

Testimony

Barbara Cottone

My name is Barb Cottone. I am an anesthesiologist fully disabled with CFS for 15 years. CFS has been investigated by many individuals from various fields over decades. Some of these studies have been relevant to the illness, but many more have not. The most damaging misrepresentation of the syndrome, surprisingly, is not that it has a psychiatric basis (which is ludicrous), but that its symptoms are based on a compromised immune system leading to a chronic infectious disease.

To be clear, I am proposing that CFS is not a chronic infectious disease. It may be triggered in many by an infectious agent, or an exposure to some toxin, as documented in Scotland in a group of workers processing wool who were exposed to pesticides. Whatever the initial insult the end result is a neurologic deficit resulting in an autonomic nervous system that does not respond properly to activity. Other problems may include orthostatic intolerance, a muted response of the HPA axis and, in particular, post-exertional malaise, which is the hallmark of the disease. Emphatically, this term "malaise" in no way describes the debilitating pain and weakness associated with ME. Headache and vertigo do contribute considerably to the disability in some patients.

As to the immune abnormalities, this is not an immunodeficiency akin to AIDS, leukemia, or immunosuppression by chemotherapy. The acronym CFIDS is thus a misnomer; it misleads patients, the general public, and practitioners alike. I have thought the immune findings in CFS to be epiphenomena and recently asked a respected researcher in a related field about this. The response was that a few studies might have been done but that even if there weren't it was unlikely more data would do anything. And I quote, "I recently returned from the IACFS meeting and my sense is that many of the people there are not really interested in "data" anymore - the whole CFS immune thing has become religion, and

there's no better "data" to show that than how the XMRV story has played out..."(end quote).

Research done on a broad spectrum of pathogens has found no one single agent underlying this illness. In the 90's, congress allotted twenty million dollars to the CDC, an organization with a mandate to define and limit any possible public health threat or potential epidemic. They found neither. On a more current note, the XMRV fiasco has not only wasted time and resources it has raised and then dashed the hopes of patients, and made a travesty out of scientific investigation into the disease.

A recent philanthropic effort with a price tag of 10 million dollars will involve the efforts of a number of virologists, epidemiologists and neuropsychiatrists, and will revisit the same realm explored for the past 30 yrs. Time, as well as money, will be wasted in another infectious disease probe funded in Oslo from 2010 to the year 2034.

It is worth noting that people so badly afflicted with CFS that they cannot crawl from bed to bath do not transmit the illness to family or caretakers via the airborne route, water contamination, or to partners by transmission of bodily fluids.

Therefore, an alternate paradigm is necessary for progress.

Two past studies that might inspire fruitful future research include papers published by the late Dr. David Streeten in the 90's, the first characterizing CFS as " form of delayed orthostatic intolerance" and a 2nd demonstrating a constricted blood volume in CFS patients.

Currently, work by Dr. Julia Newton on the relationship between exercise-related autonomic dysfunction and a decrease in pH in striated and cardiac muscle should be given high priority, as should a study at Georgetown by James Baraniuk delineating cohorts of abnormal proteins in the cerebrospinal fluid of CFS patients. This latter may aid in correlating the symptomatology and underlying pathophysiology of the

illness, and classifying subgroups. The difference in funding for these projects, and those I cited previously is exponential.

The deletion of the term ME from ICD coding, and supplanting it with CFS would have devastating consequences. Keeping the term myalgic encephalitis in the forefront, with CFS deleted or as a separate or subordinate category is key.

Paramount to the future of an understanding and treatment of CFS is emphasizing the primacy of a neurologic basis of the disease, which will give those doing the most promising research a chance to gain some desperately needed traction and be funded as they should.

Thank you for your time and patience.