August 4, 2025

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

The Honorable John Thune
Majority Leader
U.S. Senate
Washington, DC 20510

The Honorable Chuck Schumer
Minority Leader
U.S. Senate
Washington, DC 20510

The Honorable Tom Cole
Chair, House Appropriations Committee
H-307, The Capitol
Washington, DC 20515

The Honorable Rosa DeLauro
Ranking Member, House Appropriations Committee
H-307, The Capitol
Washington, DC 20515

The Honorable Susan Collins
Chair, Senate Appropriations Committee
S-128, The Capitol
Washington, DC 20510

The Honorable Patty Murray
Vice Chair, Senate Appropriations Committee
S-128, The Capitol
Washington, DC 20510

Dear Speaker Johnson, Minority Leader Jeffries, Majority Leader Thune, Minority Leader Schumer, Chair Collins, Vice Chair Murray, Chair Cole, and Ranking Member DeLauro:

The undersigned childhood cancer organizations are members of the Alliance for Childhood Cancer, which consists of patient advocacy groups, healthcare professionals, and scientific organizations representing Americans who care deeply about childhood cancer. We are deeply concerned about the long-term impact of recent actions that undermine childhood cancer research infrastructure, as well as the proposed cuts, consolidations, and significant reductions proposed in the President's Fiscal Year (FY) 2026 National Institutes of Health (NIH) Budget Request.

Survival of Children with Cancer Depends on a Stable and Robust Federal Research Commitment

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. More than 96% of survivors experience severe or life-threatening conditions, such as brain damage, heart disease, and loss of hearing and sight.[1]

Decades of sustained federal funding for medical research have significantly improved survival rates for some childhood cancers. Over the past fifty years, research has transformed childhood leukemia from an incurable disease to one with a five-year survival rate of 86%. There are at least nine different types of childhood cancers with dozens of different molecular subtypes, requiring new and targeted treatments. Survival remains poor for children with solid tumors, while those with some leukemias and lymphomas have better survival rates.

Robust federal investments in childhood and adolescent cancer research are paramount to finding new and more effective treatments for cancers where survival is poor. Children deserve a lifetime free of cancer and of the disabling late effects of therapies that keep them alive. The President's proposed budget for FY 2026 includes an almost 40% cut to the NIH and NCI – cuts that threaten these possibilities. The Congressional Budget Office concluded that even a 10% cut – one-quarter of the cut in the President's FY 2026 budget request – would result in fewer drugs developed and fewer clinical trials initiated.[2] **The Alliance for Childhood Cancer applauds the Senate Appropriations Committee for protecting and increasing funding for childhood cancer research at the NIH, and strongly urges Congress to continue its work to preserve this critical funding.**

<u>The Future of Childhood Cancer Treatment is at Risk</u>

We remain gravely concerned by the reported cancellation of over $2 billion in previously awarded grants, including over $856.7 million in cancer research grants in FY 2025 that have already been vetted by the gold standard of peer review.[3] The rarity of childhood cancers makes developing new therapies of little economic interest to the biopharmaceutical industry compared to therapies for adult cancers. As a result, it is essential that the Federal government fund research and drive progress to treat and cure these complex and life-threatening pediatric diseases.

The Administration's proposed cap on indirect costs at 15%[4] will also disrupt vital current and future translational research and clinical trials.[5,6] Small community-based research centers, which children with cancer and their families rely on, could face significant financial instability and

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[1] Bhakta, Nickhill, et al. "The Cumulative Burden of Surviving Childhood Cancer: An Initial Report from the St Jude Lifetime Cohort Study (SJLIFE)." The Lancet, vol. 390, no. 10112, 2017, pp. 2569–2582., Accessed here: https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(17)31610-0/fulltext

[2] Congressional Budget Office, Re: How Changes to Funding for the NIH and Changes in the FDA's Review Times Would Affect the Development of New Drugs, Letter to Members of Congress, July 18, 2025, https://www.budget.senate.gov/imo/media/doc/cbo_fda_nih_letter_071825.pdf

[3] Grant Witness Database: https://grant-witness.us/

[4] National Institutes of Health. (2025, February 7). Supplemental guidance to the 2024 NIH Grants Policy Statement: Indirect cost rates (NOT-OD-25-068). Office of the Director. U.S. Department of Health and Human Services. https://grants.nih.gov/grants/guide/notice-files/NOT-OD-25-068.html

[5] Children's Hospital Association. (2025, February 10). New indirect cost guidelines put quality care at risk. Children's Hospital Association. https://www.childrenshospitals.org/news/newsroom/2025/02/new-indirect-cost-guidelines-put-quality-care-at-risk

[6] Coalition for Pediatric Medical Research. (2025, February 8). Coalition statement on proposed change to NIH indirect cost rates. https://pediatricresearchcoalition.org/coalition-statement-on-proposed-change-to-nih-indirect-cost-rates/

closure, even if larger institutions with alternative funding sources may absorb some of the indirect cost cuts. These cuts pose financial and administrative threats to needed, coordinated progress against childhood cancers.

FY 2026 Proposed Cuts will Dismantle the World's Largest Children's Cancer Research Network

The Children's Oncology Group (COG), a member of the NCI National Clinical Trials Network (NCTN), is the world's largest organization devoted exclusively to childhood and adolescent cancer research. 60% of COG's $78 million annual budget comes from the NIH.[7] Childhood cancer research and the organizations that provide critical basic infrastructure, such as COG, cannot function without stable and robust federal support.[8]

Today, more than 80% of the 15,000 children and adolescents diagnosed with cancer each year in the U. S. are cared for at over 220 COG member institutions.[9] A 40% cut, as outlined in the President's Budget Request, could reduce the number of COG to 80 sites, raising the possibility that many states will be without a childhood cancer research site.[10] The proposed cut will also mean dramatic reductions in the essential data and safety requirements COG must report in order to turn research findings into the standard of care for children with cancer.

