

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 enrollment¹ and more than one-third of all children with special health needs enrolled in Medicaid². 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.

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

² "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>)

³ "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)

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 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 Porphyrins Association
Veterans for Common Sense
VOR - A Voice Of Reason
WITH Grace Initiative
Xia-Gibbs Society
Zoefia Alexandria Foundation Inc.