



November 7, 2016

Dr. Patricia A. Grady
Institute Director
National Institute of Nursing Research
31 Center Drive, Room 5B-05
Bethesda, MD 20892-2178

Re: Controversial speaker Dr. Edward Shorter and the ME/CFS community

Dear Dr. Grady,

On behalf of the Solve ME/CFS Initiative (SMCI) and as a patient with myalgic encephalomyelitis (ME), also known as chronic fatigue syndrome (CFS), I am writing to share my concern over and disappointment in your department's decision to host Dr. Edward Shorter this Wednesday, November 9, 2016. Dr. Shorter, scheduled to present a lecture titled "Chronic Fatigue Syndrome in Historical Perspective," is a controversial and inflammatory figure who denies the overwhelming scientific evidence that ME/CFS is a physiological disease. I am disappointed that your institute is providing a forum for an antiquated, disproven, and deeply harmful viewpoint to be heard.

ME/CFS is a complex disease with an array of debilitating symptoms including extreme exhaustion, orthostatic intolerance, unrefreshing sleep, memory loss, joint pain, inflamed lymph nodes, severe headache, sore throat, neurological abnormalities, and even complete organ system shutdown. The cause of ME/CFS is unknown, and there is no existing cure nor FDA-approved treatment for the disease. It is estimated that up to 20 million people worldwide suffer from ME/CFS, and the disease affects those of all ages, races, genders, and socioeconomic backgrounds, leaving patients with lower quality of life scores than those with lung cancer, stroke, or rheumatoid arthritis.¹ ME/CFS has very clear and proven biological (not psychological) traits, which include the following (as well as dozens of other measureable traits):

- Low NK cell cytotoxicity
- Abnormal MRI scans
- Abnormal cognitive-evoked EEG brain maps
- Up-regulated 2-5A antiviral pathways
- Prominent activation of pro- and anti-inflammatory cytokines
- Measureable reduced aerobic work capacity
- Abnormal gut microbiome diversity

In 2006, Dr. Anthony Komaroff of Harvard University stated, "There are now over 4,000 published studies that show underlying biological abnormalities in patients...It's not an illness that people can simply imagine and it's not a psychological illness." Ten years later, the scientific understanding of ME/CFS has confirmed the physiological grounding for ME/CFS, yet Dr. Shorter continues to call this disease a "psychic epidemic" perpetrated by "moaning and groaning victims" who are "delusional." Dr. Shorter has written pieces so disparaging of patients that they were removed from circulation by *Psychology Today*. His views are antiquated and hurtful, and his history of disparaging and demeaning remarks toward patients make him a very controversial figure to ME/CFS patients.



Solve ME/CFS Initiative

Leveraging patient-centered
research to cure ME/CFS

As we understand it, your institute invited Dr. Shorter to speak. **Our organization feels this invitation violates the high standards of the National Institutes of Health (NIH), which values strong science and verifiable research.** Dr. Shorter's extremist views have no grounding in scientific fact, and the stigma perpetrated by his views continues to harm patients. To maintain the scientific integrity of the NIH, we ask you to please consider the following if you cannot cancel his speech:

- 1) Present balanced and scientifically grounded information to NIH researchers and staff. Please balance Dr. Shorter's viewpoints with an opposing expert. We suggest you host a follow-up presentation featuring Mary Dimmock, author of *30 Years of Disdain: How HHS and a Group of Psychiatrists Buried Myalgic Encephalomyelitis*. Our organization would be happy to facilitate this connection.
- 2) Reaffirm the findings of the 2015 Institute of Medicine report, commissioned by the NIH, which confirmed ME/CFS is a physiological disease.
- 3) Prioritize ME/CFS funding with substantial investment commensurate with the burden of this devastating disease.

If our organization, with its scientific acumen, can be of assistance, please do not hesitate to contact us. Advocacy and Engagement Manager Emily Taylor, who can be reached at ETaylor@SolveCFS.org, will respond to any informational request you may have and can assist in coordinating a scientifically based and verified history of ME/CFS.

Sincerely,

Carol E. Head
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Solve ME/CFS Initiative
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(704) 354- 0016, ext. 203

CC: Dr. Francis Collins, Director of the NIH
Dr. Walter J. Koroshetz, Director of the National Institute of Neurological Disorders and Stroke (NINDS), Chair of Trans-NIH ME/CFS Working Group
Dr. Vicky Whittemore, Program Director, NINDS, and NIH Representative to the Department of Health and Human Services CFS Advisory Committee
Dr. Avindra Nath, Intramural Clinical Director, NINDS
Membership of the Trans-NIH ME/CFS Working Group
Mary Dimmock, author of *30 Years of Disdain: How HHS and a Group of Psychiatrists Buried Myalgic Encephalomyelitis*

¹ Source: Beyond Myalgic Encephalomyelitis/Chronic Fatigue Syndrome: Redefining an Illness IOM 2015 and, the Health-Related Quality of Life for Patients with Myalgic Encephalomyelitis / Chronic Fatigue Syndrome. PLoS One. 2015; 10(7): e0132421. Published online 2015 Jul 6.