

July X, 2023

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

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

The Honorable Lori Trahan  
U.S. House Of Representatives  
2439 Rayburn House Office Building  
Washington, DC 20515

The Honorable Mariannette Miller-Meeks  
U.S. House Of Representatives  
1034 Longworth House Office Building  
Washington, DC 20515

Dear Senator Grassley, Senator Bennet, Representative Trahan, and Representative Miller-Meeks:

Our **xxx** organizations are dedicated to improving the health and well-being of children – including children impacted by pediatric cancers, rare diseases, and complex medical conditions. We are pleased to offer our strong support of your legislation, the Accelerating Kids' Access to Care Act (HR XXXX / S XXXX) (AKACA). Once enacted into law, this legislation will help reduce the time it currently takes children covered by Medicaid or the Children's Health Insurance Program (CHIP) to access specialized care when providers in their home state cannot address their care needs.

Both Medicaid and the CHIP are core sources of health insurance coverage for children, with children accounting for roughly 50% of total Medicaid enrollment<sup>1</sup> and more than one-third of all children with special health needs enrolled in Medicaid<sup>2</sup>. Families with children who live with complex medical needs such as cancer, pediatric brain tumors, sickle cell disease, congenital heart disease, and other rare diseases often struggle to access and coordinate the specialized care needed to treat their child's condition. Many times, the best treatment for these children requires out-of-state travel coupled with substantial coordination between the child's family and their care team. Particularly for patients with rare conditions and for novel gene therapy treatments, it is not uncommon for there to be only one or two clinical centers in the country with specialists who have the requisite expertise to treat their condition. A 2019 study of rare disease patients and caregivers across the US found that 39% of respondents traveled more than 60 miles to receive medical care, and 17% had moved (or considered relocating) to be closer to care.<sup>3</sup> For children with cancer, an initial diagnosis or relapse can require immediate and intensive treatment or clinical trials that may not be available in the child's home state.

When a child's medical needs cannot be met by providers in their home state, the State Medicaid Agency and/or Medicaid Managed Care Organization authorizes such care with an out-of-state provider. The out-of-state provider must then be screened and enrolled by the home state's Medicaid program. While current laws and regulations allow for the child's state to rely on provider screenings done by other state Medicaid programs or by Medicare, unfortunately, there is no single federal pathway. This means providers are often required to be screened and enrolled every time they are called upon to treat a child from out-of-state. This process can delay time-sensitive care by weeks or months. During this time, a child's condition can worsen, resulting in worse health outcomes and higher health care costs.

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

<sup>2</sup> "Medicaid Access in Brief: Children and Youth with Special Health Care Needs." MACPAC, March 2023 (<https://www.macpac.gov/wp-content/uploads/2023/03/Medicaid-Access-in-Brief-Children-and-Youth-with-Special-Health-Care-Needs.pdf>)

<sup>3</sup> "Barriers and Facilitators to Rare Disease Diagnosis, Care and Treatment: 30-year Follow-up." National Organization for Rare Disorders, 2020 ([https://rarediseases.org/wp-content/uploads/2020/11/NRD-2088-Barriers-30-Yr-Survey-Report\\_FNL-2.pdf](https://rarediseases.org/wp-content/uploads/2020/11/NRD-2088-Barriers-30-Yr-Survey-Report_FNL-2.pdf))

Your legislation would address this problem by establishing a voluntary pathway for qualified providers caring for children to enroll in other states' Medicaid or CHIP programs quickly. This limited pathway, only available to providers in good standing within their home state program or Medicare, would enable them to bypass subsequent screenings, expeditiously enroll in another state Medicaid program, and step in to provide essential time-sensitive care to children when necessary.

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 accepting providers. It is a common-sense solution that will reduce burdens on health care providers, facilitate access to critical, time-sensitive treatment, and reduce the risk of care disruption and subsequent negative outcomes.

Thank you again for your leadership on behalf of all children with cancer, rare diseases, and other complex health conditions. We look forward to working with you to advance the AKACA. If you have any questions, please contact Matt Marks, Senior Manager of Federal Government Affairs with The Leukemia & Lymphoma Society, at [matthew.marks@lls.org](mailto:matthew.marks@lls.org), Nick Manetto, Principal with Faegre Drinker Consulting, at [nicholas.manetto@faegredrinker.com](mailto:nicholas.manetto@faegredrinker.com), or Mason Barrett, Policy Analyst with the National Organization for Rare Disorders, at [mbarrett@rarediseases.org](mailto:mbarrett@rarediseases.org). Thank you for your consideration.

Sincerely,

**Signers**