



September 1, 2022

The Honorable Jackie Speier
U.S. House of Representatives
2465 Rayburn House Office Building
Washington, DC 20515

The Honorable Michael McCaul
U.S. House of Representatives
2001 Rayburn House Office Building
Washington, DC 20515

Dear Representative Speier and Representative McCaul:

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. 8546, the Clinical Trial Coverage Act of 2022. Thank you for your leadership to reduce a significant financial barrier to potentially life-saving clinical trials.

Approximately 1 in 264 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 Clinical Trial Coverage 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 Clinical Trial Coverage Act moves through the legislative process. 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, or Dr. Michael Link, Co-Chair of the Alliance for Childhood Cancer, at mink@stanford.edu.

Sincerely,

The Alliance for Childhood Cancer

American Academy of Pediatrics
American Cancer Society Cancer Action Network
American Society of Pediatric Hematology/Oncology
The Andrew McDonough B+ Foundation
Association of Pediatric Hematology/Oncology Nurses
Children's Brain Tumor Foundation
Children's Cancer Cause
Children's Cancer Research Fund
Children's Oncology Group
The Leukemia & Lymphoma Society
National Brain Tumor Society
Pediatric Brain Tumor Foundation
Rally Foundation for Childhood Cancer Research
St. Baldrick's Foundation