

Submitted 10/14/2009

To the CFSAC:

Thank you for your service to the ME/CFS community.

I urge you to make these 4 recommendations to Secretary Sebelius:

1) No government funding should be made available for research using the Reeves (2005) empirical definition of Chronic Fatigue Syndrome. This definition has been shown to include many people who do not have the illness that has traditionally been called Chronic Fatigue Syndrome or Myalgic Encephalomyelitis. Any research done on the larger group defined by the Reeves definition will merely be confusing and will be a waste of taxpayer money.

2) The current leadership at the Centers for Disease Control that is responsible for research into the causes and potential therapies for Chronic Fatigue Syndrome has wasted the limited funds available for CFS in a misguided attempt to redefine it. Meanwhile, there have been no advances made by the CDC in our understanding of the disease Myalgic Encephalomyelitis/Chronic Fatigue Syndrome. The leadership should be replaced and ties to current consultants should be severed.

3) If there is going to be any progress toward a cure for Myalgic Encephalomyelitis/Chronic Fatigue Syndrome more funding is needed. Given the new information about XMRV as a possible causative agent, it is urgent that adequate funds be allocated.

4) The CDC proposed 5 year plan should be abandoned and replaced with real research looking into a biological cause using the Canadian Consensus Definition. Data should also be evaluated using the Fukuda criteria so that there can be a scientific basis for establishing a reasonable definition and comparing ongoing research with past findings. A good place to start would be to replicate the recent Whittemore Peterson Institute research.

Thank you again.

Sincerely,
Joan Grobstein, M.D.