May 14, 2021

Frank Pallone
Chairman
House Committee on Energy & Commerce

Cathy McMorris Rodgers
Ranking Member
House Committee on Energy & Commerce

Anna G. Eshoo
Chairwoman
House Committee on Energy & Commerce
Subcommittee on Health

Brett Guthrie
Ranking Member
House Committee on Energy & Commerce
Subcommittee on Health

Dear Chairman Pallone, Ranking Member McMorris-Rodgers, Subcommittee Chairwoman Eshoo and Subcommittee Ranking Member Guthrie,

The Myalgic Encephalomyelitis Action Network (#MEAction) thanks the Committee for its hearing on "The Long Haul: Forging a Path through the Lingering Effects of COVID-19." Since the majority of people with Long COVID are reporting core symptoms that align with ME/CFS,[1] it is critical the Committee ensure people living with Long COVID and ME/CFS receive the treatments they need in an expedited time frame. **We urge the Committee to hold the NIH accountable to better integrate ME/CFS knowledge, experience and cohorts into its PASC Initiative research strategy and initiate Long COVID clinical treatment trials immediately.**

ME/CFS, like Long COVID, is known to often follow a viral infection and is a serious, debilitating condition.[2] Researchers estimate that at least 10% of COVID-19 patients will develop ME/CFS.[3] This will result in an estimated 3 million additional cases of ME/CFS, more than doubling the current prevalence. Given that as many as 75% of people with ME/CFS can no longer work,[4] this will significantly harm the American economy.[5]

Unfortunately, as a result of decades of underinvestment in research,[6] there are no established biomarkers, no commercially available diagnostic tests, and no FDA-approved treatments for ME/CFS and other post-viral illnesses. But despite the lack of research funding, medical neglect, and stigma, research into ME/CFS and other post-viral illnesses has advanced our understanding of the pathologies that follow infections. This critical knowledge base can be used to accelerate Long COVID solutions. Early treatment intervention has the best chance of changing the long-term illness trajectory for these patients.[7]

As the Long COVID patient group Body Politic has pointed out in their open letter to the NIH, ME/CFS researchers "need to be at the forefront of the Long COVID research agenda, or we risk delaying our understanding and treatment of this illness… While there are a variety of post-COVID outcomes worth investigating, patients with long-term multi-systemic symptoms without clear drivers, biomarkers, or diagnostics face a unique set of challenges that requires immediate attention."[8]

Integrate ME/CFS into NIH PASC Strategy

Body Politic, The Long COVID Alliance, and the Community Advisory Committee for the NIH ME/CFS Collaborative Research Centers have all urged the NIH to explicitly integrate ME/CFS into the PASC Initiative strategy,[9] but the current PASC strategy fails to capitalize on what has been learned in ME/CFS research and clinical care.[10]

To ensure effective integration of ME/CFS into the NIH PASC strategy, we call on the NIH to prioritize funding for Long COVID studies that:

- build on prior ME/CFS and related chronic illness research,
- include ME/CFS researchers, clinicians, and patients in PASC strategic planning,
- utilize post-infectious ME/CFS patients in comparison cohorts, and
- accurately identify and track ME/CFS symptoms and diagnosis in Long COVID cohorts over appropriate study durations

Inadequate integration of decades-long ME/CFS research, clinical expertise, and infrastructure will result in wasted resources and delayed delivery of much needed treatments to patients suffering with Long COVID.

Expedite Long COVID Clinical Treatment Trials of Repurposed Drugs Used in ME/CFS

While the NIH has expedited clinical treatment trials for acute COVID, it has not done so for Long COVID.[11] The NIH should expedite Long COVID treatment trials starting with repurposed drugs used to treat ME/CFS.[12] These treatments are highly relevant for Long COVID patients whose symptoms overlap with ME/CFS and other common comorbidities.

