

## **The Real Culprits -**

### **Testimony before the CFSAC Panel (May 2009)**

**by Cort Johnson -**

Phoenix Rising (<http://aboutmecfs.org>)

We are in the middle of the CDC's 10 year review. Patients from across the spectrum are understandably upset that little has been done in the past 20 years that has assisted them with this disorder. Many have watched decades of their lives lost in a wasteland of fatigue and pain that they do not understand and can find little relief from. They've seen doctor after doctor in a fruitless search for wellness. Much of their anger has been focused, rightly or wrongly on individual investigators.

I would argue, though, that the real culprits in this story are not researcher X or Y but the people behind the scenes - the administrators - mostly unknown to the ME/CFS community - who have decided that no matter what its consequences or how many it effects this disease is not worth funding. Whatever the failings of any individual researchers they pale beside the almost criminal disregard shown by the federal agencies to the sufferers of this disorder.

One wonders how CDC personnel get the audacity to get up before an audience of suffering patients - as they did during the CDC Comment session last March - and say that they care. One wonders what that brave CDC staffer who went public with her struggle with ME/CFS CDC thought of CDC personnel using her story as proof that they are committed to assisting people with ME/CFS when they are spending, based on their own populations estimates, \$1 a year on each patient. Spending a dollar a year per patients does not demonstrate commitment; in fact it demonstrates just the opposite. If the CDC estimates are correct then the CDC is spending pocket change on a disorder that effects about 1% of the population.

It indicates that nothing has really changed in the last ten years at the CDC and that the CDC still in its heart of hearts believes that CFS patients are malingerers. I can't find anything else to justify spending pennies on a disorder that has 25% disability rates and causes 25 billion a year in economic losses. Statistics like that make me believe the CDC is not a data-driven, objective, scientific organization at all but that it's a good old boy's club riven with superstition and ad hoc reasoning. If the CDC or the NIH was driven by data then data like that would have to call forth some action. But instead of increasing funding as the estimates of ME/CFS have gone up the CDC has cut funding. Either they don't believe the data or they don't believe the disease or they're committed to something other than 'disease control' at the agency.

The same is true at the NIH. In fact the only message one could conceivably get from the program at the ORWH is that not only is the NIH not committed to this field but that it would happy to see it die. I ask you why, given the record of the ME/CFS program at the ORWH - three research centers closed, one conference in the last eight years, one small RFA that was only a quarter funded, an over 50% decline in funding, 8% new grant acceptance rates, program announcements that aren't even regularly updated - why any researcher would even think of entering this field? You don't need kill a program to allow it to die as viable entity - all you need to do is watch it go down the drain.

Because the NIH has done virtually nothing to build a struggling field the biggest funding boost in the NIH's history ever will pass like a mirage in the desert for ME/CFS researchers. Almost ten years ago the NIH moved the ME/CFS program to the ORWH which was the equivalent of sending it to Siberia. They

gave the ORWH no money run it and counted on the other Institutes - none of which had responsibility for it - to fund it. That has turned out to be incredibly naïve. In the last five years the budget for chronic fatigue syndrome research at the NIH has tumbled 50% - the highest percentage loss of any disease the NIH funds and yet the NIH has done nothing to stem it.

I say to the CDC and NIH administrators that your words are empty and that with your miserly funding you've turned your backs and continue to turn your backs on an enormous number of suffering people. The CDC should be about more than controlling the diseases that they want to control, the NIH should be more than the defending the health of the people that they want to study. Both organizations should be committed to more than furthering the career paths of their investigators. They should have the guts to tackle the messy problems as well. The fact that people are suffering should count for something.