December 2, 2024

The Honorable Chuck Schumer
Majority Leader
United States Senate
Washington, D.C. 20510

The Honorable Mitch McConnell
Republican Leader
United States Senate
Washington, D.C. 20510

The Honorable Mike Johnson
Speaker
U.S. House of Representatives
Washington, DC 20515

The Honorable Hakeem Jeffries
Minority Leader
U.S. House of Representatives
Washington, DC 20515

Dear Majority Leader Schumer, Republican Leader McConnell, Speaker Johnson, and Leader Jeffries:

Our 230 organizations are dedicated to improving the health and well-being of children across the country. Millions of children nationwide suffer from complex medical conditions, including rare diseases, pediatric cancers, and genetic conditions. We are grateful for the progress you have made this Congress on bipartisan legislation - H.R. 4758/S. 2372, the **Accelerating Kids' Access to Care Act.** If enacted, the bill will reduce barriers and red tape that children with such challenges who are covered by Medicaid or the Children's Health Insurance Program (CHIP) must navigate to receive time-sensitive care from healthcare providers located outside of their home state. The bill passed the House of Representatives unanimously on September 15, 2024, and we urge you to ensure this bill becomes law before the end of this Congress.

Families with children who live with complex medical conditions often struggle to access the specialized care necessary to meet their child's needs. It is not uncommon for there to be only one or two clinical centers across the country with the requisite knowledge to effectively treat certain conditions, particularly for patients with rare conditions or who need novel gene therapy treatments.[1] For children with cancer, an initial diagnosis or relapse can require immediate and intensive treatment or access to clinical trials that may not be available in the child's home state.

When a child must seek out-of-state care, the home state's Medicaid agency or Medicaid Managed Care Organization (MCO) must approve both the type of care being provided and the providers treating the patient. The providers must then be screened and enrolled by the child's home state's Medicaid program. While federal regulations allow states to use screening done by Medicare or the provider's home state, there is no singular pathway, creating immense variation and, too often, paperwork or processing delays to access urgently needed care. Such delays can result in the child's condition worsening as well as higher health care costs.

The Accelerating Kids' Access to Care Act would create a singular, voluntary, federal pathway to expeditiously enroll a limited subset of providers caring for children with complex conditions. This pathway would be used on an as-needed basis and would only be available to providers in good standing

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[1] https://rarediseases.org/wp-content/uploads/2020/11/NRD-2088-Barriers-30-Yr-Survey-Report_FNL-2.pdf

who complete a single rigorous screening, removing the need for redundant subsequent screenings. It would reduce delays in providing time-sensitive care to the children most in need, reduce administrative burdens and costs, and reduce the risk of care disruption and subsequent negative outcomes.

In addition to unanimously passing the House of Representatives, the legislation enjoys tremendous bipartisan, bicameral support, including cosponsorship by more than 120 House members and more than 40 Senators. It also enjoys the enthusiastic backing of a robust community of child health stakeholders.

We urge you to ensure the Accelerating Kids' Access to Care Act is acted upon by the end of the year either as a standalone measure in the Senate or as part of a larger end of the year legislative package to ensure children with medical complexities are able to get the timely access to the care they need. With 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,

Abby's Legacy Foundation
Acromegaly Community Inc.
Adrenal Insufficiency United
Adult Congenital Heart Association
Aiden's Army
Akari Foundation
Alliance for Regenerative Medicine
Alliance to Cure Cavernous Malformation
Along Comes Hope
Amanda Hope Rainbow Angels
American Academy of Pediatrics
American Association for Cancer Research
American Cancer Society Cancer Action Network
American Heart Association
American Lung Association
American Partnership for Eosinophilic Disorders
American Society for Radiation Oncology
American Society for Transplantation and Cellular Therapy
American Society of Pediatric Hematology/Oncology
American Society of Pediatric Nephrology
The Andrew McDonough B+ Foundation
Angelman Syndrome 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 Gastrointestinal Motility Disorders, Inc. AGMD
Association of Pediatric Hematology/Oncology Nurses
The Avalon Foundation
Avery's Hope
Barth Syndrome Foundation
Bear Necessities Pediatric Cancer Foundation
Bearing Hope
Beat Childhood Cancer
Boston Children's Hospital
Braden's Hope For Childhood Cancer
Breakthrough T1D (formerly JDRF)
Bubba's Light

