December 2, 2024

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

The Honorable Mike Johnson Speaker U.S. House of Representatives Washington, DC 20515 The Honorable Mitch McConnell Republican Leader United States Senate Washington, D.C. 20510

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.

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

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 Dup15g 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