Public Comment

Joseph D. Landson

My name is Joe Landson. I have been ill for eight and one half years. Thank you for hearing me out.

In reviewing the list of CFSAC recommendations, I found only one to endorse today. Not because the others are unworthy, but because they are all dependent on the one I promote now:

"Instructing the [National Institutes of Health] to issue an RFA (funded at the $7-10 million range) for projects to establish outcomes measures for ME/CFS diagnosis, prognosis and treatment which would include but not be limited to biomarker discovery and validation in patients with ME/CFS."
(This recommendation is from just six months ago, in October 2012.)

Without a way to detect and measure this illness, I feel that all the other recommendations are irrelevant. (Shows elephant.) We can't forget other recommendations, because, as we know, irrelevant never forgets, but irrelevant can't help us solve this illness. Here are three reasons why NIH research funding and focus matter:

1. As the December 2012 advisory committee meeting on Ampligen made clear, we have no consensus outcome measures. At that meeting, the Food and Drug Administration and Hemispherx did not seem to share a frame of reference for measuring the drug's effectiveness and safety in trials. How can we proceed without knowing what we are measuring? I don't see how we can choose new illness names, acronyms, educational materials, or disease definitions until such time that we have a credible, evidence-based, consensus way to identify and measure the illness. We don't have one now.

2. One of the first things a well-known researcher ever asked me was, where are the patients? Why aren't more of them here at the meeting advocating for change? Well, researchers are not the only ones who need outcome measures. To justify the cost in patients' health, time, and money in dragging themselves to these meetings, the meetings would have to produce better outcomes than… more meetings. Increased research funding could be a great way to do that; however, as the 2012 National Institutes of Health numbers show, research spending for ME/CFS declined to its lowest level since 2008. Some money that was spent went to proving what ME/CFS is not, rather than what it is; some went to illness coping schemes; some went to research seemingly unrelated to ME/CFS. With results like that, how can I in good conscience encourage other patients to attend, let alone have hope? So,

because I live nearby, you are stuck watching variations on my animal routine, over and over again.

3. Last but not least, the government has a choice. It can continue to use vague measures to pay out disability benefits indefinitely to both current and future patients -- or it can fund research to establish a firm scientific basis for identifying, demarcating, and treating this illness so that more can return to work as productive members of society -- people like attorneys and professors, mine safety workers and promising young students, doctors and Arabic translators.

I thank the FDA for their recent ME/CFS conference. Several officials there praised my testimony and said it helped. I am honored if this is so, but it's hard to believe we're making progress when the outcome measures that we patients look for – focused research funding, approved treatment, and improved information to doctors – are arguably heading in the wrong direction. I implore the NIH to allocate and disburse the resources necessary for researchers to frame this illness properly.

Thank you.