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April 23, 2024

Chairman Bernard Sanders  
Committee on Health Education Labor and Pensions  
United States Senate  
428 Senate Dirksen Office Building  
Washington, DC, 20510

Dear Chairman Sanders:

On behalf of the nation's 200+ children's hospitals and the patients and families we serve, thank you for the opportunity to respond to your draft legislative proposal on Long COVID. We appreciate your efforts to ensure the nation is better prepared to understand the risks and potential treatments for Long COVID and encourage you to prioritize the distinct needs of children, who represent 22% of the total U.S. population.<sup>1</sup> We urge Congress to invest in pediatric-focused research on Long COVID, and to advance the development of targeted strategies and guidance that can ensure timely access to pediatric-appropriate treatments.

**We strongly support efforts to advance pediatric Long COVID research to educate health care providers on the unique impacts on children, and to help ensure that our nation's children have safe and effective treatments and care.** Nearly 6 million children and adolescents in the country are affected by Long COVID and because so little is known about the wide variety of symptoms that affect these pediatric patients over time,<sup>2</sup> diagnosis remains difficult. Long COVID symptoms can be very disruptive for pediatric patients and their families, negatively impacting normal activity in school, sports or other hobbies, leading to harmful consequences for their long-term well-being. Enhancing pediatric-focused medical research for treating Long COVID in children is essential for improving their life trajectory.

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 are able to treat kids of all ages and from all backgrounds. **It is critical that pediatric-focused innovations for Long COVID are developed, appropriately reimbursed, and available to meet children's unique needs.**

Children's hospitals are dedicated to the health and well-being of our nation's children. Children's hospitals advance child health through innovations in the quality, cost, and care delivery—regardless of payer—and serve as a vital safety net for uninsured, underinsured, and publicly insured children. We serve the majority of children with serious, chronic and complex conditions, providing 95% of all pediatric cancer care, and most children in need of major surgery.

Children's hospitals are working tirelessly on studies, trials and innovations that advance knowledge and access to Long COVID treatments for children of all ages, including through a number of specialized pediatric COVID clinics. For example, some children's hospitals participate in the National Institutes of Health (NIH) Researching COVID to Enhance Recovery (RECOVER) Initiative that follows children and young adults from birth through age 25 for up to four years and collects data on the severity of disease, clinical impact, and the effects of vaccination and treatment. Another children's hospital works

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<sup>1</sup> [U.S. Census Bureau QuickFacts: United States](#)

<sup>2</sup> [CHLA Researchers and Their Collaborators in RECOVER Initiative Publish Summary of Long COVID Symptoms in Children | Children's Hospital Los Angeles](#)

jointly with the NIH on a pediatric COVID outcomes study where one thousand children are evaluated for three years following enrollment to determine long term effects of a COVID infection.

Below please find our detailed responses to specific provisions in the legislative draft.

### **Enhance the Long COVID Research Program at the NIH**

We are pleased that this draft prioritizes addressing the long-term health impacts of COVID through a centralized, coordinating structure for the majority of Long COVID research and clinical activities at the NIH. To best support the advancement of pediatric Long COVID research and treatment, it is essential to build on the foundation of the current work at NIH. The RECOVER initiative at NIH, which has enrolled more than 20,000 patients, including pediatric patients, into cohort studies is funding critical research while facilitating data sharing between grantees, which include children's hospitals. As Congress works to bolster Long COVID research at NIH, we recommend including clear directives to ensure a significant focus on pediatric care and expertise. Any new research initiatives on Long COVID must address the unique physical and mental health, as well as the developmental needs of children.

While the clinical presentation of Long COVID in children has some overlap with that of adults, distinct features exist in pediatric patients. For example, studies have shown that children are more likely than adults to develop post-COVID conditions following asymptomatic infection.<sup>3</sup> Long COVID in children can have other unique features, such as myocarditis, abnormal liver enzymes, hair loss, and skin rashes. Additionally, Long COVID symptoms, such as fatigue, brain fog, and chronic pain, can have psychological implications and affect social emotional development, especially when children are unable to participate in their usual educational and social activities.

### **Implement Policies to Expedite Long COVID Research**

We urge Congress to ensure the unique needs of children are considered and prioritized in any proposal to expedite the grant making process for Long COVID research. In particular, it is essential that pediatric experts with an understanding of pediatric-specific health and health care challenges are included in any initiatives, including the review process to prioritize grant proposals, to ensure that children's needs are addressed.

