Solve M.E.

December 12, 2023

Steven Phillips, M.D., M.P.H.
Michelle A. Williams, Sc.D.

Dear Dr. Phillips and Dr. Williams,

As representatives of a patient advocacy and research non-profit, we read your recent article "How to End the Futile Long COVID Blame Game" with alternating enthusiasm and concern. While there were elements of your article with which we agree, we feel compelled to address several inaccuracies and misplaced conclusions that could significantly adversely impact the millions of individuals for whom we tirelessly advocate.

We agree with your assessment of the link between Long Covid and ME/CFS, and the developing scientific consensus is increasingly drawing attention to the ways in which infections are linked to the development of ME/CFS. We agree that it is crucial to have patient and advocacy groups participate in research from the very beginning stages. The inclusion of input from patients will dramatically increase the quality and meaningful impact of future studies, although only if the health equity issues you raise about Long Covid and ME/CFS research are properly addressed.

Additionally, we wholeheartedly agree with the call to establish a new funding mechanism at NIH and believe that a broader approach streamlining multiple post-infection diseases (such as Long Covid, ME/CFS, Chronic Lyme, MCAS, POTS, dysautonomia and others) is warranted. At a minimum, a new NIH Institute would provide the level of oversight, budgetary decision-making power, and organizational power required to tackle a medical problem of this magnitude. To truly address the scope of the public health impact, we believe a whole government "Ryan White" style multi-agency approach is necessary, similar to how we've invested in combating HIV/AIDS.

However, there are several critical statements and conclusions in your article with which we take significant issue. First, furthering Long Covid research is not "digging in a dry well." While there is some truth to the sentiment that the $1.25 billion federal investment may not have been optimized, critical findings were made that have pointed researchers in the direction of potential biomarkers and treatments.

Further, the assertion that research into ME/CFS and Long Covid have reached maturity is inaccurate and puzzling. COVID is only just over three years old, and ME/CFS research has been massively underfunded for decades. In fact, we've made remarkable progress in our understanding of ME/CFS considering that it has only received between $5 and $15 million a year in government funding and is the lowest funded disease by the NIH despite having one of the highest disease burdens of any condition.

In comparison, according to the NIH RePORT, cancer and HIV receive yearly funding of $8 billion and $3 billion, respectively. These are not one-time investments but have been

consistent at these levels for years. The conclusion that further diagnostic and mechanistic research has a low likelihood of helping patients because we have studied ME/CFS for 30 years fails to acknowledge the historically persistent and severe underfunding of ME/CFS research.

Ending biomedical research as you recommend would leave them with no answers, no treatment, and no cure. HIV/AIDS has taught us that the need for immediate symptomatic treatments to improve quality of life should absolutely not come at the expense of the long-term research into the exact mechanisms of these illnesses and the pursuit of actual solutions to the core of the illnesses. Both are needed, and both are critical. As David Tuller noted in his own response to your *TIME* piece, "... if you don't find out what's causing the symptoms, how do you improve prognosis or know what kind of care (empathetic or not) is appropriate? How do you 'impact the welfare' of Long Covid patients if you give up the search for what's going wrong with them?" While empathy and quality of life are important, they are more characteristic of palliative care than treatment or cure.

Even now, after the one-time $1.25 billion investment in Long Covid research, we are digging with a spoon when we need a bulldozer. The enormous government investment in HIV/AIDS and cancer was critical in starting to make a tangible impact. Further, the number of those living with HIV – 1.2 million – pales in comparison to the 10-35 million living with Long Covid in the US, plus millions more with ME/CFS and other post-infection diseases. And while there are similar numbers of patients living with cancer as Long Covid and ME/CFS, cancer receives approximately 8x annually what Long covid has received once. Further, for the enormous and growing post-infection disease patient population we serve, few, if any, viable treatment options exist.

Given the early stage of Long Covid understanding, the investment should be significantly higher – at least billions annually –- to advance science. We would also argue that the scientific community already has the essential tools to study Long Covid and ME/CFS, but the pursuit requires unwavering funding support and stronger coordination at the federal level.

We require a similar investment in treatment and research for Long Covid and ME/CFS – and this means research *with* oversight and *without* silos and studying meaningful treatment. We need education that helps connect patients with resources and counters the kind of misinformation that leads well-meaning providers to cause medical harm.

In a piece for the *New England Journal of Medicine*, you called for a "well-funded domestic and international research agenda to identify causes, mechanisms, and ultimately means for prevention and treatment of Long Covid." In the two years since you sounded that alarm, the number of Long Covid sufferers has increased exponentially, and the need for research into diagnostics, treatments and cures has grown ever more urgent.

These ongoing, unmet needs are the reason for our annual Advocacy Week events, including two full days of Congress-targeted mobilization during which hundreds of advocates connect with members of Congress and their staff. Our advocates spend their limited energy on these educational efforts with the hope that policymakers will understand the unique needs of people with ME/CFS, Long Covid and other post-infection diseases and remember them when making research funding decisions. We invite you to learn directly from the patient community just how much work is still to be done by joining us for Advocacy Week 2024.

In conclusion, while your article touched on crucial issues and likely drew attention from a broad and salient audience, many of the conclusions drawn were misguided. There is a real risk that, given your prestige, your piece in this high-profile outlet will have unintended consequences and be used to justify ending funding all public and private research into Long Covid, ME/CFS and other post-infection diseases.

We urge you to acknowledge the potential harm of your statements and reconsider your position. We also invite you to engage in a dialogue with us and join us in ensuring that patients are not neglected or left waiting for the breakthroughs that will not only transform but save their lives. Please let us know when we might have a conversation. We also want to alert you that we feel we have an obligation to share our response with our constituents and plan to do so by the end of the day, Thursday, December 14th. Thank you for your time in considering our letter.

Sincerely,

Kristin Jacobson
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H. Timothy Hsiao

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