

December 23, 2013

Attn. Ceci Mundaca-Shah, MD, MPH, DrPH  
Institute of Medicine of The National Academies  
500 5<sup>th</sup> Street, NW  
Washington, DC 20001

Dear Dr. Mandaca-Shah,

We are pleased with this opportunity to make recommendations concerning the provisional committee members for the Institute of Medicine (IoM) study on Diagnostic Criteria for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome.

Myalgic encephalomyelitis/chronic fatigue syndrome (ME/CFS) is a complex, multi-systemic disease with many different case definitions that confuse medical professionals, stakeholders and the public. Some of these different definitions are based solely on symptoms that are also sometimes experienced by healthy people and people with other conditions.

In addition, the name “chronic fatigue syndrome” contributes to the widespread confusion in the medical community on the difference between ME/CFS as a very serious disease and chronic fatigue as a symptom of many different conditions, including psychological and psychiatric disorders.

The confusion from inadequate disease definitions and the name “chronic fatigue syndrome” has led to significant delays in diagnosis and recommendations of inappropriate treatments. The name has significantly impeded patient outcomes and research over the years.

The IoM is in a unique position to develop a widely accepted criteria for correctly distinguishing people with this debilitating disease. As mentioned in the statement of work for this study, we also see a tremendous opportunity for the IoM committee to recommend the harmful term “chronic fatigue syndrome” be removed from all medical terminology and the more scientific, historic and appropriate name, “myalgic encephalomyelitis,” be used in referring to the disease.

In collaboration with other organizations and other patient advocates, we researched each of the provisional members. Overall, we are pleased with the diverse perspectives and expertise the provisional members bring to this complex disease. We acknowledge that the IoM evidently put special effort in creating an overall balance. We also appreciate the IoM recognizing the importance of appointing a majority of ME/CFS experts on the committee, including quite a few that patient organizations and patients recommended to you.

However, we see a few gaps in both amount of ME/CFS expertise on the prospective committee and expertise in certain aspects of the disease, such as cardiology and endocrinology.

Below, we have listed other experts. From this list, please add another ME/CFS researcher / clinician, another disease definition expert, another infectious disease expert and a cardiologist.

- **Derek Enlander M.D.** - Director of the ME/CFS Clinic in New York and research physician on the faculty of Mount Sinai Medical Center, New York. It is a multidisciplinary research group involving internal medicine, pulmonology, cardiology, immunology, and genomics. The center is involved in a study of post-exertional malaise (PEM) in ME/CFS. (researcher / clinician)

- **Kenny De Meirleir, M.D.** - Medical Director at The Whittemore Peterson Institute for Neuro-Immune Disease. Dr. De Meirleir has extensive experience treating patients with myalgic encephalomyelitis (ME) and other chronic immune diseases. Much of Dr. De Meirleir's success with his patients stems from his comprehensive treatment approach that includes appropriate dietary changes, immune support, and specific drug treatments for chronic infectious pathogens. Dr. De Meirleir was a professor of physiology and internal medicine at the Vrije Universiteit Brussel in Belgium. (researcher / clinician)
- **Andreas Kogelnik, M.D., Ph.D.** - Founder of Open Medicine Institute. Dr. Kogelnik specializes in bioengineering, molecular biology and genomics, microbiology bioinformatics and software. He received his medical degree from Emory University and his Ph.D. in bioengineering from the Georgia Institute of Technology. His doctoral research at Stanford University was in microbiology, immunology, and bioinformatics exploring host-response profiles in severely ill patients, and data mining clinical and genomic data for translational applications. He has extensive clinical and research experience in ME/CFS. (researcher / clinician and infectious disease)
- **Leonard Jason, Ph.D.** – Director of the Center of Community Research and Psychology Professor at DePaul University. His publications have analyzed the effectiveness and inadequacies of existing ME/CFS case definitions and have shown that measuring frequency and severity of symptoms distinguishes patients with ME/CFS from those with fatigue alone. (disease definition researcher)
- **Ian Lipkin, M.D.** – Director of the Center for Infection and Immunity at Columbia University. An epidemiologist by training, Dr. Lipkin is known for detection of new pathogens and the role of infection in neurologic diseases. He also has experience in ME/CFS-related research. (infectious disease expert)
- **Jose G. Montoya, M.D.** - Director of the Stanford ME/CFS Initiative and Professor of Medicine in Infectious Disease at Stanford University Medical Center. Dr. Montoya is a clinician-researcher in ME/CFS and also studies the role of infection in chronic disease. (researcher / clinician and infectious disease)
- **Julian M. Stewart, M.D., Ph.D. or Marvin S. Medow, Ph.D.** - Both from the Center for Hypotension, New York Medical College. They have expertise in postural orthostatic tachycardia syndrome, vasovagal syncope, and/or neurally mediated hypotension, all of which is very common in ME/CFS. (cardiologists)

## Concern over Possible Bias

As mentioned earlier, research has shown that ME/CFS pathophysiology is biomedical, not psychiatric or psychological. Yet, an entrenched bias among many medical professionals has developed that the symptoms are from deconditioning or a mental health condition. So, we are very sensitive to any hint that the provisional committee members may have an outdated and disproven belief about the disease. A person with such thinking may not be open to discarding their inaccurate paradigm when presented with today's evidence.

Based on this concern and since we do not have access to these individuals, we ask you do further research into these individuals and discuss with them their current beliefs on the disease:

- **Margarita Alegria, Ph.D.** – She co-authored studies that look at the prevalence of neurasthenia, the comorbidities and association with impairment. Some of the statements in

those studies make us question if she confuses CFS and neurasthenia. We think this should be explored further.

- **Cynthia Mulrow, M.D.** - In 2001, Dr. Mulrow led the last systematic evidence review on chronic fatigue syndrome conducted by the Agency for Research and Healthcare Quality. The document supports cognitive behavior therapy and graded exercise therapy as treatments for CFS. We recognize that statement was made 12 years ago and is based on a review of the literature available at that time. She also acknowledged the varying definitions in the research review confounded the analysis. The studies promoting CBT and GET have since been criticized for their methods and interpretation of results. So, we would be concerned if Dr. Mulrow currently strongly supports cognitive behavior therapy and graded exercise as the best treatments for ME/CFS, which might reflect the belief that the disease is primarily psychological or psychiatric. This should be explored further.

We again want to thank you for the thoughtful approach reflected in the IoM work on this very important task that will affect patients' lives for years to come. Please contact us if you have any questions on our recommendations.

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Founder, CEO and President of Randave LLC  
Adjunct Faculty at University of Phoenix  
PANDORA Org Board Member

**Sister Sandra Duma, OSF, MS Ed**

ME/CFS patient since 1980  
Housebound since 1996

**Juanita Thatcher**

Patient Advocate

**Amanda Rankin**

Patient Advocate

**Shannon Cassidy**

Graduate Certificate Student, Public Health  
PANDORA Org Secretary

**Cort Johnson**

Founder Health Rising  
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**Pat Vogel**

Patient Advocate

**Donna Nowak Robillard**

Patient Advocate

**Wilhelmina Jenkins**

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