

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 214 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 118th 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.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

¹ 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

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; Aimee Ossman, Vice President, Policy 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,

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
Cincinnati Children's Hospital
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
Swift 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