

To the Chairman and Members of the CFS Advisory Committee (CFSAC):

I submit this testimony as one of the founders of the New Jersey CFS Association and its Vice President, Director of Research, Emeritus.

Regarding the CFSAC Charter, I request:

1. The Charter be renewed
2. The CFSAC meet four times a year
3. Committee members be replaced in a timely manner
4. Meeting agendas be posted in a timely manner
5. Live streaming of CFSAC meetings be added to the Charter
6. CFSAC recommendations be posted in a timely manner
7. A name change to ME/CFSAC consistent with the names used in NIH Program Announcements, i.e., CFS also called Myalgic Encephalomyelitis.

Regarding the XMRV retrovirus discovery reported at the October 29-30, 2009 meeting, I request:

1. HHS Secretary, Kathleen Sebelius, be briefed by the Whittemore Peterson Institute before the next CFSAC meeting
2. The HHS Secretary be apprised of the ME/CFS worldwide prevalence estimate, 17 million, reported in *Science* (October 23, 2009) and NIH's ME/CFS budget with an assessment of the budget's adequacy to address a disease of this magnitude and complexity.

Mary E. McNamara  
April 25, 2010