

## Testimony

R.R.

Dear Dr. Jones,

I am so glad that a renewed and serious attention is being directed to the devastating illness ME/CFS. Thank you for facilitating this shift towards greater awareness in the understanding and eradication of this serious neuroimmune disease.

I urge you to engage in formal exchange with experienced doctors who are specialists in ME/CFS and to open a continuous dialogue with ME/CFS researchers and patient groups in order to reach consensus on a useful, universal clinical definition for the illness as well as to better understand the gravity of the disease so that we may proceed with immediate action toward finding and implementing a cure.

It is of the utmost importance, after decades of neglect and minimizing, to recognize the prevalence of this disease and the potential dangers of its association with a human gammaretrovirus. In this light I beseech you to create funding for the scientific study of this disease and its treatment, and most importantly to establish ME/CFS Centers of Excellence throughout the country for this purpose, and to serve patients' needs for appropriate treatment facilities. Please give special consideration to the Whittemore Peterson Institute, who have been vanguards in the research of this disease, the University of Miami, where Dr. Klimas has tirelessly been offering hope and comfort to patients, and to all researchers and physicians who have been selflessly devoting their time to the study of this life-destroying illness, including Drs Natelson, Montoya, and Bateman.

Please encourage more research in this field by designating funds for its study, so that other researchers and doctors interested in ME/CFS might be encouraged to devote their expertise to it. Please stimulate an intramural approach so that the multiplicity of bodily systems affected by ME/CFS can be investigated in a cohesive and comprehensive manner. We need effective treatment today--as much as it was needed twenty years ago. Please help to make this happen so that countless millions of people do not continue to suffer as I have.

It is crucial that physicians and clinicians become much better educated about this disease. As it stands few doctors know anything about it beyond the word "fatigue," and are often taught to characterize it, despite overwhelming clinical evidence to the contrary, as a psychological disorder. This is a dangerous and egregious vacuum in the medical community and it needs to be filled now with accurate and up-to-date information. Patients and doctors alike need your assistance in overcoming the many obstacles--financial, educational, and political--to the successful cure for ME/CFS.

Thanking you in advance for your kind attention,

R.R.

ME/CFS patient since 2005