March 5, 2026

The Honorable Shelley Moore Capito
Chair, Subcommittee on L-HHS
Committee on Appropriations
United States Senate
Washington, DC 20510

The Honorable Robert B. Aderholt
Chair, Subcommittee on L-HHS
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

The Honorable Tammy Baldwin
Ranking Member, Subcommittee on L-HHS
Committee on Appropriations
United States Senate
Washington, DC 20510

The Honorable Rosa L. DeLauro
Ranking Member, Sub. on L-HHS
Committee on Appropriations
U.S. House of Representatives
Washington, DC 20515

Dear Chair Capito, Ranking Member Baldwin, Chair Aderholt, and Ranking Member DeLauro:

On behalf of the millions of Americans living with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), we write to respectfully urge the Subcommittees to include dedicated funding in the FY27 Labor-HHS appropriations bill to support implementation of the NIH ME/CFS Research Roadmap. Specifically, we ask the Subcommittees to provide no less than $50 million within the Office of the Director for new and expanded ME/CFS research activities consistent with the Roadmap's recommendations.

ME/CFS is a serious, multisystem disease that affects millions of Americans and continues to leave patients with no FDA-approved treatment and no validated diagnostic test. The NIH ME/CFS Research Roadmap now provides a clear, expert-informed framework for moving the field forward—including biomarker discovery, development of diagnostic tools, and interventional and clinical trials. Congress took an important first step in FY26 by recognizing the Roadmap and directing NIH to develop an implementation plan. FY27 should build on that progress by pairing direction with the resources needed to execute.

Without dedicated funding, the Roadmap risks becoming another well-developed framework that is never translated into meaningful action. A targeted funding directive would help NIH stand up the infrastructure, research capacity, and clinical trials pipeline needed to finally bring measurable progress to a field that has been chronically underfunded for far too long.

To ensure the ME/CFS Research Roadmap is implemented effectively and without further delay, we respectfully urge the Committees to include the following report language in the FY27 Labor-HHS appropriations bill:

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome [ME/CFS] Research Roadmap.—The Committee recognizes the urgent need to advance research for ME/CFS, particularly given its overlap with long COVID and its relevance across multiple Institutes and Centers, and commends NIH for approving the ME/CFS Research Roadmap and developing an implementation plan in response to prior Committee direction. Building on this work, the Committee provides no less than $50,000,000 within the Office of the Director to support implementation of the ME/CFS Research Roadmap. These funds shall be used to support new and expanded research activities consistent with the Roadmap's recommendations, including but not limited to biomarker discovery, development and validation of diagnostic tools, and interventional and clinical trials across relevant Institutes and Centers.

The Committee directs NIH to implement the ME/CFS Research Roadmap's recommendations and to include in the fiscal year 2028 Congressional Justification a discrete summary of ME/CFS-related research investments, including projects supported with these dedicated funds; a description of how Roadmap implementation is being coordinated across Institutes and Centers; and an explanation of how ME/CFS research supported under the Roadmap complements and informs NIH's research on Long COVID, post-acute infection syndromes, and related autonomic and neuro-immune disorders.

Thank you for your leadership and consideration of this request. With dedicated FY27 support, Congress can help ensure the ME/CFS Research Roadmap becomes a real vehicle for progress—not just a plan on paper—and finally move this field toward the diagnostics, treatments, and answers patients have waited far too long to see.

Sincerely,

Elizabeth Ansell
Founder and Executive Director
#NotJustFatigue

Laurie Jones
Executive Director
MEAction

Emily Taylor
President and CEO
Solve M.E.