

March 26, 2025

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  
2233 Rayburn House Office Building  
Washington, DC 20515

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

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

Our 213 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 write in support of your bipartisan legislation - H.R. 1509/S. 752, the **Accelerating Kids' Access to Care Act**, and are grateful for the progress you have made last Congress. 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. In the 118<sup>th</sup> Congress, the bill unanimously passed the House of Representatives and was included in the bipartisan negotiated health title of the end-of-year package.

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.<sup>1</sup> 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

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<sup>1</sup> National Organization for Rare Disorders. (2020). Barriers to rare disease diagnosis, care, and treatment in the US: A 30-year comparative analysis (NRD-2088). National Organization for Rare Disorders. [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)

pathway would be used on an as-needed basis and would only be available to providers in good standing who complete a single rigorous screening, removing the need for redundant subsequent screenings. Further, this pathway would only be available for services already covered under the child's home state Medicaid program. 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.

Thank you 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 Accelerating Kids' Access to Care Act 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, Director of Federal Government Affairs with The Leukemia & Lymphoma Society, at [matthew.marks@lls.org](mailto:matthew.marks@lls.org); Aimee Ossman, Vice President, Policy 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,

3/32 Foundation  
Abby's Legacy  
Adult Congenital Heart Association  
Aimed Alliance  
Akari Foundation  
Alliance for Regenerative Medicine  
Along Comes Hope  
Amanda Hope Rainbow Angels  
American Academy of Pediatrics  
American Cancer Society Cancer Action Network  
American Heart Association  
American Lung Association  
American Partnership for Eosinophilic Disorders  
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

Arkansas Children's Hospital  
Arms Wide Open Childhood Cancer Foundation  
Association for Clinical Oncology  
Association for Creatine Deficiencies  
Avery's Hope  
The Bardo Foundation  
Barth Syndrome Foundation  
Bear Necessities  
Beat Childhood Cancer  
Book for Hope, Inc.  
Boston Children's Hospital  
Braden's Hope for Childhood Cancer  
Bubba's Light, Inc.  
CACNA1A Foundation  
California Children's Hospital Association  
Camk2 Therapeutics Network  
Cancer Free Kids  
Carson Leslie Foundation  
The Catherine Elizabeth Blair Memorial Foundation  
CDH International  
CFC International  
Child Core Family Support  
Child Neurology Foundation  
Children's Brain Tumor Foundation  
Children's Cancer Cause

Children's Hospital Association  
Children's Hospital Colorado  
Children's Hospital of Philadelphia  
Children's Mercy Kansas City  
Children's Minnesota Hospital  
Children's National Hospital  
Children's Wisconsin  
Chondrosarcoma CS Foundation, Inc.  
Christina Renna Foundation  
Coalition to Cure CHD2  
Congenital Hyperinsulinism International  
Connect Melanoma  
Crohn's & Colitis Foundation  
Cure 4 the Kids  
Cure CMD  
CURE GABA-A  
Cure KCNH1 Foundation  
CureLGMD2i  
CureSearch  
Cystic Fibrosis Foundation  
Dana-Farber Cancer Institute  
Daniela Conte Foundation  
Decoding Developmental Epilepsies/Home of  
DEE-P Connections  
DLG4 SHINE Foundation  
Dravet Syndrome Foundation  
Elaine Roberts Foundation  
Elevate Childhood Cancer Research and  
Advocacy, Inc.  
Epilepsy Alliance America  
Evan's Victory Against Neuroblastoma  
Foundation  
EveryLife Foundation for Rare Diseases  
FACES: The National Craniofacial Association  
Family Voices National  
flok Health  
FocusOnRhabdo.org  
For a Day  
Foundation for Angelman Syndrome  
Therapeutics  
The FPIES Foundation  
Friedreich's Ataxia Research Alliance (FARA)  
Friends of Cathryn  
Gaucher Community Alliance

