

Elephants in the Room: Acknowledging Impediments to ME-CFS Research, Education,
and Clinical Care

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I too want to acknowledge my thanks for being here today.

Having said that, I want to officially correct the record. I am not here as an advocate for Chronic Fatigue Syndrome. I am here as a Chronic Fatigue Syndrome educator. I have been involved in Chronic Fatigue Syndrome since the early 1990's when my daughter got ill and I have been going around educating medical students, dental students, graduate students, physicians and allied health professionals for Chronic Fatigue Syndrome for many, many years.

My talk I thought initially was on-point, and then Dennis Mangan wrote me a note and considered it off-point, and I considered changing it, and then there were some issues raised this morning by the patients. I sense that there is a degree of frustration which I share with regard to the ability of patients to find qualified physicians and so this presentation may be considered as a partial answer as to why patients have a difficult time finding physicians. And I hope that in our discussion, should time permit afterward, we can delve into the more positive aspects and some of the ideas that I still have. Some of these ideas have been implemented and others have not which would increase the number of physicians who are capable of treating Chronic Fatigue Syndrome.

And that having been said, you know my name; I am Kenneth J. Friedman, and I can tell you now that I am a retired Associate Professor of Pharmacology and Physiology of the New Jersey Medical School; one of the schools of the University of Medicine and Dentistry of New Jersey also known as UMDNJ. Some of you may recall that I was the medical school professor who was prohibited by UMDNJ from revealing my faculty title or place of employment when testifying before the Chronic Fatigue Syndrome Federal Advisory Committee.

I am target of investigation for violation of UMDNJ's code of ethics. And that is one of the reasons why I am going to insist that I not be considered a patient advocate. I am accused of theft of services from the University, and the State of New Jersey, for attending and preparing for ME-CFS related activities. The investigation was initiated at the request of my chairman, Andrew P. Thomas. To my knowledge, the investigation is still active despite being retired for more than one year. Ms. Rhonda Farber, the Director of the Office of Ethics and Compliance of UMDNJ, alleges that my failure to request University reimbursement for my travel expenses to and from CFS-ME related activities is an acknowledgement that these activities were of a personal nature rather than part of my responsibilities as a University professor. Ms. Farber reasons that had I truly believed that these activities were part of my University responsibilities, I would have requested travel expense reimbursement. I, other faculty, and University administrators have engaged in off-campus activities for which we have not requested travel expense reimbursement. None of us are targets of ethics code violations for such activities. This targeting is specific for ME-CFS activities.

This kind of activity, is not unique to UMDNJ. I cite but examples:

1. A world-renowned ME-CFS physician-researcher in the United States, who works in a University-Medical School setting, was instructed by the Chair of the employing Department to stop seeing ME-CFS patients. Fortunately, that physician is looking for another place to work.
2. A world-renowned ME-CFS researcher in Europe; a holder of an NIH grant to investigate ME-CFS, put himself forward for promotion at his academic institution only to be denied. The researcher, believing the denial is related to his ME/CFS research activities, has resigned his position from the institution, resigned his position in an ME-CFS professional organization, and states that he will no longer perform ME-CFS research.

Tactics used by academic institutions to deny promotion may follow those used by UMDNJ in denying my promotion from Associate to Full Professor:

1. The lead chapter which I wrote, and the two clinical chapters that I co-wrote in *the Consensus Manual for the Primary Care and Management of Chronic Fatigue Syndrome*, are not peer-reviewed publications despite the acknowledgement contained therein thanking Dr. Anthony Komaroff: *"for reviewing the final draft, making important observations to improve it, and offering suggestions that will enhance future updates of this manual."*
2. Another excuse given is that my years of service on the Chronic Fatigue Syndrome Advisory Committee are not an indication of national recognition in the field of ME-CFS. According to the Vice-Chair of my former Department, Dr. Walter Duran, *"Anyone can serve on an advisory committee, even Magic Johnson."*

Other tactics used by UMDNJ to discourage, and ultimately prevent this faculty member from advancing his scholarly activity in Chronic Fatigue Syndrome are (and I cite two again):

1. The issuance of a Dean's Letter of Reprimand admonishing me for conduct code violations that allegedly occurred during conversations about ME/CFS. Letters to the Dean, from the each and every conversant assuring the Dean that no misconduct occurred were insufficient to prompt the Dean to remove his letter of reprimand.
2. The academic institution can declare the faculty member's ME-CFS work is not professional in nature but rather personal. The faculty member may continue his ME-CFS research; but not during regular business hours. If the faculty member wishes to perform ME-CFS work during regular business hours, he must use vacation time to do so. The faculty member can be banned from using his University e-mail account for any correspondence related to ME-CFS research, and he may be banned from using the University's internet portal to do any research about ME-CFS.

Other academic institutions manifest similar bias: A medical school, the only medical school in its state, will not permit the statewide patient advocate group to run a medical student scholarship for its students. Two reasons are given: (1) The scholarship is not a scholarship; it is an essay contest. That is the position despite the fact that 96 percent of the scholarships available to students in that state require the applicants to write an essay, and (2) ME-CFS patients set up an artificial distinction between psychiatric and organic illness, and the school does not wish its students exposed to patients who make such a distinction.

These behaviors and actions are motivated by prejudice, and contempt. This prejudice and contempt have never been brought forward, discussed, or resolved in a federal forum. This prejudice and contempt constitute impediments to ME-CFS research, education, and patient care. Indeed they are elephants in this room. Unaddressed, they are increasing in size and are adversely affecting the lives of patients and those who are brave enough or naïve enough to help them.

The federal government, through the decisions of the Department of Health and Human Services and its agencies have promoted this environment in which this prejudice and contempt flourish: The NIH which has openly criticized the quality of ME-CFS research, and the scant number of ME-CFS researchers, and then gives money to the academic institutions who denigrate those who work on ME-CFS. The Centers for Disease Control spent millions of dollars on ME-CFS education campaigns while there are no outcome studies that demonstrate that those campaigns actually improved the physician knowledge of Chronic Fatigue Syndrome, or their ability to actually help or treat ME-CFS patients. The Federal Advisory Committee listened to me on multiple occasions make presentations concerning no-cost methods of educating medical students about ME-CFS and not a single recommendation came forward to initiate a medical student education program.

If the Department of Health and Human Services and its agencies have not the courage to lead, do you at least have the courage or willingness to follow? I refer you to the March 1, 2011 announcement of a \$2 million clinical and research study of chronic Lyme disease, fibromyalgia and ME-CFS to be sponsored by the provincial government of British Columbia. Contrast this to the mantra of the NIH that has said repeatedly that there will never ever be another ME-CFS Center of Excellence!

You sit here today (and I stand here today), many of us as we sat at the first Federal Advisory Committee meeting in 2003 and 2004. We are no closer to knowing the cause of ME-CFS, we still do not have one FDA-approved pharmaceutical agent for the treatment of ME-CFS, and we do not have one effective treatment protocol for the patients.

It is time to remove the impediments!

Clear the elephants from the room!

I stand here willing to work with you, I wish you would join me, and I wish we can go forward!

Thank-you!