

My name is Craig Maupin, and I have suffered from this illness for about 20 years.

Most of my input will be a bit different, as I would like to respond to the proposed 5 year plan. I have several points I would like to mention.

1. I couldn't help but notice Dr. Reeves's summary of the Atlanta Stakeholders meeting. Having listened to that meeting, I felt Dr. Reeves misportrayed the tenor of the input. The input at the meeting challenged the objectivity of the CFS program and whether the clinical picture of CFS at the CDC is accurate.
2. I also don't think the 2008 review panel reflects a diversified or representative group of theorists of the causes of CFS. Dr. Reeves described Dr. White as an expert on autonomic dysfunction. In Atlanta, he described Dr. Gudrun Lange as a "neurologist". These researchers are classified as a psychiatrist and psychologist, respectively.
3. Is in regard to Rebecca Artman's question to Dr. Reeves (does he believe CFS is psychiatric in origin). Why would Dr. Reeves choose to collaborate predominantly with psychiatrists for what he refers to as a "non-psychiatric" illness? In Atlanta, Dr. Reeves mentioned that the CDC needs to "walk the walk", but I felt that his answer to Ms. Artman did not correlate with his walk.
4. My next comment relates to objectivity and openness of the CFS program-particularly regarding stewardship of its influence.

In 2006, the CDC held a press conference on chronic fatigue syndrome.

At the press conference, there seem to be strikingly different interpretations from CDC's CFS research team. One perception from a female researcher -no longer with the CDC--was as follows:

She said: "We've been able to show is that CFS is very heterogeneous, it's not just one thing.... We've actually demonstrated that there are probably at least four or five molecular profiles or groups of people that make up this complex of CFS..."

Dr. Reeves portrayed the study conclusions differently. He said: "This study demonstrates that the physiology of people with CFS is not able to adapt to the many challenges and stresses encountered throughout life ..."

These differences goes to the heart of responsible stewardship of the CDC's influence.

Why make an announcement based on a pathology-specific study design -a study that tossed out all results not conforming to the HPA axis? Why not wait for a study that

allowed for the entire genome? Or, at least wait to proceed at least until journalists were given access to the study?

In that same vein, and pertaining the five year plan, Dr. Reeves talked earlier about toward educating physicians and the public about prevention and control. Why not wait until studies have been published by the CDC program on prevention control? It is poor stewardship of the CDC's influence to begin educating clinicians before investigating--and being certain about --the materials.

Dr. (Wanda) Jones made the comment that this committee sees CFS through a gendered lens. I am pleased about that. The committee should be concerned about the current portrayal of CFS by some CDC contractors. This is especially true with the CDC's contractor at Emory University. We have seen studies from the team at Emory portraying parents of children with CFS as abusers. We have also seen studies contending CFS may be a response to national disasters. These are study conclusions one would expect from a program suffering from bias toward women's illnesses.

1. I have several recommendations:

- The CFS program needs to encourage inclusion of researchers who espouse other theories --Dr. Glaser and Dr. Klimas touched on this. Theories beyond stress response are often not accepted by the CDC team. NIH showed they could fund such research with their Tufts Univ... study. So, it can be done.

Researchers who espouse other theories of CFS are prevalent. They are not prevalently working with the CDC. They are also not being chosen to review its program. This issue, whatever the cause, needs to change before asking for more funds.

- Transparency. I still don't find the level of transparency acceptable. One of the questions raised in Atlanta, was did Dr. Reeves receive compensation for classes on stress/fatigue he taught for his contractor at Emory University Department of Psychiatry? We still don't have an answer.

To wrap it up, I would like to say that CFS sufferers I speak to are NOT as concerned about overall amounts of output. They are also NOT as concerned about overall spending levels. They are VERY concerned about objectiveness of CFS research, about openness to all theories, and an accurate picture of the illness being portrayed by federal agencies. These are the things I hope the CFS Advisory Committee will focus on.

I am impressed with your work, your openness and your thoroughness so far.

Thank you for your time and consideration,

Craig Maupin