and the Children's Health Insurance Program (CHIP) as their central sources of health care coverage, but Medicaid and CHIP coverage is limited to providers in a child's home state. If a child's medical condition requires them to obtain care from an out-of-state provider or care team, the provider must go through the screening and enrollment process in the child's home state Medicaid program, which can cause burdensome delays in providing time-sensitive care.

The Accelerating Kids' Access to Care Act would address these delays by creating an alternative opt-in pathway for providers in good standing to enroll in multiple state Medicaid programs, allowing them to provide essential, time-sensitive care to children who need it. The legislation pertains only to provider screening and enrollment and does not change the authority states have to authorize out-of-state care or negotiate payment with providers who accept such cases. AKACA would reduce delays in providing time-sensitive care to the children most in need, reduce administrative burdens and costs, and reduce the risk of care disruption and subsequent negative outcomes.

Mikaela Naylor Give Kids a Chance Act (H.R. 1262) – There are close to 7,000 rare “orphan” diseases without appropriate treatments, and the vast majority affect children. Despite the significant unmet need for new FDA-approved pediatric cancer therapies, pharmaceutical companies have been reluctant to develop new pediatric oncology drugs since they likely will not recoup the high costs associated with their research, development, marketing, and distribution following approval. As a result, a unique blend of federal incentives and requirements— “carrots and sticks”— are needed to usher in the next generation of newer, less toxic treatments for kids.

The Mikaela Naylor Give Kids a Chance Act of 2025 addresses some of the most pressing research needs of children and families with cancer, including extending vital research incentives, ensuring children with cancer continue to have access to the newest cures, and guaranteeing pediatric studies happen in a timely manner. The bill expands on multiple landmark

rare disease laws to reflect the changing landscape of pediatric drug development.

Appropriations Priorities

For children with cancer, federally funded intramural and extramural research is the doorway to new, less toxic treatments. Due to the smaller patient populations, drug companies do not have as strong an incentive to invest in new childhood cancer research and development as they do for their adult counterparts. The status quo often favors existing childhood cancer treatments, despite their long-term health impacts. As a result, the onus is on the federal government to fill the gap. Research institutions around the country rely on grants from the National Institutes of Health (NIH) and the National Cancer Institute (NCI) to find new discoveries, treatments, and cures. The critical and innovative intramural research being done on campus at NIH and NCI has saved countless lives and must continue to be fully funded and unimpeded in its mission to improve the lives of childhood cancer patients, survivors, and families. **We join with the leading national cancer organizations in requesting at least \$51.3 billion for NIH, including \$7.934 billion for cancer research at NCI, and \$1.5 billion for Advanced Research Projects Agency for Health (ARPA-H). Further, we strongly oppose any changes to NIH or NCI that threaten their long history of stable, uninterrupted, and robust support. Children cannot afford to wait.**

The Childhood Cancer Survivorship, Treatment, Access, Research (STAR) Act is the most comprehensive and successful childhood cancer bill ever passed and reauthorized by Congress. It expands opportunities for childhood cancer research, improves efforts to identify and track incidences of childhood cancer, and enhances the quality of life for childhood cancer survivors. The programs authorized under the Childhood Cancer STAR Act serve as the critical infrastructure that makes childhood cancer research possible. To build on this incredible work, Congress must continue to make robust targeted investments to bolster childhood cancer survivorship research and expedite the discovery of new, less toxic treatments for the thousands of children who receive a cancer diagnosis each year. **We urge Congress to provide \$35 million for this critical program, a \$5 million increase, matching the funding provided in the House Labor-HHS-Education appropriations bill.**

Initially created by President Trump in 2019, the Childhood Cancer Data Initiative is enhancing childhood cancer care and research data to improve preventive measures, treatment, quality of life, and survivorship, as well as ensure that researchers learn from every child with cancer. By building a community centered around childhood cancer care and research data, CCDI is making data more accessible for researchers and fast-tracking advances for children with cancer. With a primary goal of gathering data from every child, adolescent, and young adult diagnosed with a childhood cancer, CCDI is benefiting children diagnosed with cancer today and will lead to meaningful discoveries in the years to come. **On September 30, 2025, President Trump signed an Executive Order, doubling the CCDI budget from \$50 million to \$100 million to enable the use of artificial intelligence in the study of childhood cancer. We urge Congress to join President Trump's effort by providing \$100 million for this critical program.**

