

Public Comment
PANDORA Org Testimony

Little Orphan Annie desperately wanted to be adopted. Getting adopted into a home meant someone with resources cared about her and provided for her needs.

ME/CFS is orphaned. It has not been adopted by a medical specialty or medical professional organization of certified specialists. And primary care physicians are scared of it because of the complexity.

In 2013, our organization attended an IoM workshop of medical school deans. At that time, we were researching how to fix this problem. A medical school dean told us in casual conversation that it will be quicker if we can get ME/CFS and the other neuro-endocrine-immune diseases adopted in an existing specialty instead of trying to create a whole new specialty.

She explained that sleep medicine and allergy medicine became subspecialties of pulmonology. As you discuss collaborations post-IoM, we recommend you include a medical professional organization from an existing specialty. They can help spread the information to clinicians who can implement it. But which one?

There are good reasons to have it in neurology:

First, ME and CFS is already under neurological diseases in the ICD-10-CM, and ME and CFS is under neurological diseases in the WHO ICD-10.

Second, brain abnormalities are well-established in the science of this disease, and brain and neurocognitive tests have been claimed as possible biomarkers.

Third, the American Academy of Neurologists just announced their new journal on neuroimmunology and neuroinflammation, a perfect fit for this disease.

Fourth, centers of excellence, such as the one at NOVA, are using the term “neuroimmune” to describe ME/CFS and the associated diseases they treat and study.

“But we don’t know the etiology, yet. It might be the cause is in the immune system,” some might say.

Well, take MS as an example. There is a strong immune and likely infectious etiology. Yet, it has been adopted in neurology based on the effects. Same should be true of ME/CFS. It doesn’t have to be a perfect fit. Who would think all of sleep medicine should be in pulmonology?

This disease needs to have a group of certified specialists trained to provide clinical care. It needs a widely respected medical professional organization to set standards and guidelines.

Therefore, we recommend you include the American Academy of Neurology in any and all government, other collaborations on ME/CFS, including the post-IoM collaboration you will discuss on day two. In fact, we think a representative from that organization should be added to this committee. We plan to work on this goal from this point forward and welcome anyone interested in assisting us to contact us. Help us get adopted so we aren’t orphans any more.

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