



March 30, 2021

Walter J. Koroshetz, MD
Director, NINDS
National Institutes of Health

Captain Inger K. Damon, MD, PhD
Director, DHCPP
Centers for Disease Control and Prevention

Dear Dr. Koroshetz and Dr. Damon,

We write to **express our lack of confidence in the NIH and CDC-led interagency approach to ME/CFS. As currently enacted, your approach will not effectively advance biomedical research, medical education, or care and treatment for people living with ME/CFS.** Despite repeatedly alerting you to our community's dire needs, the Interagency Working Group (IAWG) is continuing the same ineffective pattern established by agency leaders: that of refusing to take the critical actions necessary to solve our community's long-standing crisis. This is unacceptable. #MEAction holds you and other top agency leaders directly responsible.

We remain eager, as we always have been, to partner with the NIH and CDC to solve crucial research, clinical, and policy challenges. We acknowledge the very real difficulties the current ME/CFS evidence base poses for federal policy-making and we appreciate the genuine efforts of program staff within your agencies. But we will not excuse top leaders' ongoing refusals to urgently and effectively address the decades-long ME/CFS crisis.

You already know that 1 - 2.5 million people with ME/CFS in this country have no access to diagnostic testing, no FDA-approved treatments, and no cure. People with ME/CFS battle rampant misinformation and dismissal by medical providers and remain undiagnosed for years. Most never access the severely limited pool of specialists who could improve their quality of life, and they are lucky if they avoid harmful exercise regime prescriptions. People with ME/CFS often cannot get insurance to cover the most salient testing and treatments. Though 75% of people with ME/CFS cannot work, only a small fraction successfully access disability benefits. Severely ill individuals are too sick to even visit a doctor, and they must live under threat of forced psychiatric commitment when they are hospitalized. This is the systemic crisis facing millions. With the expected doubling of ME/CFS prevalence from COVID-19, your repeated failure to urgently address this crisis will now have even more widespread, devastating effects.

In last month's IAWG meeting, you assured us that your agencies care for this community and are making progress to improve people's lives. But we have long heard assurances from agency leadership, and we have no new reason to now consider them credible. Where is an outcomes-oriented action plan for urgently meeting our community's needs? Where are the funding increases and other resources for ME/CFS research, medical education, care, and

treatment that will repair the decades of harm and neglect of people with ME/CFS? Yet again, you fail our community by offering us no credible answers, no plan, and no expanded resources.

Years of documenting the interrelated problems in ME/CFS research, medical education, treatment and care have not led to the set-aside funding that would truly remedy the researcher and academic clinician shortages, and correct for decades of stigma and other barriers that continue to hinder the ME/CFS field. Years of status quo medical education efforts have not solved the clinical care crisis. Years of multiple, inconsistently-applied ME/CFS research case definitions continue to make it impossible to comprehensively move research forward or delineate well-phenotyped subgroups. Years where basic research does not move forward, have translated to years where we are told that biomarkers and clinical trials cannot follow. The NIH and CDC created many of these systemic issues whereby people living with ME/CFS remain undiagnosed, without access to clinical care or treatment, but year after year your agencies' leadership has consistently refused to solve them.

People with ME/CFS require a clear and comprehensive cross-agency action plan with defined milestones and real resource commitments from our federal government, and especially from the NIH and CDC. The plan must be commensurate with the scale of the ME/CFS crisis and it must be urgently enacted by agency leaders who will be held accountable to urgently drive it and achieve measurable results. The NIH and CDC long COVID agendas must explicitly prioritize post-COVID ME/CFS research and medical education efforts, and they must implement clear mechanisms that will ensure effective coordination and linkages between long COVID initiatives and ME/CFS programs.

You need to become the drivers, not the obstacles, of meaningful progress for people living with ME/CFS. Without a change in how you are leading, the ME/CFS crisis will continue to grow. #MEAction cannot and will not be placated by vague assurances about future progress when they are not substantiated through the kind of robust federal response that we know our government is capable of when a crisis is acknowledged and prioritized. We demand that you change your approach now, so that we can work together to develop an outcomes-oriented action plan to achieve meaningful and measurable progress for people living with ME/CFS. If you do not, we will hold you, and top agency leaders, accountable for leaving people living with ME/CFS to suffer in their continued state of crisis.

Sincerely,

Ben HsuBorger
US Advocacy Director,
#MEAction