

TESTIMONY DELIVERED BY JENNIFER M. SPOTILA
TO THE CFS ADVISORY COMMITTEE
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Every six months or so, this Advisory Committee hears reports from federal representatives, along with testimony from patients and advocates. Every six months, you make recommendations, and then you return to your offices to deal with all the other issues that demand your attention.

For the federal ex officio members of this Committee, that means work on a wide variety of health priorities, including pandemic influenza, HIV/AIDS, heart disease, food safety, and bio-terrorism. Let's face it: your work requires you to put out fires across the public health landscape.

Let's face something else: Chronic Fatigue Syndrome is not one of those fires. Not to your agencies or to this Department of Health and Human Services. I doubt very much that any federal employee in this room has a boss who regularly asks you, "What do I need to know or do about CFS today?" This lack of urgency is pervasive throughout the Department, and it hampers the work of the CDC, NIH, and the work of this Advisory Committee itself.

I call your attention to one example, which others have noted today. There are 215 illnesses and conditions listed on NIH's Estimates of Funding. Out of those 215, only one line item is projected to have less funding in 2010 than in 2009: Chronic Fatigue Syndrome. One out of 215. CFS funding is projected to drop from \$4 million in 2009 to \$3 million in 2010. This 25% cut in funding - especially when no other category is being cut - is emblematic of this entire Department's lackadaisical approach to CFS.

We frequently hear from NIH, as Dr. Hanna said today, that the funding level is dependent on quality grant applications coming in first. I suppose we should conclude, then, that NIH is overwhelmed with quality applications for research on Pick's Disease which affects fewer than 200,000 people in the US, because that category is projected to receive a 30% increase over its funding in 2008. I don't believe that the members of this committee should be satisfied with that explanation. Even if the CFS funding level stayed the same - even if it was increased by 25% - you know it is in no way proportional to the burden of CFS on our economy and our people.

This paltry response is possible because CFS is not seen as a real public health crisis.

Patients and advocates make many requests for action at these Advisory Committee meetings. We ask for big solutions on a short timeline. There are many barriers to solving CFS, and we want you to help remove them. But we feel like our public health agencies are fiddling while our Rome burns down.

I make one request of this Committee today. I ask that, in cooperation with Dr. Jones and her staff, you brief Secretary Sibelius on Chronic Fatigue Syndrome to inform her that it is a public health crisis requiring her personal attention and the attention of her Department.

You have the collective knowledge that CFS is a devastating illness. You also have knowledge that CDC and NIH are not investing research dollars in proportion to the burden of CFS. This knowledge creates obligation. It is your obligation, as a Committee, to ensure that the Secretary is fully briefed with this same information about CFS.

You must push for awareness and action within DHHS because no one else can. The basic premise of this Advisory Committee is to ensure the Department is doing what is necessary and what is right to solve CFS. In order to do that you must first gain Secretary Sibelius's attention. My single, simple request of you today is that this Committee put CFS on the Secretary's radar. Until Secretary Sibelius recognizes CFS as the crisis that you already know that it is - until word comes from the top down that CFS is a fire - I fear nothing will change.