



Solve M.E.

From: Emily Taylor
President & CEO
Solve ME/CFS Initiative (Solve M.E.)

To: Senator Bernie Sanders & the HELP Committee
Email: LongCOVIDComments@help.senate.gov

April 23, 2024

Subject: Proposed Long COVID Moonshot Legislation

Dear Senator Sanders and the HELP Committee,

I write to you today as the CEO of Solve M.E., an organization dedicated to supporting those afflicted by Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), Long Covid, and other Infection-Associated Chronic Conditions and Illnesses (IACCI), but also as the daughter of a person with ME/CFS and the sister of a person with Long Covid. Additionally, I am joined by the hundreds of co-signed organizations and individuals who are concerned by the narrow scope of the proposed Long Covid Moonshot.

While we commend this initiative and your foresight in proposing the desperately needed Long Covid Moonshot legislation that could make a huge impact on those in our Long Covid community, we are concerned and heartbroken that, [as written](#), this initiative leaves behind millions of vulnerable and suffering Americans with Long Covid-associated conditions, but who experienced a non-Covid triggering event or gradual onset. It's estimated that **people who experience non-COVID triggers to these conditions make up about 20-25% of the IACCI community.**

At the same time, we want to acknowledge that this proposed legislation is desperately needed for the Long Covid community, and that passing it would have a huge impact on so many within our patient community.

While we share your commitment to advancing our understanding of IACCI, we must underscore a critical oversight in the current Long Covid moonshot proposal. As outlined in our recent white paper, "[A Home for Infection-Associated Chronic Conditions and Illnesses \(IACCI\) at NIH](#)," IACCI - including ME/CFS, Postural Orthostatic Tachycardia Syndrome (POTS), Dysautonomia, Fibromyalgia, Gulf War Illness, Lyme Disease, and Mast Cell Activation Syndrome (MCAS) - **affect over 73 million Americans.** These conditions, often complex and multisystemic, have long been under-researched and underfunded, a situation exacerbated by the COVID-19 pandemic which has brought millions of new patients to the realm of IACCI, including Long Covid.

Our white paper proposes very similar policy solutions as the Long Covid Moonshot, namely the establishment of a dedicated research entity within NIH, ~~with the authority to direct funding and coordinate research across different disciplines and NIH institutes.~~ Such an entity would significantly enhance our capacity to engage in the patient-centered, multidisciplinary research necessary to tackle the complexities of



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IACCIs. ***However, such a solution that addresses one group of patients while abandoning the others is hurtful and harmful to a community already ignored for decades.***

We respectfully urge you to consider adding the simple language “**and associated conditions**” in order to ensure the inclusion of IACCIs in the scope of the Long Covid Moonshot legislation. By doing so, we can ensure that we do not leave behind the millions of Americans who were suffering before the pandemic or those with a related, non-COVID triggered, experience.

COVID will not be the last pandemic and such a limited COVID-specific scope fails to address the true medical needs shared by all people with IACCIs. **Our shared goal is to #StopTheLongHaul for all individuals living with infection-association chronic conditions and illnesses, regardless of their initial trigger.**

Please find further details and our policy recommendations in our white paper available at https://solvecfs.org/wp-content/uploads/2024/04/NIH_IACCI_Entity_Paper_FINAL.pdf.

Thank you for your attention to this critical matter. We look forward to the possibility of working together to ensure a comprehensive approach to understanding and combating all infection associated chronic conditions and illnesses.

Sincerely,

Emily Taylor

President and CEO

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