

Public Comment
Andrew Bokelman

Hello. My name is Andrew Bokelman.

The HHS told us they welcome outside research about ME/CFS, but we should make sure it is evidence-based. This makes sense to me. And so now I call on the HHS to do the same. To make sure your information is evidence-based. I also ask that the HHS commit to being evidence-based, even if you have to retract something you said before, or remove it, or stop it.

And this brings me to the IOM contract. I looked at the IOM's past work with CFS. It is not evidence-based, even when this is required. An example is the gulf War Syndrome treatment guide, which contains a section for treating Chronic Fatigue Syndrome. The section recommends exercise, and to support this they reference a journal article that doesn't mention CFS. They reference an institutional web-based guide that cites no evidence. They reference the 1994 Case Definition, which says nothing about exercise. So at best, the IOM is speculating while looking at secondary resources. This is not evidence-based research.

I invite you to look at the hard copy of my testimony. I documented the few examples I gave. Spot check these to confirm what I said. Then contact me and I'll demonstrate that the rest of the treatment section does not consist of sound evidence-based research.

Or maybe you think what I say cannot be true, so no need to check. After all, the IOM is a high-profile research center that uses hand-selected panels whose work is reviewed by a separate review board. But look more closely. The review board cannot compel the primary panel to correct their choices. It can only suggest they do. Nor can they review the final draft. I confirmed this with IOM staff. They defend their laissez-faire method of quality-control by saying it preserves the independence of the panel. But the proof is in the product. And their product is not evidence-based.

Now, you could just ignore what I say and hope this won't be one more IOM disaster. But keep in mind, there is no way to undo this, once it is complete. So I call on the CFSAC and the HHS representatives here to do the right thing. Check my hard copy to see if what I said is true. And then follow up with me. Please don't dismiss my involvement because I'm a member of the public. I worked as an analyst for 20 years, and I am the one person who can articulate my reasons for believing the rest is not sound evidence-based research. The IOM is really not qualified to handle this project, and government regulations provide a way to terminate the contract.

Thank you for letting me speak.

References:

1. Gulf War and Health: Treatment for Chronic Multisymptom Illness
By Board on the Health of Select Populations, Committee on Gulf War and Health: Treatment for Chronic Multisymptom Illness, Institute of Medicine.

The CFS treatment guide begins on page 99.

2. Harber, V. J., and J. R. Sutton. 1984. Endorphins and exercise. *Sports Medicine* 1(2):154-171. <http://www.ncbi.nlm.nih.gov/pubmed/6091217> (accessed November 11, 2012).

This is the journal article that doesn't mention CFS. It did not report research on CFS. At best, the IOM is speculating, not presenting evidence.

3. CDC. Undated. Chronic Fatigue Syndrome: A Tool Kit for Providers. <http://www.cdc.gov/cfs/pdf/cfs-toolkit.pdf> (accessed November 13, 2012).

This is a web resource that contains no evidence. It is not a primary resource. And it is also the same Tool Kit that the CFSAC recommended be removed from the CDC website (see the recommendation here: <http://www.hhs.gov/advcomcfs/recommendations/06132012.html>).

4. CDC (Centers for Disease Control and Prevention). 1994. Chronic Fatigue Syndrome: The 1994 Case Definition. <http://www.cdc.gov/cfs/case-definition/1994.html> (accessed November 13, 2012).

This the 1994 definition of Chronic Fatigue Syndrome. The 1994 criteria (and the web page they are on) says nothing about exercise, one way or the other