

January 4, 2022

The Honorable Michael Bennet
U.S. Senate
261 Russell Senate Office Building
Washington, DC 20510

The Honorable Sherrod Brown
U.S. Senate
503 Hart Senate Office Building
Washington, DC 20510

The Honorable Katherine Clark
U.S. House Of Representatives
2448 Rayburn House Office Building
Washington, DC 20515

The Honorable Chuck Grassley
U.S. Senate
135 Hart Senate Office Building
Washington, DC 20510

The Honorable Rob Portman
U.S. Senate
448 Russell Senate Office Building
Washington, DC 20510

The Honorable Jaime Herrera Beutler
U.S. House Of Representatives
2352 Rayburn House Office Building
Washington, DC 20515

Dear Senator Bennet, Senator Grassley, Senator Brown, Senator Portman, Representative Clark, and Representative Herrera Beutler:

Our 28 organizations are dedicated to improving and protecting the public's health, and collectively represent millions of cancer patients in the United States. We understand that for children with cancer, access to high quality time-sensitive care can play an outsized role on treatment outcomes and side-effects a child may suffer for the rest of their life. Therefore, we write to you in strong support for the Accelerating Kids' Access to Care Act (HR 3089 / S 1544) (AKACA).

For decades, both Medicaid and the Children's Health Insurance Program (CHIP) have been core sources of health insurance coverage for children, with children accounting for roughly 50% of total Medicaid enrollment¹. Families with children living with cancer often struggle coordinating specialized care while maintaining a suitable quality of life. Many times, the best treatment for children with cancer requires out-of-state travel coupled with substantial coordination between the child's family and their care team.

In such cases, the State Medicaid Agency and/or Medicaid Managed Care Organization works with the child's health care provider to approve the child for treatment out-of-state. For the child to be approved for out-of-state care, the out-of-state provider—or sometimes an entire care team—must be screened and subsequently enrolled in the Medicaid program where the child resides. While states do have the ability to use provider screenings done by other states or by Medicare, there exists no formal process to facilitate a streamlined screening, meaning that providers regularly spend an immense amount of time to address enrollment requirements, which vary significantly by state. When this occurs, access to care is delayed and, in some cases, the child's cancer can worsen.

The AKACA would address this problem by establishing a voluntary pathway for qualified providers caring for children or adults whose condition onset before the age of eighteen to quickly enroll in other states' programs. An opt-in pathway for providers, only available to those in good standing within their home state program or Medicare, will allow providers to expeditiously step in to provide essential care to children with cancer when called upon; facilitating access to critical, time-sensitive treatment and reduce the risk of care disruption and subsequent negative outcomes.

¹ May 2021 Medicaid & CHIP Enrollment Data Highlights (<https://www.medicaid.gov/medicaid/program-information/medicaid-and-chip-enrollment-data/report-highlights/index.html>)

This legislation only pertains to provider screening and enrollment and does not change the authority states have to authorize out-of-state care and negotiate payment with providers who accept patients of this sort. Further, in CMS' Center for Medicaid and CHIP Services' (CMCS) October 21, 2021 Informational Bulletin on this issue², CMCS acknowledges the issue with delays in providing timely screening and enrollment for providers caring for out-of-state children. The AKACA would ameliorate this issue in a manner that balances improving timely access to cancer care with program integrity needs.

Thank you again for your leadership on behalf of all children with cancer. We look forward to working with you to advance the AKACA. If you have any questions regarding this critical legislation, please contact Matt Marks, Senior Manager of Federal Government Affairs with The Leukemia & Lymphoma Society at matthew.marks@lls.org or at 202-630-9198. Thank you for your consideration.

Sincerely,

Academy of Oncology Nurse & Patient Navigators (AONN)
American Association for Cancer Research
American Childhood Cancer Organization
The Andrew McDonough B+ Foundation
Aplastic Anemia & MDS International Foundation
Association of Oncology Social Work
Cancer Support Community
Cancer Care
Children's Brain Tumor Foundation
Children's Cancer Cause
Hematology/Oncology Pharmacy Association
KidneyCAN
The Leukemia & Lymphoma Society
Livestrong
Martin Truex Jr Foundation
Men's Health Network
National Brain Tumor Society
National Cancer Registrars Association
National Pancreas Foundation
Oncology Nursing Society
Pediatric Brain Tumor Foundation
Rally Foundation for Childhood Cancer Research
Sarcoma Foundation of America
SHEPHERD Foundation
St. Baldrick's Foundation
St. Jude Children's Research Hospital
Triage Cancer
TSC Alliance

² Guidance on Coordinating Care Provided by Out-of-State Providers for Children with Medically Complex Conditions, CMS Center for Medicaid and CHIP Services (<https://www.medicaid.gov/federal-policy-guidance/downloads/cib102021.pdf>)