PATIENT-LED RESEARCH COLLABORATIVE

Dear Chairman Sanders,

We commend and thank you for your proposal for a Long COVID Moonshot. This proposal responds to the calls from patient advocacy groups, clinicians, and researchers to urgently address fund research into Long COVID at the level of $1B/year for 10 years, including our co-founder's comment in *Nature* with Dr. Michael Peluso.

We are thrilled to see that the proposal includes key components that are necessary to make this research successful. We are particularly pleased to see the focus on clinical trials, specifically on non-behavioral treatments and including repurposed drugs; to see the prioritization of grants that have letters of support from patient organizations with history of Long COVID advocacy; and to see that the director is required to have experience with other infection-associated chronic conditions (IACCs) as well. We also appreciate the requirement of the NIH to provide an explanation on denials and decisions within 120 days and requiring grant processes to have a deadline of at least 4 weeks, to allow for well-thought-out proposals as well as proposals from people with Long COVID and other energy-limiting illnesses. We also appreciate that the Research Program is separate from RECOVER and that the funding would not go through or be directed towards the RECOVER Initiative, and hope that the bill text makes that explicit.

We have several recommendations for improvements to ensure that the funding will be used as efficiently as possible. This is based on our experience working on the RECOVER Initiative as well as funding and conducting our own high-quality research on Long COVID.

1. We recommend replacing "COVID-onset conditions" with "common new-onset conditions like dysautonomia, mast cell activation syndrome, and myalgic encephalomyelitis." This will enable the flexibility to allow for non-trigger-specific studies which will not only help improve our understanding of the most common diagnoses of Long COVID, but also will help the millions of patients who developed these prior to COVID and help us prepare for future pandemics.

2. We recommend explicitly requesting comparisons of COVID-induced versus non-COVID induced ME/CFS, dysautonomia (including POTS), MCAS, and potentially other conditions commonly onset as part of Long COVID. At minimum, this could take the form of prioritizing, preferencing, and/or encouraging grant applications that do this (where appropriate), and having specific calls for applications around these efforts.

3. We recommend requiring at least one expert in the aforementioned common new-onset conditions be involved as a reviewer on each grant application panel and for reviewers to receive training on research on Long COVID as well as common new-onset conditions, as not doing so has resulted in harmful or unhelpful studies and trials to be funded.

4. We recommend requiring that if a candidate for the Director of the Long COVID Research Program directed a research program on Long COVID, that they must also have biomedical research experience with at least one infection-associated chronic condition other than Long COVID, including HIV/AIDS.

5. We recommend that the Public Education and Outreach Campaign, as well as the Provider Education, be moved to agencies in HHS other than NIH, as NIH historically has not done this type of work. However, we'd encourage the Research Program to be consulted on these efforts.

6. We commend your focus on research into Long COVID in this proposal, as we believe that a large and sustained investment in biomedical research and clinical trials is necessary to adequately improve outcomes for people with Long COVID. **We recommend a full $10B over 10 years be provided to NIH for biomedical research** (currently it is spread across the other important areas of provider and public education)**.**

7. If you seek to address additional areas of the crisis that are important to be in parallel to research to both help people now and ensure research results translate to improved outcomes, then on top of providing $10B to NIH for research, we recommend adequate funding to various HHS agencies including CDC (including continuation of the Household Pulse Survey), ARPA-H, AHRQ, IHS, FDA, OASH, SAMHSA, HRSA, ACL, and CMS, as well as Veterans Administration, Department of Defense, Department of Labor, Department of Education, and Social Security Administration.

Thank you again for your leadership on this issue and for the opportunity to provide input on this important proposal which will help the millions impacted by Long COVID and associated conditions.

Sincerely,
Patient-Led Research Collaborative