



March 9, 2020

The Honorable Rosa DeLauro  
Chairman  
Appropriations Subcommittee on  
Labor, Health & Human Services  
United States House of Representatives  
2358-B Rayburn House Office Building  
Washington, DC 20515

The Honorable Tom Cole  
Ranking Member  
Appropriations Subcommittee on  
Labor, Health & Human Services  
United States House of Representatives  
1016 Longworth House Office Building  
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 (FY) 2021 Labor, Health & Human Services, Education and Related Agencies Appropriations bill, we ask you to consider our funding priorities as well as the report language related to childhood cancer.

### **NIH and NCI Funding**

We join with the leading national cancer organizations in requesting the following funding levels for medical research:

- \$3 billion increase for the National Institutes of Health (NIH), for a total of \$44.7 billion
- \$500 million increase for the National Cancer Institute (NCI) for a total of \$6.9 billion.

### **Childhood Cancer Funding**

Within these funds, we are committed to working with Congress and the National Institutes of Health 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 20<sup>th</sup> 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 FY 2021 LHHS Appropriations bill:

- **\$30 million** to fund the initiatives set forth in the Childhood Cancer STAR Act, including \$2 million to be awarded to State cancer registries to enhance and expand infrastructure to track cancer in children, adolescents, and young adults
- **\$50 million** to continue the White House’s Childhood Cancer Data Initiative, which will establish more efficient ways to share and use childhood cancer data

To ensure that childhood cancer is a top priority for the NIH, we respectfully request that Congress include the following report language in the FY 2021 Labor, Health & Human Services, Education and Related Agencies Appropriations bill.

**Department of Health and Human Services: Office of the Secretary – Report Language**

The Committee encourages the Department of Health and Human Services to complete the identification of best practices for childhood and adolescent cancer survivorship care as directed by the Childhood Cancer STAR Act. In this regard the Committee encourages the Department to consult with individuals who have expertise in late effects of disease and treatment of childhood and adolescent cancers such as oncologists, primary care providers, childhood and adolescent cancer survivors, parents of survivors, nurses, social workers, mental health professionals, physical and occupational therapists, childhood cancer patient organizations and other experts.

**National Cancer Institute: Office of Cancer Survivorship – Report Language**

The Committee recognizes the vital work performed by the Office of Cancer Survivorship. However, it has been brought to the Committee’s attention that pediatric cancer has unique needs that need to be addressed. Therefore, the Committee requests a report that outlines steps that could be taken to focus resources and attention to the youngest of cancer survivors.

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



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 Cause for Cancer Advocacy  
Children's Oncology Group  
CureSearch for Children's Cancer  
Leukemia & Lymphoma Society  
Mattie Miracle Cancer Foundation  
National Brain Tumor Society  
Pediatric Brain Tumor Foundation  
Rally Foundation for Childhood Cancer Research  
Sarcoma Foundation of America  
St. Baldrick's Foundation  
St. Jude Children's Research Hospital



March 9, 2020

The Honorable Roy Blunt  
Chairman  
Appropriations Subcommittee on  
Labor, Health & Human Services  
United States Senate  
S-128 The Capitol Building  
Washington, DC 20510

The Honorable Patty Murray  
Ranking Member  
Appropriations Subcommittee on  
Labor, Health & Human Services  
United States Senate  
154 Russell Senate Office Building  
Washington, DC 20510

Dear Chairman Blunt and Ranking Member Murray:

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Sarcoma Foundation of America  
St. Baldrick's Foundation  
St. Jude Children's Research Hospital