Reduced Impact on Improving Treatments through Clinical Trials

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 COG 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.

We are strongly concerned that the Administration's order to eliminate contracts and subgrants with outside U.S. entities will have a uniquely dire impact on the progress to

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[7] Boyle, P. (2025, April 24). What's at stake when clinical trials research gets cut. AAMC News. https://www.aamc.org/news/whats-stake-when-clinical-trials-research-gets-cut#

[8] Fletcher, L., & Nejman, A. (2025, May 8). Washington, D.C., Maryland cancer research for kids hit by NIH federal funding cuts. WJLA. https://wjla.com/features/i-team/washington-dc-maryland-cancer-research-kids-children-nih-national-institutes-of-health-trials-federal-funding-cuts-childrens-oncology-group-cog-disease-fund-trump-administration-doge-cuts-government-spending

[9] Direct communication with COG leadership. July 17, 2025.

[10] Ibid.

improve treatments for childhood cancer.[11,12] Reducing 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. **We urge Congress to continue to champion childhood cancer and rare disease research through the appropriations process and ensure our strong scientific partnerships with international partners can continue.**

Protecting Cancer Survivors in the Long Term Requires Vital Research Funding

The Childhood Cancer STAR Act (STAR Act), the most comprehensive childhood cancer legislation ever enacted by Congress, funds premier childhood cancer survivorship programs, which are currently threatened in the President's Budget Request. The STAR Act supports state-level cancer registries' work to expand critical surveillance infrastructure. Tracking the epidemiology of cancer in children, adolescents and young adults-surveillance helps researchers understand and address challenges in childhood cancer survivorship. This important work is done through the Centers for Disease Control and Prevention's (CDC's) Division of Cancer Prevention and Control (DCPC), which the President's Budget Request would eliminate. **We urge Congress to protect these critical surveillance activities at the CDC and ensure the STAR Act can be fully implemented as Congress intended**.

Workforce Instability Due to Lack of Young Investigator Support

We are very concerned that the number of pediatric oncologists will rapidly decline with reductions in NIH support for programs for newly trained physicians. Eliminating NIH grants to train young investigators in the design, conduct, and reproducibility of research could turn them away from careers in pediatric oncology and childhood cancer research.[13,14,15,16] Introducing new hurdles to a potential career in pediatric oncology, coupled with cuts to funding for research infrastructure, will impede access to care for children with cancer in the U.S.

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[11] Katherine J. Wu, "U.S. Scientist Warns NIH Funding Freeze Jeopardizes Foreign Research," The New York Times, May 6, 2025, https://www.nytimes.com/2025/05/06/health/nih-us-scientist-funding-foreign-research.html.

[12] Kozlov, M. "NIH to End Billions of Dollars in Foreign Research Grants" May 2, 2025, Nature, https://www.nature.com/articles/d41586-025-01361-z

[13] UCLA Health, "Stagnant Funding of NIH Is Shackling Young Research Scientists," March 11, 2008, UCLA Health, https://www.uclahealth.org/news/release/stagnant-funding-of-nih-is-shackling-young-research-scientists.

[14] Anna Volerman and Valerie Press, "Five Years Ago, Early Career Researchers Needed Help to Survive the Pandemic. Now They Need It Again," STAT, March 24, 2025, https://www.statnews.com/2025/03/24/early-career-researchers-medicine-nih-grants-pipeline/.

[15] Nada Fadul et al., "The Chaos of NIH Cuts Has Left Early-Career Scientists Scrambling," Wired, March 24, 2025, https://www.wired.com/story/the-chaos-of-nih-cuts-has-left-early-career-scientists-scrambling/.

[16] Karow, Julia, "Survey: Researchers Devastated by NIH Funding Cuts, Question Future of US Biomedical Science," GenomeWeb July 16, 2025, https://www.genomeweb.com/policy-legislation/survey-researchers-devastated-nih-funding-cuts-question-future-us-biomedical

Congress Must Ensure Strong Federal Support for Childhood Cancer Research Infrastructure

For the childhood cancer community, the challenges presented by a smaller number of diagnosed patients per year require both researchers and lawmakers to be flexible in their approach to critical issues such as clinical trials, research infrastructure, and incentives to develop new therapies. Cancellations of FY 2025 research grants and new policies adding bureaucratic hurdles to research underway will have a real effect on childhood cancer treatments. Further cuts to NIH, as proposed in the President's FY 2026 Budget Request, threaten to exacerbate losses and further erode research infrastructure. The Senate Appropriations Committee took a key bipartisan step in approving robust increases for cancer research at NIH. **Congress must continue this work to protect and bolster childhood cancer research infrastructure programs through sustained, robust Federal funding. Children with cancer and their families rely on NCI organizations such as COG to employ every available tool to save children's lives.**

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

The Andrew McDonough B+ Foundation

Association of Pediatric Hematology and Oncology Nurses

Association of Pediatric Oncology Social Workers

Children's Cancer Cause

Children's Brain Tumor Foundation

Dana-Farber Cancer Institute

The Leukemia & Lymphoma Society

MIB Agents Osteosarcoma Alliance

National Brain Tumor Society

Pediatric Brain Tumor Foundation

Rally Foundation for Childhood Cancer Research

St. Baldrick's Foundation

St. Jude Children's Research Hospital

Cc:

The Honorable Brett Guthrie
The Honorable Frank Pallone
The Honorable Morgan Griffith
The Honorable Diana DeGette
The Honorable Bill Cassidy
The Honorable Bernie Sanders