

CFSAC 27th May, 2009

First, I would like to thank Dr Wanda Jones for finally making these meetings accessible to those of us who are too ill to attend them. It's a project that we started working on in 2005 and ended up in the peculiar situation of the Office of Civil Rights being in violation of our civil rights. We are delighted that Dr Jones was able to break the log-jam and ensure that those who cannot attend are properly accommodated. We also thank Pandora for making it plain that there are many who wanted to attend and benefit from the meetings, but whose disability prevented them from doing so.

You will undoubtedly have heard that the definition of the illness which has come to be known as chronic fatigue syndrome is too broad. It is. The International Consensus Definition of '94 was a travesty. We were told that broadening the 1988 definition would result in better research, a greater likelihood that a cause of the illness would be discovered. Fifteen years later and we are far from seeing any indication that that assumption is correct. Those who got together for the consensus definition are still far apart. Their opinions are as polarized as they were when they created that research definition.

Which brings us to a question - why try to have a consensus definition at all? Science is not about consensus; it's about finding truth. Science is not democratic. If opinions vary as dramatically as they do re: CFS there is no point in trying to find a middle ground.

While one group continues to do fine research into biological processes, which cause our symptoms, the other steadfastly refuses to recognize that research. Are they aware of it? Do they read it? Do they even attempt to disprove it? No. The latter group simply insists that CBT & graded exercise effectively treat CFS - but ask them to define CFS & you will find that they consider it a somatization disorder, F48 in the ICD-10. Some do admit that there are cases which even their treatments do not work - subtle innuendo - those confounding patients do not want to get better. No consensus; flat out disagreement as to the nature of the disease.

A particularly offensive, and oft used explanation for wanting to stay ill is "secondary gain". Anyone with a passing familiarity with Taoism will realize that that philosophy posits that there is some good to be found in any circumstance. Q.E.D. there has to be some secondary gain. Many learn from illness. "Tuesday's with Morrie" makes that plain. But does that mean that Morrie wanted to have Lou Gerhigs disease to enrich but shorten his life? Unlikely.

Attempting to come to a consensus between two opposing groups was a mistake and is at best questionable scientific method. Science has nothing to do with a democratic vote.

The failure of the '94 criteria has led the CDC, has decided to broaden the definition further. This is outrageous. One of the principals in the CBT & GET School, Judith Prins, already shortened the '94 criteria in her writings. Using a little footnote she acknowledged that she had eviscerated the '94 criteria. With the ethics of Madoff, in subsequent writings she referred to that previous paper's version of the '94 criteria.

No. It's time to adopt the Canadian Criteria, which at least is written by clinicians who have long dealt with those suffering from the malady once known as myalgic encephalomyelitis. The further one gets from actual case studies, the further one gets from finding a way to ease suffering. It is unacceptable for one group of theoreticians to ignore replicable scientific studies and be considered the equal of those who approach the illness scientifically. Government money should be spent to replicate those studies as the CDC program seems incapable of coming up with much useful on it's own. And when I say replicate - please - replicate. Do not fund studies such as the one done by Freeman, which used different methodology. The first blood volume study used the CR51 method, Freeman used Evans blue dye.

So please play fair. You are playing with a lot of lives and a great deal of suffering.

I am thrilled to finally be able to stand up long enough to shower. My treatments? Neurontin, valcyte (no more HHV6) daily infusions of saline to increase blood volume, amantadine, various supplements including B-12 and weekly self-administered shots. I've even learned to access my port-a-cath. In over three years I've not had an infection. I did try CBT & graded exercise. The CBT is a useful adjunctive therapy. The graded exercise - and indeed the exertion necessary to get to the CBT classes - caused a relapse.

Jean Harrison