Since 2009, the Department of Defense's Peer Reviewed Cancer Research Program (PRCRP) has supported innovative research in cancers designated by Congress as relevant to those in

military service and their families. Childhood cancer, the leading disease killer of children, adolescents, and young adults (AYAs) in the United States, affects families without prejudice regardless of geographical location, occupation, or income and impacts the military readiness of our service men and women. Childhood, adolescent, and young adult cancers differ in biology and types from older adults and, therefore, require targeted research. The lives of many children, adolescents, and young adults depend on vigorous and innovative research programs like PRCRP to enhance understanding of these deadly tumors and discover new treatments that are more effective and less toxic. **We urge Congress to include \$180 million in funding for the PRCRP, a \$50 million increase, the same funding level provided in the House Labor-HHS-Education appropriations bill. Further, Congress must continue including pediatric, AYA cancers, pediatric brain tumors, neuroblastoma, sarcomas, germ cell cancers, blood cancers, lymphoma, and thyroid cancer as eligible funding topics under the program.**

Finally, due to their smaller patient populations, regulators and researchers must take unique approaches to challenges in collecting childhood cancer data. These challenges require unique research collaborations among investigators worldwide. The Children's Oncology Group (COG), the world's largest organization devoted exclusively to childhood and adolescent cancer research, unites over 12,000 experts at its 220 leading hospitals, universities, and cancer centers across the U.S. and trusted international partners.

International childhood cancer programs are essential to long-term scientific partnerships with COG. They enroll patients in hard-to-complete trials for rare cancers and contribute significant scientific research expertise. Without our international partners, childhood cancer data collection, which is required to make breakthrough discoveries, would take decades longer to achieve. International childhood cancer research partnerships are essential to developing new, effective, and less toxic treatments for children with cancer in the U.S.

Policies which reduce the number of clinical trials available will prevent children for whom standard treatments are ineffective from accessing newer, potentially more effective therapies. Childhood cancer grantees need the financial flexibility to collaborate with international research partners to ensure more children with cancer in the U.S. become survivors. Congress must continue to champion childhood cancer and rare disease research through the appropriations process and ensure our strong scientific partnerships with international partners can continue. **We urge Congress to include the following language included in the Senate Labor-HHS-Education bill in any final appropriations package:**

Advancing Clinical Trials Through Subawards.—The Committee is concerned about the impact of the Administration's policy to prohibit scientists from directing any funding to international research partners and the impact on clinical trials and human subjects research. Pediatric cancer, rare disease, HIV and infectious disease research rely on clinical trial participants and biospecimens from foreign countries in order to aggregate enough samples or patients for robust research. The Committee directs NIH to allow reimbursements and other funding arrangements with research partners abroad to foster pediatric cancer, rare disease, HIV and infectious disease research.

Thank you for your leadership on behalf of children with cancer. We look forward to working

with you to improve the lives of childhood cancer patients, survivors, and families. Should you have any questions or need additional information, please contact Rosalie Abbott, Co-Chair of the Alliance for Childhood Cancer, at Rosalie.abbott@stbaldricks.org, or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at mlink@stanford.edu.

Sincerely,

The Alliance for Childhood Cancer

American Association for Cancer Research
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Society of Pediatric Hematology/Oncology
Association of Pediatric Hematology-Oncology Nurses
Association of Pediatric Oncology Social Workers
Andrew McDonough B+ Foundation
Blood Cancer United
Children's Brain Tumor Foundation
Children's Cancer Cause
Dana-Farber Cancer Institute
Mattie Miracle Cancer Foundation
MIB Agents Osteosarcoma
National Brain Tumor Society
National Comprehensive Cancer Network
Pediatric Brain Tumor Foundation
Rally Foundation for Childhood Cancer Research
St. Baldrick's Foundation
St. Jude Children's Research Hospital