CACNA1A Foundation
California Children’s Hospital Association
Cancer Support Community
CancerCare
CancerFree KIDS
Carson Leslie Foundation
CCAGCC
CDH International
CFC International
Chelsea's Hope Lafora Children Research Fund
Child Neurology Foundation
Children’s Brain Tumor Foundation
Children’s Cancer Cause
Children’s Hospital of Philadelphia
Children’s Wisconsin
Children's Hospital Association
Children's Hospital Colorado
Children's Hospital Los Angeles
Children's National Medical Center
Children's Oncology Group Foundation
Chondrosarcoma CS Foundation
Christina Renna
Chronic Disease Coalition
Cincinnati Children's
Coalition Against Childhood Cancer (CAC2)
Coalition to Cure CHD2
Columbia University Irving Medical Center
Congenital Hyperinsulinism International
Connect Melanoma
Crohn's & Colitis Foundation
Cure 4 The Kids Foundation
Cure CMD
CURE Epilepsy
CURE GABA-A
Cure KCNH1 Foundation
Cure Sanfilippo Foundation
CureLGMD2i Foundation
CureSearch for Children's Cancer
Cystic Fibrosis Foundation
Cystic Fibrosis Research Institute
Dana-Farber Cancer Institute
Daniela Conte Foundation
Developmental and Epileptic Encephalopathies Project (DEE-P Connections)
DLG4 SHINE Foundation
Dragon Master Initiative
Dravet Syndrome Foundation
Dup15q Alliance
Elaine Roberts Foundation
Epilepsy Foundation of America
Epilespy Alliance America
EveryLife Foundation for Rare Diseases
FACES: The National Craniofacial Association
The Familiescn2A Foundation Inc
Family Voices - National
flok Health
FocusOnRhabdo.org
FOD Family Support Group
For A Day Foundation
Foundation for Angelman Syndrome Therapeutics (FAST)
The FPIES Foundation
Friedreich's Ataxia Research Alliance (FARA)
Friends of Cathryn Foundation
Gaucher Community Alliance
Gillette Children's
The Global Foundation for Peroxisomal Disorders
Glut1 Deficiency Foundation
Gold Rush Cure
GRIN2B Foundation
Haystack Project
HCU Network America
Hemophilia Federation of America
Hemophilia Foundation of Southern California
Hereditary Angioedema Association
Hope for HIE
Hope for Hypothlamic Hamartomas
Hope for Stomach Cancer
Hydrocephalus Association
HypoPARAthyroidism Association
International Foundation for CDKL5 Research
International Rett Syndrome Foundation
International SCN8A Alliance
Jack's Angels
Joey’s Wings Foundation
Jordan’s Guardian Angels
Julia's Grace Foundation

JUST TRYAN IT
KidneyCAN
Kids v Cancer
Kier's Kidz
KIF1A.ORG
Ladybug House
The LCC Foundation
Lennox-Gastaut Syndrome (LGS) Foundation
The Leukemia & Lymphoma Society
The Life Raft Group
Living LFS
Lupus and Allied Diseases Association, Inc.
MACC Fund
Mattie Miracle Foundation
M-CM Network
Mellie J Foundation
The Mended Hearts, Inc.
MIB Agents Osteosarcoma
Mighty Millie Foundation
Mississippi Metabolics Foundation
Missouri Hospital Association
Mithil Prasad Foundation
Momcology®
A Moment of Magic
Muscular Dystrophy Association
Mystic Force Foundation
The National Adrenal Diseases Foundation
National Ataxia Foundation
National Brain Tumor Society
National Eczema Association
National Esosinophilia Myalgia Syndrome Network
National Fragile X Foundation
National Kidney Foundation
National MALS Foundation
National Multiple Sclerosis Society
National Organization for Rare Disorders
National Patient Advocate Foundation
The National PKU Alliance
Nationwide Children's Hospital
Neev Kolte & Brave Ronil Foundation
Nemours Children's Health
Neuroblastoma Children's Cancer Society (NCCS)
New Approaches to Neuroblastoma Therapy Parent Advisory Council (NANT - PAC)
NMDP (formerly National Marrow Donor Program)
North American Society for Pediatric Gastroenterology, Hepatology and Nutrition
Northwest Indiana Cancer Kids Foundation
NTM Info & Research
Oncology Nursing Society
Organic Acidemia Association
Our Amazing Fighters
Parent Project Muscular Dystrophy
Pediatric Brain Tumor Foundation
The Pediatric Brain Tumor Foundation
People Against Childhood Cancer (PAC2)
Phoenix Children's
Pine Tree Apple Classic Fund
PREP4Gold
Princess Nora's Warrior Foundation
Project FAVA
Pull-thru Network, Inc
Pulmonary Hypertension Association
PURA Syndrome Foundation
PWSA | USA - Prader-Willi Syndrome Association
Rady Children's Hospital
Rally Foundation for Childhood Cancer Research
Rare and Undiagnosed Network (RUN)
Rare Epilepsy Network (REN)
Rare Trait Hope Fund
RASopathies Network
Remember The Girls
Rett's Roost
Richi Childhood Cancer Foundation Inc.
Riley Children's Health
The RYR-1 Foundation
Sarcoma Foundation of America
SATB2 Gene Foundation
Saving Sophie
SebastianStrong Foundation
Sickle Cell Disease Association of America
The Simon Foundation
Society for Immunotherapy of Cancer
Solving Kids' Cancer

Sophia's Fund
Spina Bifida Association
St. Baldrick's Foundation
St. Jude Children's Research Hospital
Stanford Medicine Children's Health
Steffens Scleroderma and Degos Disease Foundation
The Sturge-Weber Foundation
STXBP1 Foundation
Superior Mesenteric Artery Syndrome Research Awareness and Support
SYNGAP1 Foundation
The TBCK Foundation
Team Telomere
Texas Children’s Hospital
Triage Cancer
TSC Alliance
United Mitochondrial Disease Foundation
United MSD Foundation
University of Iowa Health Care Stead Family Children's Hospital
UT Southwestern Rare Disease Center of Excellence
Vasculitis Foundation
VOR - A Voice Of Reason
Weill Cornell Medicine

CC:
The Honorable Ron Wyden
The Honorable Mike Crapo
The Honorable Cathy McMorris Rodgers
The Honorable Frank Pallone
The Honorable Chuck Grassley
The Honorable Michael Bennet
The Honorable Mariannette Miller-Meeks
The Honorable Lori Trahan