

Testimony
Mary E. McNamara

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 findings of the Lo, et al study (*PNAS*, August 23, 2010) which found evidence of MLV-related viruses in CFS patients which expands upon the Lombardi, et al XMRV discovery in CFS (*Science*, October 23, 2009), I request that:

1. Secretary Sebelius meet with the Whittemore Peterson Institute founders and researchers before the next CFSAC meeting to acknowledge their discovery and to ask them how HHS can help them continue their groundbreaking research and clinical work.
2. The number of human gamma retrovirus cases worldwide be reported at each CFSAC meeting.
3. ME/CFS clinical trials, number of patients enrolled, and health outcomes be reported at each CFSAC meeting.
4. The Trans-NIH Working Group on Chronic Fatigue Syndrome be reorganized with NIAID, NHLBI, NCI, NINDS, NHGRI, NICHD, NCCAM represented; and be re-staffed by individuals with skills, knowledge and abilities focused on: infectious disease (virology, retrovirology, opportunistic infections, diagnostic tests, treatments, prevention); immunology (clinical, acquired immune dysfunctions, diagnostic tests, treatments); neurology; and genetics.
5. The skills, knowledge and abilities of ME/CFS staff, grant peer reviewers, and decision makers be examined to ensure qualification to work on an infectious disease, with acquired immune system dysregulation; infection-related neurological abnormalities, blood volume loss, orthostatic intolerance, P450 dysregulation, and other debilitating infection-related health issues; and that nonqualified staff be reassigned.
6. Speaking on the *Global Health Initiative* at Johns Hopkins August 16, 2010, Secretary of State, Hillary Clinton, said, “*No nation in history has done more to improve global health. ... One of the intersecting goals of being the leader in global health... has to do with the health of our own people.*” Given GHI’s success in treating millions of people suffering from infectious diseases, I request that Secretary Clinton be briefed on ME/CFS’s magnitude, 17 million globally, and societal cost, \$9.1 billion annually; and that the Initiative’s components, namely--
expertise (infectious diseases, including retroviral disease);
principles (improved health and quality of life outcomes);
programs (clinics, diagnostic tests, treatments, prevention); and

funding levels (\$63 billion over the next 6 years)
be used as a blueprint to establish specialized care (i.e., local clinics, trained
physicians, standard diagnostic work-ups, treatments) for the men, women, and
children suffering from this debilitating disease in the U.S. and abroad.

Mary E. McNamara
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