Children of all ages should be included in clinical research on Long COVID. Children are a unique population with distinct developmental and physiological differences, and unintended harm could occur if research studies are limited to adults. Studies of medical interventions for pediatric Long COVID patients must reflect children's physical and mental health needs throughout their development, while also taking into consideration the specialized needs of medically complex children. Long COVID risk appears to be higher in children with medical complexity and those younger than five years old.<sup>4</sup>

In addition, while it is important to initiate grant prioritization in a timely manner since it can lead to faster turnaround in treatments, as the proposal suggests, it is also critical for NIH to fund studies of the longer-term effects and outcomes for individuals experiencing Long COVID, especially children who might experience lasting impacts on their development. Similarly, while pharmaceutical interventions are a priority, non-pharmacological interventions may be equally important for the management of chronic symptoms in children, particularly fatigue, brain fog, lack of concentration, or headaches which have been shown to respond to psychological interventions in other contexts.

Furthermore, we encourage you to seek technical assistance from NIH to better understand how they are currently making prioritization decisions specific to pediatrics within the RECOVER Initiative, and their on-going data sharing efforts. Decisions on the prioritization grant of proposals, must consider multiple factors, including what research is already underway, the gaps that experts identify in the current research base, as well as the emerging trends in Long COVID challenges faced by

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<sup>3</sup> [What is long-haul COVID and how common is it? - Children's National \(childrensnational.org\)](https://www.childrensnational.org/what-is-long-haul-covid-and-how-common-is-it/)

<sup>4</sup> [Study Finds Long Covid-19 in Children Less Common Than in Adults. Children's Hospital Colorado. 2022](https://www.childrenshospital.com/press-releases/2022/02/study-finds-long-covid-19-in-children-less-common-than-in-adults)

patients, including pediatric patients. Soliciting feedback directly from the lead investigators, particularly in the children's hospitals that are conducting this research, will help identify pediatric research gaps, as well as potential challenges and delays that might be addressed or improved in any new initiatives.

We also support the recommendation in this proposal that some funds be utilized to examine how Long COVID programs and interventions reach the public, and any potential accessibility issues that may arise. These evaluations must examine how children and families access care for Long COVID, and any barriers families face with timely access and coverage for treatment. It is not uncommon for children, particularly those with medical complexity or specialized health care needs, to travel out of their community, region or state to receive the care that can only be provided at a children's hospital. To that end, we encourage federal agencies to work together to conduct a comprehensive study of our health care system's response to Long COVID, identifying access barriers for both children and adults as well as strategies to mitigate health disparities.

### **Strengthen Data Sharing Systems and Include Pediatric Patients**

We appreciate this proposal's recognition of the need for a comprehensive and inclusive data collection plan to understand the risk factors, common symptoms, and effective treatments for Long COVID. We recommend that the proposal for robust data collection build on the expertise and ongoing data sharing efforts developed through NIH's own RECOVER Initiative. As you continue to develop this proposal, we encourage further clarity on information collected from pediatric patients in NIH studies and recommend privacy protections for all participants.

Providing additional clarity on how pediatric patient data will be used and shared will be critical in gaining the trust of parents considering whether to enroll their children in a data hub. To that end, **we support S. 2560, the *Long COVID Support Act*, introduced by Senator Tim Kaine, D-Va., and Senator Todd Young, R-Ind., which includes a voluntary patient registry with robust privacy protections for participants.** Furthermore, recruitment to participate in such a registry must also include outreach to pediatric patients, their parents and caregivers, and individuals from communities disproportionately impacted by COVID-19. The inclusion of pediatric participants is necessary to facilitate the development of pediatric specific interventions and treatments for Long COVID, but also is vital to enable the study of longer-term effects of Long COVID on children and youth as they age into adulthood.

In addition, Congress should work with the federal biomedical research enterprise to develop a requisite data collection and reporting structure that would allow for an accurate picture of how many children are enrolled in Long COVID clinical studies and trials and where gaps exist. This data should be broken down by pediatric subgroup (e.g., neonates, infants, children, adolescents, etc.) to provide a more complete picture of which populations of children are underrepresented.

### **Ensure Pediatric Representation on Research Advisory Board**

As Congress considers the composition of the Long COVID research advisory board, we urge you to include pediatric health care providers and researchers with expertise in treating Long COVID in children. A variety of pediatric-specific medical specialties must be represented on the advisory board, as the treatment of Long COVID often involves more than one specialized provider, such as neurology, pulmonology, and psychiatry. It is critical that any research on preventing, treating, and understanding the mechanisms of Long COVID include medical interventions for children since there are so many crucial unknowns around the causes of pediatric Long COVID.