If Long COVID patients with hard-to-diagnose long-term symptoms that are not the result of hospitalization or easily detectable organ damage need to await elucidation of the disease mechanisms, subtypes, and biomarkers, it will take years to deliver needed treatments; this will preclude intervention for Long COVID patients at the critical early stage of illness. Delaying treatment trials also ignores the opportunity to translate clinical learning and experience into knowledge about disease mechanisms. We must take this opportunity to ameliorate symptom severity, improve quality of life, and potentially support recovery from Long COVID by intervening early in the course of the illness.

As Long COVID patient Lisa McCorkell testified at the hearing, “Post-viral illnesses are not new. The cracks that Long COVID has exposed in our system are not new. It’s just that now more people are paying attention.” **We urge the Committee to use its oversight role to hold the NIH accountable to integrate ME/CFS knowledge, experience, and cohorts into its PASC Initiative and to expedite Long COVID clinical treatment trials with repurposed drugs used in ME/CFS.**

Sincerely,

Ben HsuBorger
U.S. Advocacy Director
#MEAction

References

1. https://www.medrxiv.org/content/10.1101/2020.12.24.20248802v2

2. The National Academy of Medicine found patients with ME/CFS to be “more functionally impaired” than those with other disabling illnesses, including type 2 diabetes, congestive heart failure, multiple sclerosis, and end-stage renal disease. At least 25% are house- or bed-bound as a result of their symptoms. http://www.nap.edu/read/19012/page/31

3. https://www.frontiersin.org/articles/10.3389/fmed.2020.606824/full

4. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5565838/

5. The pre-pandemic annual cost of ME/CFS is estimated to be $36-51 billion. https://www.tandfonline.com/doi/full/10.1080/21641846.2021.1878716; https://pubmed.ncbi.nlm.nih.gov/25695122/

6. NIH funding of ME/CFS is roughly 7% of what would be commensurate with the disease burden. https://content.iospress.com/articles/work/wor203173

7. Hornig, Mady, et al. “Distinct Plasma Immune Signatures in ME/CFS Are Present Early in the Course of Illness.” Science Advances, vol. 1, no. 1, Feb. 2015, p. e1400121. DOI.org (Crossref), doi:10.1126/sciadv.1400121 https://advances.sciencemag.org/content/1/1/e1400121

8. https://www.wearebodypolitic.com/bodytype/2021/4/22/open-letter-to-nih

9. https://www.wearebodypolitic.com/bodytype/2021/4/22/open-letter-to-nih; https://cfsformecfs.org/2021/04/19/a-letter-from-our-community-advisory-committee/ https://longcovidalliance.org/wp-content/uploads/2021/02/NIH-Long-COVID-Alliance-NIH-Recommendations-Letter-Final-with-signers.pdf;

10. Not only do the current PASC Initiative Research Opportunity Announcements (OTA-21-015A, OTA-21-015B) do nothing to include ME/CFS as a topic of special interest for researchers to explore, they do not include a single reference to ME/CFS even where it is obviously called for and where other chronic conditions are listed.

11. The NIH-wide strategic plan for COVID-19 research has a strong focus on vaccines, preventions, and treatment of acute illness. It includes Long COVID as well but it does not discuss treatment trials for those Long COVID patients who do not have evidence of organ/tissue damage, It also does not discuss the importance of leveraging the knowledge and experience gained from ME/CFS research and clinical care, https://covid19.nih.gov/sites/default/files/2021-05/NIH-Wide-COVID-19-StratPlan_2021_508.pdf

12. Clinician experts in treating ME/CFS and other post-viral illnesses have pioneered the repurposing of drugs for these illnesses, several of which have already been used for Long COVID. This includes treatments for comorbidities such as mast cell activation syndrome (MCAS) and postural orthostatic tachycardia syndrome (POTS), which have been reported in Long COVID. https://mecfscliniciancoalition.org/Treatment-Recs-MECFS-Clinician-Coalition-V1