

Dear Sirs and Madams;

I am writing to post a comment for the Monday, May 10, 2010 CFSAC meeting.

I am Gerald R. Campbell, Ph.D. (Rockefeller University, molecular biology), now living on disability income as I have had CFS/ME for now nearly 19 years. I know enough cell biology, immunology, metabolism, virology, and experimental designs to know how to devise cogent ideas of how and why certain experiments are done.

I have seen the CDC, under Dr. Reeves, create a study which effectively ended research into HHV-6a and its large correlation with CFS and multiple sclerosis; This experiment was deliberately done with a reagent that did not distinguish between HHV6a and HHV6b - the former present in over 80% of CFS patients but less than 5% of healthy controls; the latter virus is found in 70+% of all Americans. The combined reagent could not distinguish between the virus associated with CFS and MS, and the remaining immunity from a childhood illness. Thus the CDC announced that they had definitively found that there was no link between hhv-6 and CFS - as was intended when that experiment was designed.

I have recently received a copy of the Forum, a publication of the National CFIDS Foundation. In that publication is an article concerning a challenge to Britain's National Health Service (NHS) clinical trial of Cognitive Behavioral Therapy (CBT) and Graded Exercise Therapy (GET). This prospective trial is known as the PACE trial, and has been devised by a small circle of psychiatrists, in conjunction with UNUMProvident, a very large (and particularly despicable, as shown by numerous class-action trial verdicts and settlements) American disability insurance seller. The stated goal is to prove that CBT and GET are the most effective treatment for CFS.

From the get-go, this trial has had its trial structure, types of measurements to be made, measurement outcomes and how they will relate to the success of the trial; how and where the data will be extracted, grouped, and otherwise massaged; all developed in secret. Recently Professor Malcolm Hooper has obtained some of the details of the design for the PACE trial;

this is the substance of his complaint to the British NHS about that trial.

The one fact that is readily accessible is that the entire trial is based on the Cambridge definition of CFS - which is basically, if you are tired for more than 6 months, you have CFS. There is no exclusion for pre-existing psychiatric conditions; but since the majority of people with major depression have fatigue as a symptom, they will be included in that group. As it is already known that CBT and GET are effective for treating major depression, it appears obvious that the inclusion of depressed patients in the "CFS" group is designed to provide a positive result, regardless of the effect on people who have CFS by any of the more stringent definitions.

While many of the details of the PACE trial design are questionable from a scientific standpoint, I believe that it is the instructions that are to be given to the therapists interacting with the patients directly that are particularly objectionable. As stated in the PACE trial plan, researchers are to "IGNORE SYMPTOMS ARISING FROM THE INTERVENTIONS, A SITUATION THAT MAY IN SOME CASES RESULT IN DEATH." (emphasis added)

I have never, in my years of going to doctors and going through clinical trials, even once seen a trial organized where the effects of the trial are to be completely ignored. I have not until now heard of a clinical trial where if an intervention starts threatening a patient's life, you are just supposed to ignore him - just let him go die. Historically this is an even worse abuse than the Tuskegee trial where they knowingly let infected individuals live infected in chronic progressive syphilis, until they died during the study or were so badly damaged that when the study ended they were made wards of the state.

These instructions alone are so abhorrent that this study should be abandoned, and the principal architects should lose their NHS grant privileges if not their medical licenses.

Why would this group want "CFS patients" to continue to not be treated, or even worse, to be treated as this trial intends? Why are CFS patients so threatening that the British NHS wants to literally kill them?

Is there a record of some new pathogen that modern medicine cannot identify and treat? Is it an escapee from a germ warfare

lab? Is this whole farce merely a political power play? It is likely that if this reform goes through then more such reorganizations will follow, leading to a time where every syndrome that a doctor sees is either so minor that it can be fixed immediately and cheaply; or designated a psychiatric disorder.

This psychologization process has been going on for years in Britain, and including more and more depressed, anxious, and other such psychiatric patient populations to make into what they call "a cohesive, well-studied group".

The reason that I am writing, and have extensively detailed this one British trial, is that, led by the CDC under Dr. Reeves' leadership, the U.S. seems to have been heading the same way. (In fact, the major designed of the PACE trial has been used extensively as a consultant by the CDC under Dr. Reeves.) Though they at least have not (as of yet, anyway) run medical trials whose major intent seems to be to kill off a whole class of sick people, the CDC has already proposed a definition of CFS that is largely like the Cambridge definition, and research funds have been either wasted on the study of psychological treatments, experiments designed to fail (e.g. HHV-6), or been outright stolen.

While I can only sit and watch as future policies are instituted, I believe that the change of leadership at the CFSAC, and at the CDC's Division of CFS, gives us a unique opportunity right now to begin to change the whole mindset that has operated there for years. Hopefully this country will step up and look at the medical evidence - the loss of mitochondrial function the day after exercise, changes in blood volume and ionic components, the symptomatic parallels that follow exercise, including nerve hypersensitivity, changes in excreted metabolites, variable sensory and focus of eyes, etc. etc.

If they manage that, maybe they will even run the Georgia childhood and teen epidemiologic study that they have had funded twice - and both times had its funding embezzelled.