



May 17, 2021

Francis S. Collins, M.D., Ph.D.
Director, National Institutes of Health (NIH)

Dear Dr. Collins,

Attached is a [copy of the letter](#) that #MEAction sent to the House Committee on Energy and Commerce, Subcommittee on Health. In that letter, we urge the Subcommittee to use their oversight role to best accelerate Long COVID research. Specifically, we call on the Subcommittee to make certain that the NIH:

1. ensures effective integration of ME/CFS knowledge, experience, and cohorts into the PASC Initiative, and
2. expedites clinical treatment trials of repurposed drugs used in ME/CFS for those Long COVID patients whose long-term symptoms overlap with ME/CFS and are not the result of hospitalization or detectable organ damage.

#MEAction joins [Body Politic](#), [The Long COVID Alliance](#), the [Community Advisory Committee for the NIH ME/CFS Collaborative Research Centers](#) and others in urging NIH to do more to prioritize integration of ME/CFS into the PASC Initiative.

Furthermore, this subset of Long COVID patients—those whose long-term symptoms overlap with ME/CFS and are not the result of hospitalization or detectable organ damage—deserves urgent clinical treatment trials and must not be forced to wait years for the elucidation of the disease mechanisms, subtypes, and biomarkers. **Interventions are available today that could reduce their disease burden. Moreover, early intervention has the greatest chance of improving long-term health outcomes.**

Your testimony before the Subcommittee and the recently updated [NIH-Wide Strategic Plan for COVID-19 Research](#) showed gaps in addressing these two points. **In particular, they fail to explicitly describe and leverage both research and clinical learnings about ME/CFS in order to accelerate delivery of treatments for these Long COVID patients.**

Because NIH has not effectively accelerated ME/CFS research, many people with Long COVID have been left without research-informed treatments or adequate care. We urge you to use this unique research opportunity to ensure no one with COVID-related, chronic, complex disease is left behind.

Sincerely,

Ben HsuBorger
U.S. Advocacy Director, #MEAction

CC:

Amy P. Patterson, M.D., Deputy Director for Clinical Research and Strategic Initiatives, NHLBI
Anthony S. Fauci, M.D., Director of National Institute of Allergy and Infectious Diseases (NIAID)
Walter J. Koroshetz, M.D., Director of National Institute of Neurological Disorders and Stroke (NINDS)

Nina Schor, M.D., Ph.D., Deputy Director, NINDS

Steven M. Holland, M.D., Director, Division of Intramural Research NIAID

Avindra Nath, M.D., Clinical Director, Division of Intramural Research NINDS

Matthew J. Fenton, Ph.D. Director, Division of Extramural Activities NIAID

Vicky Whittemore, Ph.D. Program Director NINDS

Joseph J. Breen, Ph.D., Section Chief NIAID