



#NOTJUSTFATIGUE URGES NIH TO ADDRESS FUNDING FOR ME/CFS, ENSURE INCLUSION IN THE RECOVER INITIATIVE

As the Senate Appropriations Committee advances a directive requiring NIH to incorporate ME/CFS into the RECOVER Initiative, expert researchers are offering concrete recommendations on implementation.

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Washington D.C. — [#NotJustFatigue](#), a leading advocacy group for people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS), joins the Senate Appropriations Committee, expert researchers, and countless individuals across the country in calling for increased federal funding for ME/CFS research and the incorporation of ME/CFS into the RECOVER Initiative.

Despite the extensive personal and economic toll associated with ME/CFS, along with the lack of approved treatments or diagnostics by the Food and Drug Administration (FDA), federal funding of research and treatment at the National Institutes of Health (NIH) has remained limited (an [estimated](#) \$13 million in 2022, 2023, and 2024). Independent researchers have [concluded](#) that “ME/CFS has traditionally been one of the lowest funded diseases,” and a [2022 study](#) on the relation between the burden of diseases and relative research funding found that “NIH funding for ME/CFS research would need to expand... to approximately \$472–\$600 million annually, up to a 40-fold increase, to be commensurate with that of similarly burdensome diseases.”

SENATE APPROPRIATIONS COMMITTEE SUPPORTS ME/CFS INCLUSION

#NotJustFatigue applauds the Senate Appropriations Committee for including crucial language in their Fiscal Year 2025 (FY25) Labor, Health and Human Services, and Education (Labor-HHS) appropriations [report](#) (see pg. 145-146) directing the NIH to incorporate ME/CFS into the RECOVER Initiative. “The inclusion of ME/CFS in the Senate Appropriations Committee’s directive is a monumental step forward,” said **Elizabeth Ansell, the founder of #NotJustFatigue** who also lives with ME/CFS. “We are hopeful that this will lead to increased attention from the NIH and the advancement of crucial research for the ME/CFS community.”

Specifically, the Senate’s report recognizes that Long COVID “resembles other post-acute infection syndromes (PAISs), such as fibromyalgia, ME/CFS and related conditions, known as chronic overlapping pain conditions (COPCs) or nociplastic syndromes.” The report encourages NIH to broaden its approach within the RECOVER Initiative to include research on these overlapping conditions. The report emphasizes the importance of prioritizing clinical trials that evaluate therapies with demonstrated efficacy for COPCs or nociplastic syndromes alongside Long COVID therapies. Additionally, it recommends using the 2024 NASEM Long COVID definition to guide the selection of symptoms and conditions for treatment research and stresses the need to rebalance the research program to prioritize clinical trials.

EXPERT RESEARCHERS BACK SENATE'S REPORT LANGUAGE WITH THOUGHTFUL RECOMMENDATIONS

In response to the Senate's report language, a group of leading ME/CFS researchers recently sent a detailed [letter](#) to NIH Director Monica M. Bertagnolli, M.D., providing a roadmap for how NIH can successfully integrate ME/CFS into the RECOVER Initiative. The letter acknowledges the Senate's recognition of the significant overlap between ME/CFS and Long COVID and advocates for the inclusion of people with ME/CFS in all relevant clinical trials. The researchers point out that approximately 45% of Long COVID patients meet the diagnostic criteria for ME/CFS, underscoring the necessity of studying these conditions in tandem. They argue that without including people with ME/CFS, the research would miss a critical opportunity to understand the full spectrum of post-viral illnesses.

The researchers also emphasize the need for rigorous comparative studies to distinguish between the pathophysiology of ME/CFS and Long COVID. By identifying both the commonalities and differences, NIH can develop more effective, targeted treatments that address the specific needs of both impacted groups. The letter also recommends leveraging existing ME/CFS research networks and biobanks to build on previous research and expedite progress. This comprehensive approach is essential not only for the advancement of ME/CFS research but also for the broader understanding of chronic post-infectious syndromes.

NIH'S ENGAGEMENT AND NEXT STEPS

#NotJustFatigue acknowledges the positive comments made by NIH Director Dr. Monica Bertagnolli during her recent [interview](#) with *The Sick Times* regarding the inclusion of ME/CFS in the broader research agenda for Long COVID. Dr. Bertagnolli's comments suggest a commitment to considering ME/CFS in upcoming research initiatives, and that the upcoming [RECOVER-TLC meeting](#) in September presents an opportunity for further dialogue and collaboration.

#NotJustFatigue encourages the ME/CFS community to participate in the RECOVER-TLC meeting scheduled for September 23-25, 2024 (individuals can register [here](#) until September 6). This is a key opportunity for the ME/CFS community to influence future NIH research and ensure that the unique challenges and needs of people with ME/CFS are recognized, especially given the overlap with Long COVID. "Now, more than ever, it is crucial for the ME/CFS community to stay engaged and make their voices heard," urged **Ms. Ansell**. "Active involvement from patients and researchers will be crucial to maintaining momentum and ensuring continued progress."

ABOUT #NOTJUSTFATIGUE

[#NotJustFatigue](#) is a nonprofit organization dedicated to addressing the dire lack in public awareness and federal funding to address ME/CFS. Guided by the values and experiences of individuals who have experienced the toll of this disease first-hand, we are committed to speaking the truth about ME/CFS and connecting with people in a way that medical and political rhetoric cannot. Confronting a long history of neglect, #NotJustFatigue aims to bring those with the disease out of the shadows and forge a path forward to confront this devastating condition.