

Testimony

Mike Munoz

I am executive director of the Rocky Mountain CFS, ME and FM Association and on the Steering Committee for the coalition 4 ME/CFS. The coalition made the proposal to NCHS to have CFS restored to G93.3, as it is in the World Health Organization's ICD-10.

The Coalition 4 ME/CFS has nine member organizations. For years, the CFSAC and other experts in the US noted that the classification in the ICD clinical manuals in the US should be restored to match the WHO ICD-10. Commonly, a medical professional makes such proposals. However, despite the CFSAC recommendations in 2004 and 2005 and this year that this should be done, no one had taken the initiative to make a proposal. Therefore, the Coalition 4 ME/CFS stepped up and presented a scientific proposal with the assistance of scientists.

Since the Coalition made the proposal, in harmony with the CFSAC recommendations, we thought it odd, and we were troubled that we were not granted some time on the morning of Nov. 8 when this committee was discussing the issue. I was put on the waiting list, but I am thankful to have the opportunity now to address some issues.

First, I want to make clear that CFS is already classified in the index area of the WHO ICD-10 under G93.3. We and you are not asking for something new or different. Quite the contrary, we want to get the US to come in line with the rest of the world. The world is an international community and CFS is an international disease. Is this disease somehow different in the US than the rest of the world? Of course not. So why should the classification of it be different in the U.S.?

The coalition includes organizations that have existed at least 10 years. And other organizations that have been in existence longer have informed us that they will be sending letters of support of Coalition Option.

Second, having CFS listed under “chronic fatigue unspecified” erroneously indicates little is known about this disease. Having CFS coded the same as ME, as the rest of the world does, indicates CFS is a neurological disease with muscular pain and inflammation in the brain or spinal cord. Studies show this is the case with CFS cohorts. Also, research now recognizes the CFS of the US is ME in other countries as many studies refer to the disease using both terms. We must end the multiple names, based on national preference, and multiple criteria that impede research progress. By accurately showing what has been labeled as CFS in the US is actually the ME of Europe and recognizing that ME research applies to those with CFS diagnosis and CFS research applies to those with ME diagnosis will advance scientific and clinical understanding of the disease. And we must distinguish and eliminate from our cohorts those who have “chronic fatigue unspecified.” Let’s get this disease less complicated and make progress toward it having one name and one definition. Coalition Option 1 does that. NCHS Option 2 does not.

Third, the premise the NCHS gave for separating CFS from ME and PVFS is that CFS does not have a viral trigger. As you all know, and research has shown, this is incorrect. CFS often, in fact in majority of the cases, has a viral trigger. Even the CDC acknowledges that.

Fourth, to all those, including myself, who do not like the definitions for CFS and do not like the term, note that as long as it has its own diagnostic code, it will continue to exist as a separate illness from ME. And in the US, guess which one will be studied and be diagnosed? However, if you want CFS and its criteria to disappear, then you have to indicate it is actually ME they have. By putting CFS in the code with ME, you show that. We want to make the CFS term obsolete. That won’t happen as long as it has a separate diagnostic code.

Fifth, the Coalition is very concerned and strongly discourages NCHS Option 2 because it makes ME and PVFS get a new label of “other chronic fatigue syndromes.” I don’t even have to explain why this is a huge problem.

Sixth, the Coalition’s Option 1 is in line with the National Institutes of Health that now refers to the disease as ME/CFS. It is in line with the very popular Canadian Consensus Criteria, which has stricter criteria for the one disease that

it labels as “ME/CFS.” It is also in line with the new International Consensus Criteria that says in the first sentence: “Myalgic encephalomyelitis, also referred to in the literature as chronic fatigue syndrome, is a complex disease involving profound dysregulation of the central nervous system ...” Notice, one disease, two terms, is dysregulation of the center nervous system.

A rose by any other name smells just as sweet. And ME, by any other name, is still a Central Nervous System disease that often has viral triggers and is disabling.

Thank you for the opportunity and the Coalition 4 ME/CFS looks forward to working with the CFSAC on future initiatives.

I would like to thank the committee for the opportunity to speak