

Pathways to Prevention Workshop: Advancing the Research on Myalgic Encephalomyelitis/ Chronic Fatigue Syndrome

Comment - Pat Fero, MEPD Wisconsin ME and CFS Association, Inc. (Line numbers show a first specific word citation that may indicate repetition of the term. Version 389 lines)

I applaud the committee's work in trying to understand the scientific literature and the confusion over every aspect of ME/CFS. Committee members with a vague knowledge of ME and CFS, but expertise in other areas, may have a more objective view of a research history where millions of dollars have been spent (1987 – 2015) yielding few published studies with replicated results, far less interested researchers, a spiral down in NIH funding (2000 – 2009) and an angry patient population.

Over a span of 20 years, I have watched as committees convene then file reports. We have a plethora of NIH statements from meetings, seminars, workshops and from conferences. This P2P report is similar to all the rest except there is a reasonable attempt to explain the research problems without obfuscating what lay before us. In fact, the report is fairly simple.

Describe ME/CFS. You did the best you could (2-9), but the report itself shows confusion. Patients feel that confusion everyday. Continued disbelief, disdain, misdiagnosis, and lack of treatment options, results in hopelessness. (8,9)

What is ME/CFS? At times in the report, ME/CFS is called "a multifaceted condition (2)", "the disease (11)" or an "illness (21)" Other than in the use the word syndrome as a label, (chronic fatigue syndrome); the committee states that ME/CFS "exists." (32)

I think that scientists might understand that ME/CFS is a merely a construct with no scientific meaning. Perhaps a label change at public health levels was an attempt to recognize patient frustration with the term **fatigue** by renaming the Condition, Disease and Illness as ME/CFS. Yet in line (3) fatigue is written as the major feature of the Condition, Disease and Illness. Fatigue is ubiquitous. Continuing to point out fatigue as a major feature of the Condition, Disease or Illness is illogical. In addition, piling ME into the CFS white elephant bin doubles the amount of junk. In general, humans do not like huge, longstanding icky messes, so they dump the whole thing rather than find the gem at the bottom of the heap.

ME/CFS simply cannot be viewed scientifically and won't be taken seriously by other scientists or community doctors. Patients get stuck.

I hope that first time committee members of P2P or IOM or CFSAC, who look at the tangled history of CFS and ME, would understand that patient advocates' anger and sometimes hostile reaction to public health agencies response and "program activities" is reasonable, not irrational.

Please remember that advocates represent the bedbound and homebound 24/7. There is no relief, a vacation or time off. We press on. Each of us knows hundreds of people whose quality of life is poor, so poor that ordinary stimulation from the outside world is almost non-existent. (In several places the Committee members acknowledge poor quality of life.)

I am no longer an advocates who can press on. This statement is one last attempt to say that I believe

that numerous NIH employees understand the complexity and confusion, the severity of disability for adults and children and the extreme frustration.

Yet, why does it continue? My view is that the problem is now monolithic. Better to move sand hills than a mountain. ME and CFS does not have an NIH home other than the Office of Research and Women's Health where it was dumped in 2002 (Meeting minutes, May 30, 2002 – Item VI - REPORT OF THE DMID COUNCIL SUBCOMMITTEE - Carole A. Heilman, Ph.D., Director, DMI.) ORWH does not have it's own budget. It appears that ORWH searches for money to fund studies that are not on the priority list of other Institutes. This has to change. NIH must hire a full time employee, a scientist with extraordinary abilities to sort out the mess and to develop research strategies with the support of NIH institutes. This job cannot be Gulag duty.

My in person observation is that people who direct anything to do with ME/CFS, come and go pretty quickly. Some are dedicated and it shows. Others have another full time job. Working on ME/CFS doubles their workload and increases their aggravation at "those damn patients." Yet others sit at committee meetings, pass candy, have side conversations, ignore speakers and generally behave poorly = born in a barn rude. You have to see it to know. We are sick, not stupid. I have observed such open disdain for this work that I began to think that DHHS employees assigned to work in ME/CFS are sent to the Gulag.

"Limited knowledge and research funding creates an additional burden for patients and health care providers. (7) Limited knowledge is more than a burden, which is defined as an **encumbrance**, strain, care, problem, worry, difficulty, trouble and so on. The burden is having to endure daily illness with no help in sight. The advocate burden is watching death after death with only a web page memorial as if those lives matter only to us in passing.

For at least 25 years, I followed the funding, the meeting reports, and the scientific literature. I have been told with each new imitative to leave the past behind. *A fresh start would be best. Build agency and patient collaboration.* I am an old timer with 35 years of the illness. My expertise is relevant. Many advocates who are part of the history have knowledge that cannot be discarded.

It is rational to look at NIH evaluation both from within and from an outside agency that is pertinent to this 2015 report. The first comment below is a response from the NIH in answer to questions from the Government Accountability Office report. (GAO/HEHS-00-98 Chronic Fatigue Syndrome Pg. 23)

"Since **1987**, NIH has issued four program announcements to stimulate research on CFS. The first two program announcements were supported by NIAID only; the first, in 1987, focused on epidemiology; the second, in 1992, focused on exercise-induced fatigue and disease origin and development. In 1994, NIH issued its first joint program announcement, involving three institutes, which focused on studies of the causes, natural history, and origin and development of CFS. The most recent program announcement, issued in 1996, involves eight different units within NIH and supports studies on the effects of CFS on the body."

The second comment is from the GAO in summary: (GAO/HEHS-00-98 Chronic Fatigue Syndrome Pg. 47)

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“Work on NIAID’s goal of furthering prevention would be premature given the limited understanding of the causes of CFS, and NIH has not supported efforts in this direction. “ (PG 47)

If Committee members look at the GAO report, they would find that we are stuck, *all* of us. WHO can make sense of this and many similar directives for the last 20 years or more? I can’t. So the buck has to stop, but with what office, what institute and with what director?

“Unfortunately, ME/CFS is an area where the research and medical community has frustrated its constituents, by failing to assess and treat the disease and by allowing patients to be stigmatized.”
(10, 11)

The research and medical community has not *allowed* anything of the sort. I object on their behalf. I wonder if this sentence is just poorly written, is purposely written to take a swipe at accountability, but missed the mark, or is just another attempt to poorly validate our frustration and stigmatization?

In 2015, DHHS and the agencies that deal with our Condition, Disease and Illness might accept responsibility for past lack of collaboration in developing a strategic plan, for bumping our disease into existing NIH funded Centers that do research and see patients with pain, sleep and fatigue disorders. These are symptoms. These centers do not focus on our Condition, Disease or Illness as an entity worth investigating.

Private researchers and doctors have taken the patient population and the many research case definitions to try to focus on a specific aspect of ME and CFS. Clinical studies are small, but the most advanced research is coming from these scientists and their collaborators, which could include an NIH, awarded scientist or a CDC supported researcher. Can the NIH return to the research centers that were opened in the early 90’s, but closed in 2002?

I appreciate the Committee members who spent time to look at research direction and misdirection. I sincerely hope that a team emerges, those who would say ENOUGH and those who would stop blaming the patients and others for this mess.

Pat Fero, MEPD

35 years sick

Son with CFS diagnosis, age 9 and age 15, died in 2005, age 23. Forensic pathology: Viral myocarditis with fibrosis

