

Comments to CFSAC 10/09

I am not sure if there is any point for me to continue providing comments for these meetings since not one of the recommendations that I and many others submitted for the last meeting were acted upon: correctly defining CFS, replacing Dr. Reeves, using the Virochip for government CFS research, etc. etc. Thankfully, the Whittemore Peterson Institute has successfully and correctly undertaken this research, and have made astounding progress in little time and with relatively little funding. They have filled the research void created by the CDC. They have cut through the intentional obfuscation perpetuated by Dr. Reeves himself. After over 20 years of illness I finally have hope for a treatment and someday, a cure.

Dr. Reeves' response to this research has been horrifying, unprofessional, and unscientific. What kind of scientist publicly claims that they doubt that they will be able to replicate results when they have never used that protocol or technology? This bias is indicative of Dr. Reeves' entrenchment in a psychological approach (despite his supposed virology training) to CFS research. He is not capable of contributing to the body of CFS knowledge because he is unable to see beyond his own biases.

Dr. Reeves is critical of the patient sample in the Whittemore Peterson study. My response is this: what if Dr. Reeves had been responsible for AIDS research? Would he have looked at the blood of diagnosed AIDS patients, or would he have conducted a three year study, using a random sample where he selected his participants by calling people on the phone and asking them if they felt unwell? How many people would have died if Dr. Reeves had been responsible for AIDS research?

The CDC was handed a CFS retrovirus and probes in the 1980s, and still failed to replicate the results. They were unable to correctly follow the protocol. The fact that Dr. Reeves is already stating that he doesn't think that he can replicate this study is suspicious, since presumably the CDC has some of the same patient blood samples used in the Whittemore Peterson study. If the CDC had been so convinced that there were no viruses present in CFS then why did they not immediately test their archived samples with the Virochip?

Just because the CDC has continued to redefine CFS and jettison its biomarkers does not mean that they have changed the disease. I was diagnosed in 1989: since then the definition has been modified to the point that it bears no resemblance to that disease, but I and possibly millions of others still have that original disease. Why have all CFS biomarkers been systematically removed? How many other diseases have been redefined twice within 18 years of their discovery? Why have all biomarkers, extensively documented in countless studies, been ignored by the CDC? It's ludicrous that the CDC's most recent "empirical" definition has eliminated a key biomarker, post-exertional malaise, and replaced it with "unwellness". How is "unwellness" a useful term? In what disease does the patient not experience "unwellness"?

CFS is not "unwellness". It is a degenerative, AIDS-like disease that causes severe immune dysfunction and chronic infections/cancers. Unlike AIDS, however, CFS has had little funding, little recognition, and no treatment. It may take us longer to die from CFS

than those who have AIDS, but ultimately CFS destroys our quality of life and drastically shortens our lifespan.

I am assuming that Dr. Reeves will make the case that the disease related to XMRV is not CFS-or at least not the CFS that he has been looking at. If so, then my question is: What were you looking at, and how did you miss an infectious disease like XAND given your resources, the available research, and the very well-defined patient populations in the 1980s? This either speaks to gross incompetence, or intentional negligence.

Given Dr. Reeves' history I have no doubt that he will be unable to replicate the results of the Whittemore Peterson Institute. The CFS program at the CDC must have new, objective leadership. They need someone who is competent in infectious diseases research, and not someone who is trying to make a name for himself in the psychiatry field. The CFS program at the CDC has been spinning its wheels for around 25 years now, at great expense to taxpayers and even greater expense to those of us whose lives have been destroyed by this disease.

If Dr. Reeves is not removed from his position, then a new department, specializing in XAND must be created. The funding that was allocated for CFS, the infectious disease that appeared in the 1980s, must be reallocated for XMRV research, since Dr. Reeves is not studying the correct illness. While I am certain that whatever it was that Dr. Reeves has been studying is relevant, it by his admission not an infectious, life-threatening disease. XMRV and the treatment of XAND must be a priority at the CDC. Thank you for reading my comments-Lolly McDermott