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May 16, 2024

The Honorable Cathy McMorris Rodgers  
Chair  
Energy and Commerce Committee  
2125 Rayburn House Office Building  
Washington, DC 20515

The Honorable Frank Pallone  
Ranking Member  
Energy and Commerce Committee  
2322A Rayburn House Office Building  
Washington, DC 20515

The Honorable Brett Guthrie  
Chairman  
Energy and Commerce Committee  
2434 Rayburn House Office Building  
Washington, DC 20515

The Honorable Anna Eshoo  
Ranking Member  
Energy and Commerce Committee  
272 Cannon House Office Building  
Washington, DC 20515

Dear Chair Rodgers, Ranking Member Pallone, Chairman Guthrie, and Ranking Member Eshoo:

On behalf of the Children's Hospital Association (CHA), representing over 200 children's hospitals nationwide, we are grateful that the Health Subcommittee is marking up a number of bills today that will benefit the health of America's children. We strongly support the advancement of legislative proposals to address critical gaps in pediatric medical research and treatment, especially the Accelerating Kids' Access to Care Act.

Children and families affected by rare diseases and other chronic or complex conditions often face barriers to accessing care that is timely and coordinated given the range of specialists and subspecialists that may be involved in their care and the regionalized nature of pediatric specialty care. It is not uncommon for children, particularly those with medical complexity or specialized health care needs, to travel out of their community, state, or region to receive the care that can only be provided at a children's hospital. For these children, a children's hospital is the focal point of care, as pediatric specialists are frequently needed to provide expertise in treating their rare and complex clinical conditions. In recognizing these immense challenges, we emphasize the importance of legislative solutions that address the barriers faced by children and families seeking specialized care, particularly those compelled to travel for treatment at children's hospitals.

**CHA strongly supports the Accelerating Kids' Access to Care Act (H.R. 4758)** sponsored by Representatives Trahan and Miller-Meeks and appreciates the committee including it in this markup. The strongly bicameral, bipartisan bill will improve children's access to needed out-of-state care by streamlining the burdensome and time-consuming Medicaid provider screening and enrollment process. We look forward to continuing to work with the committee to advance.

Medicaid plays a pivotal role for children, providing coverage for about half of the nation's children, including 3 million children in military-connected families, and essential wrap-around care to many children with complex needs who have private insurance. Children on Medicaid often require out-of-state care, particularly those with medically

*Champions for Children's Health*

complex conditions like cancer or other rare diseases treated in children's hospitals. Today, children on Medicaid needing care outside their home states often experience delays due to the cumbersome provider enrollment process. By facilitating and streamlining this enrollment, the bill ensures that pediatric patients with rare diseases have timely access to specialized care, irrespective of their location. We appreciate the commitment of the sponsors to improve the overall well-being of pediatric patients, including those served by children's hospitals across the country. We appreciate that the bill is included in today's subcommittee markup and look forward to supporting its continued movement through the legislative process to ensure children get the care they need when and where they need it.

Children are not little adults. They are constantly growing and developing, and their health care needs, the delivery system to meet those needs, and support systems (e.g., schools, childcare settings) are different from those of adults. Pediatric care requires specialized medications, therapeutics, and equipment, as well as extra time, monitoring, and specially trained health care providers who are compassionate and understand kids of all ages and from all backgrounds. It is critical that pediatric-focused innovations for rare diseases, including childhood cancers, are developed, reimbursed, and available to meet children's unique needs.

Children's hospitals dedicate significant efforts to advancing knowledge and improving access to essential treatments for children facing childhood cancers and rare diseases through studies, trials, and innovations. Unfortunately, the promising outcomes of their work often face obstacles in becoming readily available bedside treatments, as manufacturers' and payers' policies can hinder children's access to care. Recognizing the urgency, children's hospitals, as hubs for pediatric medical research, emphasize the need to address impediments and incentivize the development, study, dissemination, and accessibility of these crucial treatments for children with rare diseases. In appreciation of the subcommittee's steadfast commitment to addressing critical issues affecting the well-being of the nation's children and families, CHA also supports the following bills slated for consideration during today's markup:

**H.R. 3433 – Give Kids A Chance Act:** CHA enthusiastically supports H.R. 3433, Give Kids A Chance Act, sponsored by Representatives McCaul and Eshoo. This legislation grants the FDA the authority to guide drug companies in conducting targeted clinical trials for combinations of pediatric cancer treatments. Currently, most pediatric cancer trials focus on children with advanced cancer, and the FDA is limited to directing trials for one drug given by itself. However, one-drug treatments are very unlikely to help children with advanced cancers. In fact, almost all curative treatments for cancer in adults and children are with drug combinations. That is why it is so important to explore drug combinations in pediatric as well as adult patients. The bill marks a significant step in advancing pediatric oncology research, providing hope to children and families grappling with these devastating diseases. The sponsors' dedication to prioritizing research and development for pediatric cancer treatments is commendable and aligns seamlessly with our mission to enhance the overall well-being of children nationwide.

**H.R. 7384 – Creating Hope Reauthorization Act:** CHA proudly supports H.R. 7384, Creating Hope Reauthorization Act led by Representatives McCaul, Eshoo, Bilirakis, Barragán, Trahan, and Burgess. This bipartisan legislation extends the authority to issue priority review vouchers, providing crucial incentives for the development of treatments targeting rare pediatric diseases. Since this program's inception, these vouchers have played a pivotal role in accelerating pharmaceutical innovation and expediting the approval process for therapies that address the unique health care needs of children with rare diseases. By extending this authority until September 30, 2030, this legislation ensures a sustained commitment to advancing the treatment of rare pediatric medical

conditions. We commend the bipartisan efforts behind this bill, and as supporters of the original legislation, we urge the committee to advance the Creating Hope Reauthorization Act, which continues to contribute to advancements in pediatric rare disease treatments.

These bills collectively address crucial gaps in pediatric medical research and treatment, demonstrating a steadfast commitment to improving the accessibility of lifesaving health care for children. From streamlining Medicaid processes to enhancing pediatric cancer research, each bill addresses unique challenges faced by pediatric patients. Moreover, the extension of priority review vouchers underscores a vital measure in incentivizing treatments for rare pediatric diseases, thereby contributing to advancements in pediatric rare disease treatments and the overall health outcomes of our nation's youngest citizens.

As CHA stands in strong support of these legislative proposals, we are confident that the subcommittee's consideration will lead to positive outcomes for pediatric patients and their families. Thank you for your continued bipartisan efforts to champion policies that positively impact the health and well-being of children. If you have any questions, please contact Aimee Ossman at [Aimee.Ossman@childrenshospitals.org](mailto:Aimee.Ossman@childrenshospitals.org).

Sincerely,

A handwritten signature in black ink, appearing to read 'Leah Evangelista', written in a cursive style.

Leah Evangelista  
Chief Public Affairs Officer  
Children's Hospital Association

CC: Reps. Barragán, Bilirakis, Burgess, McCaul, Miller-Meeks, and Trahan