



December 16, 2022

The Honorable Frank Pallone
Chairman
House Committee on Energy & Commerce
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member
House Committee on Energy & Commerce
2322 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Pallone and Ranking Member McMorris Rodgers:

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 urge you to take action on H.R. 3089/S. 1544, the Accelerating Kids' Access to Care Act before the conclusion of the 117th Congress.

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 require specialized care from a specific provider which may include a practitioner with unique subspecialty expertise or a facility that maintains care teams and resources with the expertise to address the unique needs of the child's medical condition. Unfortunately, these providers or facilities are not available in every state. As a result, many children do not have access to specialized care in their home state.

For children with complex medical needs such as cancer, patients are routinely required to travel out of state to receive care from a specific specialist or care team, or to participate in a clinical trial. More than half of children in the United States rely on Medicaid and the Children's Health Insurance Program (CHIP) as their central sources of health care coverage, but Medicaid and CHIP coverage is limited to providers in a child's home state. Under current requirements, if a child's medical condition requires them to obtain care from an out-of-state provider or an out-of-state care team, the provider must go through the screening and



enrollment process in the child's home state Medicaid program. This paperwork process significantly varies by state and causes burdensome, unnecessary delays in providing time-sensitive care, which unfortunately can cause a child's condition to worsen.

The Accelerating Kids' Access to Care Act would address these delays by creating an alternative opt-in pathway for providers in good standing to enroll in multiple state Medicaid programs, allowing them to provide essential, time-sensitive care to children who need it. The legislation pertains only to provider screening and enrollment and does not change the authority states have to authorize out-of-state care or negotiate payment with providers who accept such cases.

The Accelerating Kids' Access to Care Act enjoys bipartisan support from 98 cosponsors in the House of Representatives and 23 cosponsors in the Senate. The legislation has received technical assistance (TA) from the Centers for Medicare & Medicaid Services (CMS) and the Department of Health and Human Services, and a modified version of the legislation to reflect this feedback was included in the Senate Finance Committee's youth mental health draft legislation. We urge you to take immediate action on this bill so children who require critical, time-sensitive care have access to providers who can best meet their needs without burdensome paperwork delays.

Thank you for your leadership on behalf of children with cancer. We look forward to working with you as the Accelerating Kids' Access to Care 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 milink@stanford.edu.

Sincerely,

The Alliance for Childhood Cancer

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
The 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

CC: Speaker Nancy Pelosi
Majority Leader Steny Hoyer
Majority Whip James E. Clyburn
Minority Leader Kevin McCarthy
Minority Whip Steve Scalise



December 16, 2022

The Honorable Ron Wyden
Chair
Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mike Crapo
Ranking Member
Senate Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

Dear Chair Wyden and Ranking Member Crapo:

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CC: Majority Leader Charles Schumer
Majority Whip Richard J. Durbin
Minority Leader Mitch McConnell
Minority Whip John Thune