#ME
ACTION

Dr. Jay Bhattacharya, Director
National Institutes of Health
1 Center Drive, Room B1-126
Bethesda, Maryland 20892-0001

Dear Dr. Bhattacharya,

Thank you for your attention to the crisis facing millions of Americans with chronic diseases. We are writing from #MEAction, a non-profit that advocates for people with myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) in coalition with the below signers and organizations.

As you may know, ME/CFS is under-researched and that has had serious consequences. Twenty-five percent of people with ME/CFS are housebound or bedbound, and only 13% are able to work full-time. With no FDA-approved treatment, people living with ME/CFS have been left without adequate treatment and medical care.

Last year, NINDS convened an ME/CFS Research Roadmap Working Group tasked with providing scientific guidance with an emphasis on identifying research leading to clinical trials. Our working group– composed of experts on ME/CFS, including researchers, clinicians, individuals with lived experience, and representatives of non-profit advocacy and research organizations– presented the ME/CFS Research Roadmap at the NANDS Council meeting on May 15, 2024.

However, this crucial work could be lost, as there is no funding to implement the ME/CFS Research Roadmap. The NIH budget for ME/CFS is $13 million for fiscal year 2024/25 – the lowest in comparison to its disease burden of any disease monitored by NIH. The NIH’s ongoing decision not to invest in ME/CFS deters researchers from submitting grants and entering the field. Without a funded roadmap, new researchers and researchers from other disciplines will see no incentive to work on this urgent, evolving problem.

We are fully aware of the pressures you face regarding funding, but if you prioritize ME/CFS, you could make progress where no other leader at NIH has. We request that the NIH Office of the Director allocate $50 million to execute the ME/CFS Research Roadmap to work towards solutions for the millions of Americans living with ME/CFS.

#MEAction formally requests a meeting with you to discuss this important issue. We look forward to your response and thank you for your attention.

Sincerely,
#MEAction and the undersigned

Organizations

CFS Associazione Italiana odv
Giada Da Ros

Long Covid Advocacy
Claire Every

Millions Missing Canada
Scott Simpson

Famílies per la Revolta Educativa
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World ME Alliance
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