

October 14, 2009

To the Chronic Fatigue Syndrome Advisory Committee:

It has become increasingly clear that the wrong type of CFS research has been done for more than 20 years. For example, neither the CDC nor the NIH (with the exception of NK cells) have shown any interest in pathogens or the immune system in more than ten years.

I hope that future study of this disease by the CDC will outlaw the use of questionnaires--or at least any questionnaire that does not confine its questions to fatigue and function.

I hope they will instead try to use physiological measures of fatigue such as the mitochondria assays done by Acumen Labs in the UK or the two-day exercise test as done by Staci Stevens at the Pacific Fatigue Lab. And I hope they will fund studies such as those of Drs. Kathleen and Allan Light, who study the pathways that generate muscle fatigue. In other words, validate the profound, severe, persistent "fatigue" in Chronic Fatigue Syndrome, and find out at the molecular level why it is made worse by exercise.

I also hope this committee will ask that Dr. William Reeves be replaced. We need a real scientist--someone who is younger and smarter than Dr. Reeves, and most important, someone who does not show the extreme contempt for patients that Dr. Reeves has publicly demonstrated many times in the past.

As an example, regarding the privately funded discovery of the new XMRV retrovirus, Dr. Reeves told the New York Times, "We and others are looking at our own specimens and trying to confirm it,"² he said, adding, "If we validate it, great. My expectation is that we will not."²

Of COURSE Dr. Reeves will not be able to confirm the findings of the Whittemore-Peterson Institute, the Cleveland Clinic and the NCI. Those organizations used a strict definition and tested only specimens from very, very sick people.

Dr. Reeves has so broadened the definition of CFS that it can include anyone who is depressed or didn't go to bed early enough. Any research based on Dr. Reeves' definition and Dr. Reeves' specimens won't be worth the paper it's written on.

Sincerely,
Sue Bailey