

To the Chronic Fatigue Syndrome Advisory Committee, HHS

The P2P report - indeed, almost everything coming from the federal government - suggests that there are no objective tests for CFS or ME.

First, CFS and M.E., Are not the same thing, though many M.E. Patients (particularly in the US) have CFS diagnoses. It is important to recognize the differences. M.E. has a history dating back to the 1950s, when the British Commonwealth nations adopts it as a replacement for the diagnosis "atypical polio." The US chose instead to use Epidemic Neuromyesthenia. While specialists such as Alex Shelekov recognized that the two were the same thing, the practical effect of the different names was to separate research and information, such that few in the US knew about M.E. By the 1970s, for a number of reasons, the name "Epidemic Neuromyesthenia" fell into disuse. Had the Tahoe-Truckee outbreak occurred in Surray, UK, instead of Nevada, the patients would have been diagnosed with M.E., the supposedly temporary name CFS would have been unnecessary, and we would all be much further along.

The category CFS has causes a great deal of confusion among both clinicians and researchers, leading to prejudicial treatment and very little research. The committee needs to distinguish between the two conditions. M.E. is a disease. CFS is a social construct, meaning different things to too many people. The two are not the same.

It is most important that if you use the name M.E., you MUST recognize its history, and, in particular, the work of earlier specialists such as Melvin Ramsay in the UK, who wrote a textbook on M.E. In the 1980s.

Second - and for me, most important today:

For a SUBSET of us, there are clearly OBJECTIVE TESTS that can lead to SUCCESSFUL TREATMENT. I would like to request that we be recognized as having a specific disease and that these tests and avenues for treatment be given funding by NIH. It is cruel to hide what we know on the requirement that it fit all patients, given the confusion over definitions.

These are all tests that have consistently reflected the extent and severity of my own bout with the disease, as I am a member of this subset. I share this with many others. We do not know which comes first, but we have enough correlations to move forward if NIH would provide funding.

Immune testing:

- \*\*Natural killer cell function - used by a number of clinicians now
- 37 kDa Rnase-L defect
- Abnormal cytokine patterns

Active or reactivated Viruses:

Most important: the beta herpesviruses plus EBV:

- HHV-4 - EBV
- HHV-5 - Cytomegalovirus
- HHV-6 - both variants, particularly A
- HHV-7

Coxsackie B (also found in M.E. Research before the phrase CFS was introduced -----

Viruses others I know have tested positive for, but I do not

Parvovirus  
Chlamydia  
Adenoviruses

Treatments: immune and antiviral medications

Other objective tests that can show abnormalities:

MRIs, fMRIs, SPECT scans  
CPET testing

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Correlated conditions that should be tested for and treated:

NMH/POTS  
Hypothyroidism and Hashimoto's  
Secondary and situational depression  
Sleep difficulties  
Muscle pain

This subgroup of patients should have access to and be encouraged to use effort-saving devices such as wheelchairs. Unless being successfully treated for underlying infections, they should avoid activities which raise heart rate more than 100 bpm. They should rest when their body tells them to rest, including lying down flat if it allows them more energy with which to work later.

But it is MOST important - it is CRITICAL - that they be recognized as patients with long-term neurotropic viral infections, and treated carefully as all such patients should. There are not enough immune and antiviral treatments out there, and treatment is individual, but they need to be tried because if the infections and immune defects can be found and brought under control, patients in this subgroup CAN IMPROVE.

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Finally, there needs to be more research on the most severe cases; those who are mainly bedridden and/or housebound. Those who need a caregiver. We know too much to allow them to remain invisible and untreated.

Thank you for your time.

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