Testimony

Charlotte von Salis, J.D.

Hello. My name is Charlotte von Salis. I was struck down with ME/CFS in 1990 and continue to be quite sick. My testimony today is directed at the NIH representative on the Committee.

Pat Fero and I have meticulously investigated suspicious grants awarded for CFS research from 2000 through 2010. Our work reveals that an estimated $18.5 million was spent on non-CFS studies. (Please refer to Pat's testimony for specifics).

This is appalling. This money was used for purposes that materially deviate from their intended use. We will follow up with the appropriate authorities.

It is also appalling that NIH lied to us by presenting these grants as CFS expenditure. Considering the paltry funding CFS receives (a whopping $6,000,000 for 2010), it is especially insulting. Even average taxpayers would be unhappy to know about this misappropriation of federal funds considering the tight economy.

The $18.5 million figure does not even include questionable grants, often renewed for years that resulted in little of substance for CFS. One of my favorites involves the use of Viagra for symptomatic relief of CFS. Don't laugh; the hypothesis is that Viagra could improve blood flow to the brain. However, after five years of funding to the tune of close to $180 thousand (actual figure $178,019), some of which is tied to a clinical trial, this researcher has not managed to complete enrolling the 30 people he wants to study.

Why is this happening? Take a look at the Funding Opportunities for CFS listed on the Trans-NIH ME/CFS Research Working Group website. The two that are specific to CFS really aren't. The NIH

Institutes and Centers that might fund such grants are looking for applications that study CFS as a co-morbid condition. This encourages researchers to throw in the words “Chronic Fatigue Syndrome” in an attempt to garner some funding for their non-CFS interests. As a result, we end up with studies such as “Neurohumoral and Hemodynamic Profiles in Postural Tachycardia and Chronic Fatigue Syndromes”, implying CFS is not worthy of study by itself.

We know better. There have been numerous studies on the pathogenesis and potential etiology of CFS. There’s no reason that these earlier and smaller studies cannot be built on. Continuing to study symptoms is a waste of time and money.

What’s sorely needed is more targeted funding. I ask that Dr. Collins give us back that misspent funding as a Request for Applications with $18.5 million attached. I ask that this RFA be phrased to encourage clinical trials of new and existing drugs (such as Rituximab) as well as larger studies to follow up on the evidence of biomarkers and possible etiologic agents like low natural killer cell function, abnormal cytokine activity, and reactivated infections.

You owe us that much, at least. Dr. Collins can make this happen without any directive from Secretary Sebelius.

[Note: I have used CFS throughout my testimony because all research to date has been on CFS despite evidence that CFS is based on an outbreak of Myalgic Encephalomyelits or M.E. in the mid-1980s.]