

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<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), Aimee Ossman, Vice President, Policy Analysis with the Children's Hospital Association, at [aimee.ossman@childrenshospitals.org](mailto:aimee.ossman@childrenshospitals.org), 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,

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 of 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  
*Cancer Care*  
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 EVAN Foundation  
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 Lilabeau 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

The Pablove Foundation  
Parent Project Muscular Dystrophy  
Partnership Health Center  
The Pediatric Brain Tumor Foundation  
People Against Childhood Cancer (PAC2)  
Pheo Para Alliance  
Pine Tree Apple Classic Fund  
Pompe Warrior Foundation  
PREP4Gold  
Princess Nora's Warrior Foundation  
Pull-thru Network, Inc  
Pulmonary Hypertension Association  
Rally Foundation for Childhood Cancer Research  
Rare Epilepsy Network (REN) Coordinating  
Committee  
RASopathies Network  
Richi Childhood Cancer Foundation Inc.  
Riley Children's Health  
The Ross K. MacNeill Foundation  
Rutgers Cancer Institute of New Jersey  
The RYR-1 Foundation  
Sarcoma Foundation of America  
SATB2 Gene Foundation  
Saving Sophie  
The Scott Carter Foundation  
Seattle Children's  
SebastianStrong Foundation  
The Simon Foundation for Continence  
SLC6A1 Connect

The Smasherson Foundation  
Solving Kids' Cancer  
Sophia's Fund  
Spina Bifida Association  
St. Baldrick's Foundation  
St. Jude Children's Research Hospital  
Stanford Children's Health  
Steven G. Research Fund  
Stop Children's Cancer, Inc.  
STXBP1 Foundation  
Swiftly Foundation  
Syngap1 Foundation  
TargetCancer Foundation  
Taylor Matthews Foundation  
Team Telomere  
Team Titin, Inc.  
Texas Children's Hospital  
This Star Won't Go Out  
Tough2gether Foundation  
Triage Cancer  
TSC Alliance  
United MSD Foundation  
United Porphyrrias Association  
Veterans for Common Sense  
VOR - A Voice Of Reason  
WITH Grace Initiative  
Xia-Gibbs Society  
Zoefia Alexandria Foundation Inc.