

April 14, 2021

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 2022 (FY22) 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 **\$46.111 billion** (a \$3.177 billion increase) for National Institutes of Health (NIH) in FY22 including **\$7.609 billion** for cancer research at the National Cancer Institute (NCI).

Childhood Cancer Funding: Within these funds, we are committed to working with Congress and the NIH to ensure that childhood cancer becomes a higher priority. Each year in the U.S. an estimated 15,780 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. Two-thirds of children treated for childhood cancer will suffer long-term effects from treatment including loss of hearing and sight, heart disease, secondary cancers, learning disabilities, infertility and more.



Therefore, we ask for the following funding that is specific to Childhood Cancer in the FY22 Labor, Health & Human Services, Education and Related Agencies Appropriations bill:

Childhood Cancer STAR Act – \$30 million, the same funding level as last year.

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 FY22 Labor, Health & Human Services, Education and Related Agencies Appropriations bill:

National Cancer Institute Report Language

Pediatric Cancer Expertise – The Committee recognizes that the Childhood Cancer STAR Act (Public Law No: 115-180) calls on the Director of the National Cancer Institute (NCI) to ensure that all applicable study sections, committees, advisory groups, and panels at the NCI include one or more qualified pediatric oncologists, as appropriate. Therefore, the Committee requests an update on the actions the NCI has taken to ensure appropriate pediatric cancer expertise is included on all panels.

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.

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 for Clinical Oncology Association of Pediatric Hematology/Oncology Nurses Association of Pediatric Oncology Social Workers Andrew McDonough B+ Foundation Children's Brain Tumor Foundation Children's Cancer Cause Children's Oncology Group Leukemia & Lymphoma Society Mattie Miracle Cancer Foundation National Brain Tumor Society Pediatric Brain Tumor Society Pediatric Brain Tumor Foundation Rally Foundation for Childhood Cancer Research St. Baldrick's Foundation St. Jude Children's Research Hospital