



November 14, 2023

The Honorable Michael McCaul  
U.S. House of Representatives  
2300 Rayburn House Office Building  
Washington, DC 20515

The Honorable Ami Bera  
U.S. House of Representatives  
172 Cannon House Office Building  
Washington, DC 20515

The Honorable Mike Kelly  
U.S. House of Representatives  
1707 Longworth House Office Building  
Washington, DC 20515

Dear Representative McCaul, Representative Brea, and Representative Kelly:

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 offer our endorsement of H.R. 5647, the Childhood Cancer Clinical Trials Act. Thank you for your leadership in reducing a significant financial barrier to potentially life-saving clinical trials.

Approximately 1 in 263 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 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.

Children with cancer face unique health care concerns and often do not have the same access to FDA-approved treatments as adults. Oftentimes, these trials are only available at large academic medical centers that may be far away from where the patient lives, frequently requiring out-of-state travel. While the Affordable Care Act requires coverage of in-network care for clinical trials, insurers are still permitted to deny routine care during a clinical trial that is located out of the patient's insurance network, which can prevent a child from accessing the clinical trial they need. For many childhood cancer patients, clinical trials provide the best or only treatment option available and appropriate for their condition.

The Childhood Cancer Clinical Trials Act would reduce this financial barrier by requiring insurers to cover out-of-network routine care for a clinical trial if the provider operating the trial



is not in-network. Reducing this barrier will increase access for children to participate in clinical trials, which will advance better treatments and outcomes for patients with childhood cancer.

Thank you for your leadership on behalf of children with cancer. The Alliance for Childhood Cancer welcomes the opportunity to further discuss the unique challenges of childhood cancer drug development and research. We look forward to working with you as the Childhood Cancer Clinical Trials Act moves through the legislative process. 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](mailto:rosalie.abbott@stbaldricks.org) or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at [mlink@stanford.edu](mailto:mlink@stanford.edu).

Sincerely,

**The Alliance for Childhood Cancer**

American Association for Cancer Research  
American Cancer Society Cancer Action Network  
American Childhood Cancer Organization  
Andrew McDonough B+ Foundation  
Association for Clinical Oncology  
American Society of Pediatric Hematology/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  
Dana-Farber Cancer Institute  
The Leukemia & Lymphoma Society  
Mattie Miracle Cancer Foundation  
MIB Agents  
National Brain Tumor Society  
Pediatric Brain Tumor Foundation  
Rally Foundation for Childhood Cancer Research  
St. Baldrick's Foundation  
St. Jude Children's Research Hospital

