

Here are my comments to be circulated at the CFSAC meeting October 29-30, 2009.

I have suffered with CFIDS for over 20 years. Prior to getting sick I was very active physically. I worked full-time until 8 years ago (although it had been very difficult to keep working prior to going out on disability) and currently subsist on SSDI.

I am extremely concerned about the CDC's empirical "definition" of Chronic Fatigue Syndrome. This definition states that the most important feature of the disease is unexplained degrees of 'unwellness' that interfere significantly with people's work, personal, social, etc. activities. This empirical definition has been broadened from the previous CDC definition such that it now includes thousands (if not millions) of persons who do not have the objective physical abnormalities which have been shown in numerous studies to exist in persons with CFS.

Concomitant with this fatally flawed definition are indications that Dr. Reeves' wants to model U.S. CFS treatment after that of the UK - i.e., treating CFS as a psychological malady, using such treatments as cognitive behavioral therapy and graded exercise.

I strongly urge you to use instead the Canadian definition of CFS, which includes the hallmark of CFS, post-exertional malaise (PEM), as an essential element of this illness.

Bruce Carruthers M.D. and Marjorie van de Sand, B.Ed. writing in "A Clinical Case Definition and Guidelines for Medical Practitioners" (the Canadian definition) concisely state why a proper definition is crucial:

"The Greek origin of syndrome is **syn-** together, and **drome**, a track for running. One must determine the tracks of travel and observe the travel of a patient's syndrome components. Because research definitions define a static collection of symptom entities, they have ignored or downplayed the critical dynamic features of this syndrome, as lived by patients. The normal fatigue/pain pattern directly related to felt causal action and adjusted by activity/rest rhythms is broken in ME/CFS. As a result there are cumulative physical and cognitive fatigue/pain and "crashing" patterns, which are criterial in this Clinical Definition. The objective postural cardiac output abnormalities correlate with the degree of reactive fatigue and overall severity of ME/CFS. These findings could supply an objective marker for fatigue severity and duration and help explain why ME/CFS can be so disabling. It is important for the clinician to observe the dynamics of the whole cluster of symptoms in their interaction, additive effects and the disruption to patients' lives over longer periods of time."

If you have any doubt about the reality of PEM, see the work being done at the University of the Pacific at Stockton, California (see <http://aboutmecfs.org/News/PRJan09Pacific.aspx> - space constraints prevent me from including the entire article here, but I've included an excerpt below). They finally listened to what CFS patients have been saying for over 20 years - that extreme fatigue hits AFTER exertion, so they are doing research on patients both pre- and POST-exertion. Their post-exertion studies are showing extreme debilitation in CFS patients who previously tested somewhat normally. PEM does not exist in any other condition.

Here is an excerpt from the article in Phoenix Rising: An ME/CFS Newsletter, January 2009, about the work being done at the University of the Pacific:

". . . Run by three exercise physiologists, Dr. Christopher Snell (Ph.D), Dr. Mark Van Ness (Ph.D) and Staci Stevens (M.A.), a former grad student and now a researcher with chronic fatigue syndrome (ME/CFS), the lab focuses on a very basic and still very misunderstood aspect of CFS – why patients have so much trouble with exercise.

"Staci Stevens, the founding Executive Director of the Pacific Fatigue Lab explained. "Many researchers look at ME/CFS patients when they're at rest- at baseline. But as any ME/CFS patient knows, the real problems occur when their systems are under stress due to too much activity. We're taking a close look the physiology of CFS patients as they undertake the most stressful activity of all – exercise."

Since oxygen plays a key role in energy production, exercise physiologists use oxygen consumption during exercise to tell how much energy a person's body is capable of producing. Having people pedal a

stationary bicycle until they can pedal no more tells researchers how much air their lungs can take in

(Ventilation Max) and therefore how much oxygen they use to produce energy (VO2 Max) at their peak

level of effort. Since oxygen plays a key role in the energy production process this test effectively tells

researchers how much energy is being produced. Given the fatigue and post-exertional problems often noted in ME/CFS one would think aerobic exercise tests would have played a key role in legitimizing this disease, but instead they've given rise to further skepticism. The ability of many patients to pass them has added to confusion about a disease characterized by the word fatigue. How could CFS patients be *so* fatigued if they're able to generate normal amounts of energy?

"A New Approach. The Pacific Fatigue Lab researchers realized, however, that while researchers may have been asking the right questions they were asking them in the wrong way. Many ME/CFS patients can, after all, get through a single 'workout' or a single day or single afternoon at work okay only to 'crash' afterwards. Until now, though, no one's taken a close look at the ME/CFS patient's ability to produce energy when they're in a crash – an odd oversight in a disease whose symptoms are so tied to activity. (Indeed, study after study is showing that many variables which test out normal or near normal when ME/CFS patients are at rest are abnormal when their systems are put under stress). With the Pacific Fatigue Lab doing a new exercise testing regime, two exercise tests two days in a row and other tests (now known as the Stevens' Protocol) they've given the post-exertional problems ME/CFS patients have reported for so many years a chance to show up – and they have. Their results are both profound and disturbing. About half of the ME/CFS patients they've tested do, in fact, 'fail' or significantly under perform in the first single exercise test – they cannot generate normal

amounts of energy even when they're 'rested'. It's the rest of the patients that are so intriguing, though. When you give these patients a second test a day later many of them will fail as well-- and fail spectacularly. The amount of impairment the Lab sees can be astonishing - some patients suffer as much as a 50% drop in their ability to produce energy the next day. Ms. Stevens spoke of a twentysomething man whose next day exercise tests were worse than those of a normal 85 year old. In a hospital setting his cardiopulmonary exercise profile would suggest he had heart failure."

Why isn't the CDC following up on this most very basic research??? This should be their number one priority.

Giving someone anti-depressants does not treat PEM. There IS no current treatment for PEM, but if PEM is made a non-essential element of the CFS definition, there never will be a treatment for PEM, and PEM is precisely the reason why I have had to subsist on SSDI for the past 8 years. Prior to this I was very active physically. Now I can only do the bare minimum needed for survival - grocery shop, do the dishes occasionally (cleaning house is a thing of the past), empty the cat litter box once a week if I'm lucky.

Here is a comment of Dr. Reeves after the announcement by the Whittemore-Peterson Institute about the discovery of the XMRV retrovirus in CFS patients: "We and others are looking at our own specimens and trying to confirm it," he said, adding, "If we validate it, great. My expectation is that we will not."

This is not the comment of someone who is looking for the truth. His "expectations" are that he will find what he wants to find. Dr. Reeves needs to go. He is doing incalculable harm to the CFS community with his empirical definition and treatment proposals. We need someone with objectivity and a commitment to the CFS community - to actually listen to patients. Under Reeves' stewardship, millions of scarce funds have been wasted on a meaningless study using a meaningless definition.

Isn't it telling that the CDC has not been involved in either the discovery of the XMRV virus or the research by the University of the Pacific at Stockton into the reality of post-exertional malaise? When the CDC has supposedly been investigating CFS for over 20 years?

Additionally, it would be of great benefit to change the name of CFS, as I am afraid the name itself has discouraged any real research into this illness. I've seen several doctors over the past decade and only one has any inkling of what CFS is.

Sincerely,

Mary Barker