

In November, [Dr. Edward Shorter](#), Professor of the History of Medicine at the University of Toronto, was invited to give a talk at NIH on “Chronic Fatigue Syndrome in Historical Perspective.” Given that Dr. Shorter has a long history of denying the biological basis of ME/CFS, this invitation was extremely frustrating to the ME/CFS community, who has been harmed for decades by the stigma and mistreatment resulting from such biased and unfounded views.

Dr. Shorter’s dismissal of this disease goes back to at least a 1992 Ciba Foundation International Symposium on ME/CFS, where he warned attendees about the “stressed-out or somaticizing patients who seek to disguise an emotional complaint” and who want to “upgrade” their nebulous condition to a “legitimate disease.”

Dr. Shorter’s views have apparently not changed in the quarter-century since. In response to the Institute of Medicine (IOM, now called the National Academy of Medicine) report in February 2015, Dr. Shorter published a short-lived [commentary](#) in Psychology Today, in which he said the following:

- The IOM committee was “a committee that the CFS patients’ lobby has roped, captured, and hogtied.” The IOM report was an “embarrassment . . . valueless, junk science at its worst.”
- “Nothing has changed since [1992] in scientific terms. There have been no convincing new studies, no breakthrough findings of organicity, nothing. And there never will be.”
- “[B]ringing militant advocates into such a discussion is equivalent to a committee of geographers that includes members of the Flat Earth Society.”
- “The public hearings were a circus, with moaning and groaning victims right and left.”
- “[W]hat many of these patients have is a kind of delusional somatization, the unshakeable belief that something is wrong with their bodies rather than their minds.”

According to a patient who attended the November presentation at NIH, Shorter reiterated many of these themes and the idea that the concept of this disease is based, not on its biology, but rather on the patients’ ideas of what constitutes a legitimate disease. In other words, patients, enabled by their doctors, have “constructed” this disease by attributing insignificant symptoms to a presumed serious organic illness. And now, in Shorter’s view, the IOM itself has succumbed to patient pressure and further legitimized what he views as a bogus disease.

Shorter’s views may be extreme but they are certainly not unique. Over the years, others have attributed ME/CFS to hysteria, to a mood disorder, and to patients escaping “into the sick role in order to escape cultural expectations.” Even today, PACE and similar studies are based on the claim that the debility of the disease is due to deconditioning which in turn is the result of patients’ false cognitions and maladaptive fear of activity. These studies claim that patients who “think” they have an organic disease have a poorer prognosis. Notably, the evidence supporting these claims are studies that have used

non-selective CFS case definitions that require *only* chronic fatigue and include patients with primary mental illness.

In response to the announcement of Shorter's visit, [Jennifer Spotila](#) and the [Solve ME/CFS Initiative](#) both wrote letters to NIH to protest the invitation, stating that Dr. Shorter's extreme views are not just outdated but have no basis in scientific fact. Spotila added that these views are no more appropriate in scientific discussions on ME/CFS than HIV denialists' views would be in HIV/AIDS discussions.

The Trans-NIH ME/CFS WorkGroup responded that the lecture was "not sponsored by either the ME/CFS Special Interest Group or the Trans-NIH ME/CFS Working Group, which means that it does not reflect the ideas, opinions, or policy of the NIH or the scientists now working on this disease." NIH added, "The exchange of information and divergent opinions, followed by critical analysis, is essential to moving any field forward." But Spotila noted that this did not address the concerns with Shorter's presentation. The community appreciates the importance of exchanging differing scientific views. The objection is to giving the microphone to an ME/CFS denier who, against all objective evidence, has long "insulted and denigrated ME/CFS patients" and is now doing the same to the National Academy of Medicine.

The Trans-NIH ME/CFS Workgroup statement concluded that Shorter's talk "will have no impact on NIH's interest in doing everything we can to advance the science of ME/CFS."

But advancing the science of ME/CFS requires that leaders at all levels, both in and out of government, explicitly and publicly reject these flawed disease views, the bad science behind them, and especially those who continue to promote them. Echoing the deep grievance of patients severely harmed by the stubborn persistence of this false narrative in research and clinical care for thirty years, Spotila said, "It is past time to discard the psychogenic myths of CFS's past, once and for all."