

## Testimony

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### CFSAC Testimony for October 2010

In May, I requested that the CFSAC focus on correctly defining CFS and funding. Six months later I still have the same requests. In light of the controversy caused by CDC/ other researchers' inability to identify MLV-related viruses, there is a real urgency to act as soon as possible. We need funding now, but it must be for the correct disease.

The CDC has been studying "unwellness", instead of CFS, for at least five years, as a result of their renegade "Empirical" CFS definition. The taxpayer funding allocated to the CDC was specifically for CFS research, not for the illness of their choosing. The CFS funding that was diverted to ABT/Emory to study psychiatric disorders must be returned, as should any other monies used to study "unwellness" instead of CFS. Furthermore, the authors of the "Empirical" definition should not be allowed to participate as members or as ex-officio of the CFSAC.

Regarding ex-officio members of the CFSAC: an expert in infectious diseases or virology from the NIH would be very helpful. Is it possible to recruit an NIH representative in either of those areas? CFSAC should involve those who have that kind of expertise in order to promote research and funding.

Please lobby for funding for Centers of Excellence, so that CFS patients throughout the country will be able to receive the appropriate care from knowledgeable physicians. Please include the Whittemore Peterson Institute as one of these Centers. The Whittemore Peterson Institute has contributed more to CFS research in its short existence than any single government agency. This is the type of innovative research that CFS patients need, and that the taxpayers appreciate: it must be supported. A Center that would serve the needs of patients on the East Coast has already been approved for NJ: it just needs funding.

CFS patients are being accused of being “impatient”, yet there are people, including myself, who have been sick with CFS for over 20 years. There is still no FDA-approved treatment for our disease. Our quality of life has been destroyed, and we are facing major medical complications due to decades of untreated illness. Long-term CFS patients are dying from this disease. Please lobby for clinical trials and for the fast-tracking of CFS treatments. We need clinical trials and treatments NOW, not in another 20 years. There are medications that are proven to be effective against CFS: these must be made available to CFS patients as soon as possible.

CFS must be seen for what it is: a public health emergency. The government has known of the existence of an infectious retrovirus in CFS for over a year (in addition to the retrovirus identified by Dr. Elaine DeFreitas in the early 1990s), and the original research has since been confirmed by its own agencies. The government must act now: there is no excuse for a delay. “Confusion” is no excuse: the government knows very well that three different definitions have been used for CFS in the US during the disease’s 20-odd years of existence, in addition to the countless definitions used worldwide. It’s now been demonstrated that two of the US

definitions, Holmes and Fukuda, and the Canadian definition, are useful in identifying patients with retroviral infections. The “confusion” should end there. While the various officials obfuscate, this disease continues to spread and to kill. This is unconscionable.

Now is the time to prevent further transmission of the disease, and to provide medical treatments for those already stricken. It is not a time for egos and agendas to interfere with public health. We need funding for clearly-defined CFS, and we need it now. Thank you for your time and consideration, Lolly McDermott