P2P Comments from Anita Patton

this comment is in reference to line 10 and 11:

My name is Anita Patton and I have had ME/CFS for over 28 years.

This is a disease that is like having both MS and AIDS at the same time. It is debilitating and horrific. It causes immense suffering to the patient. It is a disease of the central nervous system affected as shown by cytokines in the spinal fluid as a result of reactivated viruses such as HHV6, Epstein Barr, Coxsackie, Herpes Simplex, and Varicella. There can be subclass IgG deficiencies and primary immune deficiency. That means the patient is unable to fight infection. There is often low natural killer cells. The inflammation causes interstitial cystitis, gastroparesis, B & T cell abnormalities and encephalitis - which is swelling in the brain and spinal cord.

The recent AHRQ draft evidence review needs to have the multitude of research and scientific articles added to it. Many of the most pronounced research studies and treatment trials were left out of this report.

The March 2014 Stanford ME/CFS symposium examined epidemiology, cytokines, abnormal MRIs, autoimmune responses, and the microbial problems in the gut. There are markedly reduced aerobic energy productions during exercise. These studies were left out of the AHRQ.

As a patient, I want to thank the members of CFSAC for devoting time to move our research forward. I also want to say that I volunteer to help with administrative work at Simmaron Research, a research foundation in Nevada advised by Dr. Daniel Peterson. I am grateful that Simmaron is collaborating with Columbia University, the Centers for Disease Control, National Cancer Institute, University of Nevada Reno and Australia's Griffith University on immunological research, like:

the microbiome of ME/CFS
Genomic and functional analysis of immune receptors
data analysis of immune measures of patients on Ampligen
year 3 of the multi-site clinical assessment
a nested pathogen study in cancer subset
and many other research studies awaiting publication.

Ampligen needs to be approved immediately. It has been proved both safe and effective. There are many patients who could benefit from Ampligen therapy.

I would ask this Committee to use its expertise to make recommendations to the NIH P2P panel, which convenes next week. You should recommend that the P2P Panel recommend future scientific research focus on:

- Immune abnormalities,
- Auto-immune characteristics

- Diagnostic tests
- Centers of excellence
- More and larger clinical trials
- Lastly, and most importantly, P2P should recommend that NIH fund research commensurate with the severity and burden of ME/CFS at a minimum of $100 million per year, like it does with Multiple Sclerosis.

You have made recommendations like this for years, and they should be entered into the P2P process.

Thank you for your work.

If you get only one thing, get this = research and clinical need to be the same.