



March 1, 2022

The Honorable Patrick Leahy
Chair
Senate Committee on Appropriations
437 Russell Senate Office Building
Washington, DC 20510

The Honorable Richard Shelby
Vice Chair
Senate Committee on Appropriations
304 Russell Senate Office Building
Washington, DC 20510

The Honorable Rosa DeLauro
Chair
House Committee on Appropriations
2413 Rayburn House Office Building
Washington, DC 20515

The Honorable Kay Granger
Ranking Member
House Committee on Appropriations
1026 Longworth House Office Building
Washington, DC 20515

Dear Senators Leahy and Shelby and Representatives DeLauro and Granger,

Thank you for your continuous efforts to finalize a fiscal year (FY) 2022 budget package and for your hard work resolving significant differences in doing so. Today, we call your attention to a harmful seven-month funding gap for the ME/CFS research centers funded by the National Institutes of Health (NIH) and urge you to pass a budget swiftly to prevent other programs from being impacted by budget uncertainty – an issue that has become particularly pressing given the direct link between ME/CFS and Long COVID.

As you may know, Myalgic Encephalomyelitis (ME), often referred to as chronic fatigue syndrome (CFS) or ME/CFS, is a serious, complex, and severely debilitating disease. The exact cause or causes are unknown, but an infection is attributed as the trigger for the disease in a large majority — 72 percent — of the casesⁱ. Symptoms affect several body systems and include post-exertional malaise,ⁱⁱ unrefreshing sleep, weakness, muscle and joint pain, impaired memory or mental concentration, tender lymph nodes, sore throat, headaches, and insomnia. Diagnosis of ME/CFS is challenging as no specific tests for the disease have been established, and if diagnosis is made possible, patients face further difficulty in treatment as no FDA-approved therapies exist. Importantly a recent studyⁱⁱⁱ of Long COVID patients three months after infection *found that nearly half met the criteria for ME/CFS*.^{iv} With approximately 30% of COVID cases leading to Long COVID, that would put us at more than 11 million new ME/CFS cases in the US due to COVID-19.

In 2017, the NIH funded three Collaborative Research Centers (CRCs) for ME/CFS as well as a Data Management Coordination Center — these ME/CFS research hubs are critical NIH investments. The centers are central to the nationwide repository of knowledge about ME/CFS and post-infection illness and help facilitate critical academic, research, and medical infrastructure knowledge on the subject. Recently, descriptions of a similar post-infection disease were reported by people who were infected by SARS-CoV-2 (COVID-19) in the months after the start of the COVID-19 pandemic, now known as Long COVID. It is critical for those who experience post-COVID-19 illnesses that we invest and leverage the existing resources of related post-infection illnesses like ME/CFS, utilizing the CRCs to do so.



Solve M.E.



Long Covid
INITIATIVE
Solving post-infection diseases

The first published study confirmed that fatigue, post-exertion malaise, and cognitive dysfunction^v were the top three symptoms that individuals with Long COVID experienced seven months after their acute infections, pointing to the significant overlap with ME/CFS. The strikingly similar symptoms paired with the recent findings of: (1) autoimmunity; (2) reactivation of viruses such as Epstein-Barr virus (EBV);^{vi} (3) immune dysfunction;^{vii} (4) autonomic nervous system; and (5) gut involvement^{viii} all indicate that the predominant form of Long COVID not only meets the diagnostic criteria but also has the essential characteristics of ME/CFS — including in the pediatric population.^{ix} ME/CFS has long been considered a post-infection disease with EBV as the leading trigger. The evidence is clear that ME/CFS is inextricably linked to Long COVID, the most recent version of a post-infection disease.

Recently, the NIH published a long-expected request for applications (RFA) and announced the funding levels for the centers would remain unchanged. This news severely disappointed the ME/CFS Community.^{x xi} However, we understand that budget uncertainty has impacts, especially on small multi-institute projects like the ME/CFS Collaborative Research Centers. While budget uncertainties contributed to delays, the timeline of these RFAs leave an unfortunate seven-month funding gap that threatens the success of the program. The ME/CFS CRCs — specifically designed to study, investigate, and educate about post-infection illness — are a logical and organic home for research on overlapping biological mechanisms being simultaneously investigated in Long COVID. Without the expected increase in funding and leadership from the NIH, the CRCs are unable to research these critical issues.

In an environment of budget delays and uncertainty, the NIH has missed an immense opportunity to leverage existing expertise and infrastructure investments to address Long COVID and post-infection illness. It is vital to meet this critical deadline of March 11 and pass the full FY22 Omnibus package. Critical priorities and programs — like post-infection illness research — have stagnated. We hope as your committees look forward to FY 23, you will prioritize opportunities to address the impact of budget delays on vulnerable programs like those in post-infection illness.

Sincerely,

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President & CEO
Solve M.E.

CC: Senators Markey, Van Hollen, Hoeven, Murkowski, Kaine, and Collins and Representatives Eshoo, Lofgren Bergman, and McGovern

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- ^v Davis, H., Assaf, G., McCorkell, L., Wei, H., Low, R., Re'em, Y., Redfield, S., Austin, J. and Akrami, A., 2021. Characterizing long COVID in an international cohort: 7 months of symptoms and their impact. *EClinicalMedicine*, [online] 38, p.101019. Available at: <<https://doi.org/10.1016/j.eclinm.2021.101019> > [Accessed 25 February 2022].
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- ^{ix} Siberry, Vikram G. R. MS*, †; Rowe, Peter C. MD*, † Pediatric Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome, *The Pediatric Infectious Disease Journal*: February 4, 2022 - Volume - Issue - doi: [10.1097/INF.0000000000003477](https://doi.org/10.1097/INF.0000000000003477)
- ^x Hsuborger, B., 2022. *NIH Comes up Short Once Again*. [online] #MEAction Network. Available at: <https://www.meaction.net/2022/02/17/nih-comes-up-short-once-again/?mc_cid=f872a1fce5&mc_eid=9bc4ece714> [Accessed 25 February 2022].
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