September 8, 2022

The Honorable Ron Wyden
Chairman
Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Mike Crapo
Ranking Member Committee on Finance
219 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Frank Pallone
Chairman
Committee on Energy & Commerce
United States Congress
2125 Rayburn House Office Building
Washington, DC 20515

The Honorable Cathy McMorris Rodgers
Ranking Member Committee on Energy & Commerce
United States Congress 2322 Rayburn House Office Building
Washington, DC 20515

Dear Chairman Wyden, Ranking Member Crapo, Chairman Pallone, and Ranking Member McMorris Rodgers,

On behalf of the 25 to 30 million Americans living with a rare disease, the undersigned 110 organizations write in support of the Accelerating Kids' Access to Care Act (H.R. 3089/S. 1544). We urge you to proceed with legislative hearings within your respective committees at the earliest opportunity, and to

include this important legislation as part of any year-end package. This bipartisan proposal led by Representatives Katherine Clark (D-MA.) and Jaime Herrera Beutler (R-WA.) and Senators Michael Bennet (D-CO) and Charles Grassley (R-IA) would improve the ability of children with rare diseases to access timely care and reduce the significant burden that is often borne by their families as they navigate a complex health care system.

It is estimated that there are over 7,000 rare diseases, which are defined in the United States as diseases affecting 200,000 or fewer individuals. People with rare diseases face many challenges, but one of the most difficult is finding specialists and providers who are knowledgeable and able to treat a specific rare condition. Patients often find that, even when they are appropriately diagnosed, their provider is illequipped to treat their rare disease, either because of technical limitations or because they lack the knowledge and experience to treat such rare conditions. Indeed, it is not uncommon for there to be just one or two clinical centers in the entire nation with a specialist who is knowledgeable and can treat a specific rare disease. As a result, patients with rare disorders often have to travel significant distances and cross state lines for their care. For example, in a 2019 survey of rare disease patients and caregivers, 39% of respondents reported that they needed to travel 60 or more miles to access medical care related to their rare disease.[1]

As the largest sources of insurance coverage for children with special health care needs, Medicaid and the Children's Health Insurance Program (CHIP), serve a vital role in facilitating care for children with rare disorders.[2] However, it is often incredibly difficult for children with Medicaid or CHIP coverage to obtain care from an out-of-state provider. Currently, if a child needs to access medical care out-of-state, the provider (or the entire care team) must be screened and enrolled by the child's home-state Medicaid program. This process is often burdensome for the providers themselves as well as the patient's family and can cause unnecessary and dangerous delays in providing time-sensitive medical treatment.

The Accelerating Kids' Access to Care Act would address this issue by creating a streamlined screening and enrollment process through which eligible pediatric care providers may enroll in another state's Medicaid program. Eligible providers are limited to those providing care to children, or, in limited cases, people who are receiving care for a condition developed in childhood. Eligible providers must also be in good standing with either their home-state Medicaid program, or Medicare, to be eligible for this pathway. Use of the pathway is entirely voluntary and does not alter state government authority to authorize out-of-state treatment and negotiate payment with out-of-state providers. Ultimately, this proposal is commonsense legislation that would reduce administrative red-tape and provide important support to children with rare disorders and their families, without compromising Medicaid's program integrity.

On behalf of children with rare, serious, and complex medical conditions, we again urge your committees to advance and enact the Accelerating Kids' Access to Care Act this year. Thank you for your consideration. Should you have any questions regarding the statements above, please contact Corinne Alberts at calberts@rarediseases.org

[1] https://rarediseases.org/wp-content/uploads/2020/11/NRD-2088-Barriers-30-Yr-Survey-Report_FNL-2.pdf
[2] Medicaid's Role for Children with Special Health Care Needs: A Look at Eligibility, Services, and Spending. Kaiser Family Foundation (KFF). 2019. https://www.kff.org/medicaid/issue-brief/medicaids-role-for-children-withspecial-health-care-needs-a-look-at-eligibility-services-and-spending/. Accessed October 26, 2020.

Sincerely,

National Organization for Rare Disorders
Acromegaly Community, Inc.
Alpha-1 Foundation
Alport Syndrome Foundation
American Academy of Pediatrics
American Behcet's Disease Association (ABDA)
American Cancer Society Cancer Action Network
APFED (American Partnership for Eosinophilic Disorders)
APS Foundation of America, Inc
Association for Clinical Oncology
Association for Creatine Deficiencies
Association of Pediatric Hematology/Oncology Nurses
Avery's Hope
AXYS
Barth Syndrome Foundation
Bobby Jones Chiari & Syringomyelia Foundation
Born a Hero, Research Foundation
Canavan Foundation
CDH International
Charcot-Marie-Tooth Association
Children's Cancer Cause
Children's PKU Network
Chondrosarcoma CS Foundation, Inc.
Choroideremia Research Foundation
Chromosome Disorder Outreach Inc.
Coffin Lowry Syndrome
Congenital Hyperinsulinism International
Coriell Institute for Medical Research, Inc.
Cure CMD
Cure HHT
Cure SMA
Cystic Fibrosis Research institute
Dup15q Alliance
Epilepsy Foundation
Fabry Support & Information Group
FACES: The National Craniofacial Association
FOD Family Support Group
FOXG1 Research Foundation
Gaucher Community Alliance
Glut1 Deficiency Foundation
Gorlin Syndrome Alliance
HCU Network America
Hemophilia Federation of America
Hemophilia Foundation of Southern California
Hepatitis B Foundation
Histiocytosis Association, Inc.
Hypersomnia Foundation
International Autoimmune Encephalitis Society
International Foundation for Gastrointestinal Disorders
ISMRD
Jamal's Helping Hands
KBG Foundation
LGMD-1D DNAJB6 Foundation
LGS Foundation
Li-Fraumeni Syndrome Association
Malan Syndrome Foundation
Marshall's Mountain
M-CM Network
Mississippi Metabolics Foundation
MitoAction
MSUD Family Support Group
Muscular Dystrophy Association
National Ataxia Foundation
National Bone Marrow Transplant Link
National Brain Tumor Society
National MALS Foundation
National PKU Alliance
National PKU News
NBIA Disorders Association
NephCure Kidney International
NF2 BioSolutions
NW Rare Disease Coalition
Organic Acidemia Association
Pediatric Brain Tumor Foundation
Phelan-McDermid Syndrome Foundation
Pheo Para Alliance
Platelet Disorder Support Association
Pompe Warrior Foundation
Project 8p Foundation
PTEN Hamartoma Tumor Syndrome Foundation
Pull-thru Network, Inc
Rare Sisters Batten Foundation
Rare Trait Hope Fund
RASopathies Network USA

Reflex Sympathetic Dystrophy Syndrome Association
Ring14 USA
SATB2 Gene Foundation
SLC6A1 Connect
Spina Bifida Association
St. Baldrick's Foundation
St. Jude Children's Research Hospital
Stone Soup Group-Alaska
STXBP1 Foundation
TargetCancer Foundation
Team Telomere
The DESSH Foundation
The E.WE Foundation
The FPIES Foundation
The Global Foundation for Peroxisomal Disorders
The Jansens Foundation
The Leukemia & Lymphoma Society
The Life Raft Group
The RYR-1 Foundation
The Simon Foundation for Continence
TSC Alliance
United Porphyrias Association
VHL Alliance
VOR-A Voice of Reason
Wilhelm Foundation
Xia-Gibbs Society, Inc

CC: The Honorable Charles Grassley
The Honorable Michael Bennet
The Honorable Katherine Clark
The Honorable Jaime Herrera Beutler