In addition, we strongly recommend that the advisory board include mental and behavioral health professionals with pediatric expertise. Treating Long COVID in children requires a focus on ways to alleviate its impacts on their social, emotional and cognitive development in addition to its physical impacts. Pediatric Long COVID patients who suffer from severe fatigue, difficulty with focus, or chronic pain may struggle to attend school and participate in their usual recreational activities. We know that social isolation, and lack of engagement in education and recreational settings can negatively impact children and adolescents' mental health and long-term well-being.

Furthermore, we encourage the advisory board to include pediatric-specific research as part of the draft's proposal to study the effectiveness of treating Long COVID with drugs that are not yet FDA-approved. In particular, the board should pursue the

development of targeted strategies and guidance that can ensure timely access to sufficient pediatric-appropriate medications for Long COVID therapies. Additionally, we recommend that resources be directed to research on pediatric dosing and formulations and that delivery mechanisms be available and ready for rapid deployment.

### **Design a Public Education and Outreach Campaign to Reach Families**

We are pleased that the draft proposes to task the CDC, in coordination with the NIH, to develop a public education campaign on Long COVID that will include information on children. We ask Congress to work with federal, state, and local health entities to consider the appropriate community supports to reach pediatric patients, their families, and caregivers.

Key external partners, such as children's hospitals, can help disseminate and amplify key Long COVID messages by being trusted community voices. In addition to children's hospitals, it's especially critical that daycare centers, schools, community pediatricians, pediatric specialists, child mental health providers, pediatric pharmacists, pediatric physical and occupational therapists, pediatric nutritionists, and pediatric medical suppliers are considered partners in education and outreach efforts. Partners with pediatric expertise will also help to ensure that the appropriate resources are provided through this campaign, detailing the unique services and support designed for children and families that they need.

### **Ensure Provider Education Reaches Pediatric Providers**

We urge Congress to include pediatric health care providers and allied health professionals in continuing education efforts to address the unique health care needs of children who experience Long COVID. Their involvement is essential to building consensus on clinical terms for Long COVID studies focused on children and to sharing the state of the science in this field.

As we mention above, pediatric care requires specially trained health care providers who are compassionate and understand kids of all ages and all backgrounds. Our hospitals employ a variety of pediatric specialists when treating Long COVID, including pediatric neurologists, therapists, behavioral psychologists, social workers, and nurses, among others.<sup>5</sup> Specialists in other clinical disciplines help create an individualized treatment plan for each patient and this close collaboration helps ensure coordination of care and convenience for pediatric patients and their families.

## **Other Pediatric Considerations**

### **Reimbursement**

We urge Congress to explore ways to help ensure that children's access to Long COVID therapies is not impeded by burdensome reimbursement processes. In some instances, essential care for Long COVID has been delayed for children because of onerous utilization review requirements.

As we mention above, our children's hospitals work on impactful studies, trials and innovations that advance knowledge and access to needed COVID-19 treatments for children of all ages. However, their promising work is not always translated into accessible bedside treatments due to manufacturers' and payers' policies that can impede children's access to these very treatments. Utilization management controls can be particularly problematic when the FDA has approved a therapy for a limited age range. A child may age out of the label approval while waiting for the payer reimbursement to be approved or payment procedures to be developed for a newer therapy.

In addition, payers are also increasingly placing additional clinical monitoring requirements on treatments, delaying the approval of their use. Children's hospitals have had to hire additional FTEs to simply handle the approval and acquisition management for therapies and it is not uncommon for a hospital to spend hours navigating prior approval processes and

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<sup>5</sup> [Pediatric Post-COVID-19 Rehabilitation Clinic \(kennedykrieger.org\)](https://www.kennedykrieger.org/pediatric-post-covid-19-rehabilitation-clinic)

submitting multiple appeals of denials. At the end of this long, time and resource-intensive process, the payer will often approve the use of the therapy. Unfortunately, children and their families are caught in the middle resulting in care delays.

Thank you again for the opportunity to provide feedback. We look forward to working with you to ensure the needs of children are met when addressing Long COVID research and education efforts. Please contact Cynthia Whitney at [Cynthia.Whitney@childrenshospitals.org](mailto:Cynthia.Whitney@childrenshospitals.org), (202) 753-5328, or Natalie Torentinos at [Natalie.Torentinos@childrenshospitals.org](mailto:Natalie.Torentinos@childrenshospitals.org), (202) 753-5372 should you need more information.

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