



April 22, 2022

The Honorable Rosa DeLauro  
Chairwoman  
Appropriations Subcommittee on  
Labor, Health & Human Services  
United States House of Representatives  
Washington, DC 20515

The Honorable Tom Cole  
Ranking Member  
Appropriations Subcommittee on  
Labor, Health & Human Services  
United States House of Representatives  
Washington, DC 20515

Dear Chairwoman DeLauro and Ranking Member Cole:

The undersigned childhood cancer organizations, consisting of patient advocacy groups, healthcare professionals and scientific organizations, represent millions of Americans who care deeply about childhood cancer. As such, we appreciate your tremendous ongoing leadership in Congress to make childhood cancer a national child health priority.

As Congress considers the Fiscal Year 2023 (FY23) Labor, Health & Human Services, Education and Related Agencies Appropriations bill, we ask you to consider our funding priorities as well as the included report language related to childhood cancer.

### **NIH and NCI Funding**

We join with the leading national cancer organizations in requesting at least **\$49.048 billion** for National Institutes of Health (NIH) in FY23, including **\$7.766 billion** for cancer research at the National Cancer Institute (NCI).

**Childhood Cancer Funding:** Each year in the U.S. approximately 16,000 children are diagnosed with cancer. Approximately 1 in 264 children in the U.S. are diagnosed with cancer before their 20th birthday. Annually there are more than 300,000 children diagnosed with cancer worldwide. Unfortunately, cancer remains the most common cause of death by disease for children in America.

We have made significant advances to develop better treatments for the most common forms of childhood cancer. However, for many other types, progress is limited, and for too many children there is no available cure. By the age of 50, more than 99% of survivors have had 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.



Therefore, we ask for the following funding that is specific to Childhood Cancer in the FY23 Labor, Health & Human Services, Education and Related Agencies Appropriations bill:

- **Childhood Cancer STAR Act – \$30 million**, the same funding level as last year, including \$4 million in funding for childhood cancer surveillance at the Centers for Disease Control and Prevention (CDC) to better identify and track incidences of child, adolescent, and young adult cancer in more states.
- **Childhood Cancer Data Initiative – \$50 million**, the same funding level as last year.

We respectfully request that Congress include the following report language in the FY23 Labor, Health & Human Services, Education and Related Agencies Appropriations bill:

**National Cancer Institute  
Report Language**

**NCI Clinical Trials Reporting of Data** – The Committee recognizes that children have often been historically underrepresented in clinical trials. The Committee therefore encourages the National Cancer Institute (NCI) to compile data on the number of adult trials that allow patients aged 12 and over, and to report on the number of patients under 18 who are actually enrolled in those trials to help ensure children are appropriately represented in clinical trials.

Thank you for your consideration and continued support in the fight against childhood cancer. Should you have any questions or need additional information, please contact Sarah Milberg, Co-Chair of the Alliance for Childhood Cancer, at [smilberg@allianceforchildhoodcancer.org](mailto:smilberg@allianceforchildhoodcancer.org), or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at [mink@stanford.edu](mailto:mink@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  
Andrew McDonough B+ Foundation  
Association for Clinical Oncology  
Association of Pediatric Hematology/Oncology Nurses



Association of Pediatric Oncology Social Workers  
Children's Brain Tumor Foundation  
Children's Cancer Cause  
Children's Cancer Research Fund  
Children's Oncology Group  
Leukemia & Lymphoma Society  
Mattie Miracle Cancer Foundation  
National Brain Tumor Society  
Pediatric Brain Tumor Foundation  
Rally Foundation for Childhood Cancer Research  
St. Baldrick's Foundation  
St. Jude Children's Research Hospital