

First, I want to commend the CFSAC for their recommendation for new leadership at the CDC. I am hopeful that after 25 years of psychologizing a viral neuroimmune disease that the CDC's CFS program may now actually be capable of conducting relevant research.

I see the CFSAC as having two major tasks. One is to support the adoption of the Canadian CFS definition as THE definition for CFS. I was originally diagnosed with CFS under Holmes, and the current Empirical definition bears no resemblance to the disease that I have. The Empirical and Fukuda definitions are hindering research because they are not specific enough. We need a definition that actually describes the disease, not one that describes multiple disease entities as well as psychiatric disorders. We need the Canadian definition. Until CFS is accurately defined, research results will be contradictory and CFS patients will be in danger of being labeled with a somatoform disorder diagnosis.

The other major issue is funding. The government has ignored and reframed CFS for long enough. It is time for the government to address this disease and this will require a substantial amount of money. The CFSAC must make lobbying for research funds a priority. The government's response to the XMRV finding has been pathetic so far. The burden on research should not be born by independent researchers alone. If the government is unable or unwilling to conduct true CFS research, then they must provide funding for independent researchers to do the job. An infectious retrovirus deserves immediate attention! There is no treatment and no understanding of how XMRV is spread, and no funding: meanwhile people are dying, desperately ill, and infecting their children. This is unconscionable.

I hope that the CFSAC will focus efforts on these two areas. Without these changes it will be impossible to advance CFS research in any meaningful way.

Thank you for your efforts. Lolly McDermott