July 19, 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 215 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 4758 / S 2372) (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\(^1\) and more than one-third of all children with special health needs enrolled in Medicaid\(^2\). 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.\(^3\) 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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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, Aimee Ossman, Vice President, Policy Analysis with the Children’s Hospital Association, at aimee.ossman@childrenshospitals.org, or Mason Barrett, Policy Analyst with the National Organization for Rare Disorders, at mbarrett@rarediseases.org. Thank you for your consideration.

Sincerely,

Academy of Oncology Nurse & Patient Navigators
Aiden’s Army
Akari Foundation
Along Comes Hope
Amanda Hope Rainbow Angels
American Academy of Allergy, Asthma & Immunology
American Academy of Pediatrics
American Association for Cancer Research
American Cancer Society Cancer Action Network
American Childhood Cancer Organization
American Heart Association
American Lung Association
American Partnership for Eosinophilic Disorders
American Society for Pediatric Hematology/Oncology
The Andrew McDonough B+ Foundation
Ann & Robert H. Lurie Children’s Hospital of Chicago
Aplastic Anemia and MDS International Foundation
APS Foundation of America, Inc
Arms Wide Open Childhood Cancer Foundation
Arthritis Foundation
Association for Clinical Oncology
Association for Creatine Deficiencies
Association of Pediatric Hematology/Oncology Nurses
Asthma and Allergy Foundation of America
Avery’s Hope

The Bardo Foundation
Barth Syndrome Foundation
Bear Necessities Pediatric Cancer Foundation
Bearing Hope
Beat Childhood Cancer Foundation
BJC Health System and Washington University School of Medicine
Bobby Jones Chiari & Syringomyelia Foundation
Boston Children’s Hospital
Braden’s Hope For Childhood Cancer Foundation
Cancer Support Community
CancerCare
CancerFree KIDS
Carson Leslie Foundation
CDH International
Child Neurology Foundation
Childhood Cancer Awareness Group of Coffee County
Children’s Brain Tumor Foundation
Children’s Cancer Cause
Children’s Hospital Association
Children’s Hospital Colorado
Children’s Hospital of Philadelphia
Children’s Hospital of Wisconsin
Children’s Mercy Kansas City
Children’s of Alabama
Children’s Oncology Group Foundation
Chondrosarcoma Foundation
Choroideremia Research Foundation
Christina Renna Foundation
Chronic Disease Coalition
Cincinnati Children's Coalition Against Childhood Cancer (CAC2)  
Congenital Hyperinsulinism International  
Connect Melanoma  
Crohn's & Colitis Foundation  
Cure 4 The Kids Foundation  
Cure CMD  
CURE Epilepsy  
Cystic Fibrosis Foundation  
Cystic Fibrosis Research Institute  
Dana-Farber Cancer Institute  
Daniela Conte Foundation  
Dragon Master Initiative  
Dup15q Alliance  
The E.WE Foundation  
Elaine Roberts Foundation  
Emory University Hospital  
Epilepsy Alliance America  
Epilepsy Foundation  
The EveryLife Foundation for Rare Diseases  
FACES: The National Craniofacial Association  
Family Voices  
FOD (Fatty Oxidation Disorders) Family Support Group  
For A Day Foundation  
FOXG1 Research Foundation  
The FPIES Foundation  
Friends of Cathryn Foundation  
Gaucher Community Alliance  
Gillette Children’s Specialty Healthcare  
The Global Foundation for Peroxisomal Disorders  
Glut1 Deficiency Foundation  
Gold Rush Cure  
Gorlin Syndrome Alliance  
HCU Network America  
Hemophilia Federation of America  
Hemophilia Foundation of Southern California  
Hepatitis B Foundation  
Histiocytosis Association, Inc.  
Hydrocephalus Association  
Hypersomnia Foundation  
Immune Deficiency Foundation  
International Autoimmune Encephalitis Society  
International Foundation for Gastrointestinal Disorders  
International WAGR Syndrome Association  
Jack's Angels  
The Jansen’s Foundation  
JDRF  
Joey's Wings Foundation  
Julia's Grace Foundation  
JUST TRYAN IT  

KidneyCAN  
Kids v Cancer  
Kier's Kidz  
Ladybug House  
Lennox-Gastaut Syndrome (LGS) Foundation  
The Leukemia & Lymphoma Society  
The Life Raft Group  
The Lilabean Foundation  
Livestrong  
Living LFS  
Lupus and Allied Diseases Association, Inc.  
Lupus Foundation of America  
Massachusetts General Hospital  
Mattie Miracle Cancer Foundation  
M-CM Network  
The Mended Hearts, Inc.  
Mesothelioma Applied Research Foundation  
MIB Agents  
Michigan Medicine  
Mighty Millie Foundation  
Mississippi Metabolics Foundation  
Missouri Hospital Association  
Mithil Prasad Foundation  
Momcology®  
A Moment of Magic  
The Morgan Adams Foundation  
MSUD-Family Support Group  
Muscular Dystrophy Association  
Mystic Force Foundation  
National Ataxia Foundation  
National Brain Tumor Society  
National Cancer Registrars Association  
National Eczema Association  
National Eosinophilia Myalgia Syndrome Network  
National Fragile X Foundation  
National MALS Foundation  
National Marrow Donor Program  
National MPS Society  
National MS Society  
National Organization for Rare Disorders  
National Pancreas Foundation  
National Patient Advocate Foundation  
National PKU Alliance  
National Psoriasis Foundation  
Nationwide Children's Hospital  
Nemours Children's Health  
Neuroblastoma Children’s Cancer Society (NCCS)  
Neurofibromatosis Midwest  
NewYork-Presbyterian  
Northwest Indiana Cancer Kids Foundation  
Oncology Nursing Society  
Organic Acidemia Association  
Our Amazing Fighters
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