

From: Mary Barker
Sent: Wednesday, May 27, 2009 5:48 PM
To: OS OPHS CFSAC (HHS/OPHS)
Subject: Meeting 5/27/09

First, thanks for letting us watch this live. I wish I had submitted this sooner, but was not feeling well. Anyways, here is my submission for your consideration:

My name is Mary Barker. I have a problem with my doctor. My leg was hurting quite badly and I thought it was broken, but when I went to see my doctor, he x-rayed my arm and said I was fine. I said, no, no, it's my leg that hurts, not my arm, but he wouldn't listen. Crazy, right? So I go see another doctor (and keep in mind this is costing me money each time), and the same thing happens. Even though I specifically tell the doctor that my leg hurts like heck, they keep x-raying my arm instead and tell me I'm fine. What the heck is going on?

Well, that's a somewhat clumsy but I think apt analogy for the approach taken by the medical establishment to the puzzle of CFIDS. As you should know, POST-exertional malaise is a hallmark of CFIDS (keeping in mind that the word malaise is completely inadequate to describe the bone-crushing fatigue lasting for days which can follow rather minimal exertion). Incredibly enough, however, almost no one has studied CFS patients POST-exertion. It's like they're taking x-rays of the wrong limb. If you study CFS patients PRE-exertion, instead of POST-exertion, you'll get different results and won't find what you need to know.

The Pacific Fatigue Lab at the University of the Pacific at Stockton, California, however, has finally listened to what people have been saying for the last few decades. They are doing exercise tolerances studies of CFS patient BOTH prior to and POST -exertion and are getting extraordinary telling results. The POST-exertion studies are showing severely incapacitating levels of disability in otherwise somewhat normal seeming persons (although the pre-exertion energy levels are still not that great). See <http://aboutmecfs.org:80/News/PRJan09Pacific.aspx>

Dr. Reeves said today that if there was a simple biomarker for CFS, it would have been found already. Well, not if you persist in x-raying the wrong limb. I suggest he take a look at the Fatigue Lab's findings.

In listening to the committee members talk today, I did not hear a single one mention POST-exertion. They all mentioned fatigue, and talk about interviewing anyone complaining of fatigue. But fatigue, as you well know, can have dozens of causes: low thyroid, weakened adrenals, food allergies, crappy diet, lack of exercise (for those capable of exercise), lack of sleep, anemia, celiac disease, and on and on and on. Thus it is meaningless and counter-productive to include everyone who complains of fatigue in your studies of CFS.

But POST-exertional fatigue without an obvious cause is relatively rare and can be easily studied. The Fatigue Lab is doing just that. Post-exertional disability is a major bio-marker and very easily determined.

So please quit x-raying the wrong limb, and try listening to us instead.

Also, Sarah Myhill in the UK has written a paper about mitochondrial dysfunction and CFIDS, which includes a very simple and elegant explanation for post-exertional malaise. Here is a link and I strongly encourage you to read this paper also. Her paper also explains quite clearly why graded exercise is so dangerous for CFIDS patients. See: <http://www.drmvhill.co.uk/article.cfm?id=381>

I have suffered from CFS with accompanying post-exertional malaise for over 10 years. It has basically stopped my life. I can't work, my marriage broke up and am on disability. I could go on but others today were more eloquent than I could ever be. Thank you for your attention.

Mary Barker