Testimony

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I am Dr. Janet Smith, a CFS patient, a practicing physician, and a member of the board for Simmaron Research, Inc. I would like to thank the CFSAC Committee for allowing me to testify via telephone.

My urological practice started in 1987. I became ill with ME/CFS February 1994 after a viral infection turned to pneumonia. I have been one of the fortunate people because I can still function in a modified manner. However, the last 72 hours has proven that each day is a challenge. I felt very well Saturday morning then in the evening I started with aches, headache, chills, etc and by Sunday morning could not even get out of bed to go to the bathroom. I was in tears, unable to make a phone call for help, unable to sit up because the muscle aches were so bad. Then I realized that this is what most people with ME/CFS experience every day without hope for the future and the feeling that life can't go on like this. Suicides are occurring routinely in the ME/CFS patient group. We need hope. We need help. We need it NOW-not in 5 years, not in 10 years, but NOW. I am asking you committee to convey to all, the ME/CFS is real and we need answers, diagnostic markers, and treatments NOW. Physicians who have treated both AIDS patients and ME/CFS patients concur that ME/CFS patients are much sicker than their HIV patients.

In the last 2 years the ME/CFS community has undergone tremendous highs and lows. We need to carry what energy we have right now to say that we need help. There is new research for diagnosis and treatments that are occurring in the world. Norway physicians are using a chemotherapy drug with good results. Researchers at Bond University, Australia, are looking at biomarkers including in spinal fluid. This is an international disease that needs to be recognized and researched. There needs to be an ICD-10 classification for ME.

There needs to be a better way to keep track of biospecimens from people with ME/CFS. A grant to the International Association of CFS/ME could be made to be an informational exchange of biospecimens with contact information, what type of specimens, etc.

New nonprofit organizations are aggressively asking for private contributions to fund research such as the Chronic Fatigue Initiative, NIDAlliance (http://www.nidalliance.org/) in honor of Jenny Tannebaum, and Simmaron Research, Inc, founded by Dr Daniel Peterson. Dr. Peterson left the Whittemore Peterson Institute (WPI) March 2010. His goal is to aggressive find markers and treatment for ME/CFS as he has tried to do for almost 30 years. Finally, his voice is being heard and the is much hope for the future.

There is also great concern that the original pioneers like Dr Peterson, Dr. Klimas, etc. are all getting older and there does not seem to be much interest among young physicians to take over the role and enthusiasm. Therefore, Regional centers of excellence, which have been requested from this panel for years, continue to be go ignored by this administration. These centers could accurately evaluate and diagnose patients and return them to their local physicians with treatment plans.

Many patients respond to proven treatments, even though most treatments are addressed to individual symptoms. Fellowships need to be funded a background in neuro-immunology similar to Multiple Sclerosis fellowships.

My hope for the future is that medical textbooks will have a whole section on ME/CFS with etiology, diagnosis, and treatments and that all physicians will know what ME/CFS is.