Gillette Children's Specialty Healthcare  
The Global Foundation for Peroxisomal  
Disorders  
Gold Rush Cure  
The Grayson Foundation  
GRIN2B Foundation  
HCU Network America  
Hemophilia Foundation of Southern California  
Hereditary Angioedema Association  
Histiocytosis Association, Inc.  
Hope for HIE  
Hope for Stomach Cancer  
Hope4ATRT Foundation  
Hues For Hope  
Hydrocephalus Association  
HypoPARathyroidism Association  
Immune Deficiency Foundation  
International Autoimmune Encephalitis Society  
International Foundation for CDKL5 Research  
International Foundation for Gastrointestinal  
Disorders  
International SCN8A Alliance  
Jack's Angels  
Joey's Wings Foundation  
Julia's Grace Foundation  
JUST TRYAN IT  
K-T Support Group  
Kaylan Strong's Fight Like a Warrior Foundation  
KidneyCAN  
Kiers Kidz  
KIF1A.ORG  
Ladybug House  
The LCC Foundation  
Leia's Kids  
Lennox-Gastaut Syndrome (LGS) Foundation  
The Leukemia & Lymphoma Society  
Lilabeen Foundation  
Little Hearts of Hope  
LivingLFS  
Love, Chloe Foundation  
Lupus and Allied Diseases Association, Inc.  
M-CM Network  
MACC Fund  
Mattie's Miracle Cancer Foundation

Mellie J Foundation  
The Mended Hearts, Inc.  
MIB Agents Osteosarcoma Alliance  
Mighty Millie Foundation  
Mississippi Metabolics Foundation  
Mithil Prasad Foundation  
Momcology®  
A Moment of Magic  
Morgan Adams Foundation  
MSUD Family Support Group  
Muscular Dystrophy Association  
Mystic Force Foundation  
NANT-PAC  
National Ataxia Foundation  
National Brain Tumor Society  
National Cancer Registrars Association  
National Fragile X Foundation  
National Multiple Sclerosis Society  
National Organization for Rare Disorders  
The National Pancreas Foundation  
National Patient Advocate Foundation  
National PKU Alliance  
Nationwide Children's Hospital  
Neev Kolte & Brave Ronil Foundation  
Nemours Children's Health  
NephCure  
Neuroblastoma Children's Cancer Society  
NMDP (formerly National Marrow Donor Program)  
Northwest Indiana Cancer Kids  
NTM Info & Research  
Organic Acidemia Association  
Our Amazing Fighters  
Pablove  
Parent Project Muscular Dystrophy  
Pediatric Brain Tumor Foundation  
People Against Childhood Cancer  
Pine Tree Apple Classic Fund  
Prader-Willi Syndrome Association | USA  
PREP4Gold  
Project FAVA  
Pulmonary Hypertension Association  
Rady Children's Health  
Rally Foundation for Childhood Cancer Research

Rare and Undiagnosed Network (RUN)  
Rare Trait Hope Fund  
RASopathies Network  
Rett's Roost  
Richi Childhood Cancer Foundation  
The Ross K. MacNeill Foundation  
The RYR-1 Foundation  
Sam Day Foundation  
Sarcoma Foundation of America  
SATB2 Gene Foundation  
Saving Sophie Foundation  
The Scott Carter Foundation  
Sebastian Strong Foundation  
Sickle Cell Disease Association of America, Inc.  
SLC6A1 Connect  
Smasherson Foundation, The  
Society for Immunotherapy of Cancer  
Solving Kids Cancer  
Spina Bifida Association  
St. Baldrick's Foundation  
The Steven G Cancer Foundation  
Stop Children's Cancer  
STXBP1 Foundation  
Superior Mesenteric Artery Syndrome Research  
Awareness and Support  
Swiftly Foundation  
The Taylor Matthews Foundation, a Tay-Bandz Organization  
The TBCK Foundation  
The Institute for Gene Therapies  
This Star Won't Go Out  
Tough4Together  
Triage Cancer  
TSC Alliance  
UH Rainbow Babies & Children's Hospital  
United Mitochondrial Disease Foundation  
United MSD Foundation  
University of Iowa Health Care Stead Family Children's Hospital  
Vasculitis Foundation  
VOR - A Voice Of Reason  
WITH Grace Initiative  
Yuvaan Tiwari Foundation  
Zoefia Alexandria Foundation