

PAT SONNETT

CFSAC Testimony of Pat Sonnett Washington, October 2009

I. INTRODUCTION

My name is Pat Sonnett and I live in Miami, Florida. I would first like to thank each of you on the CFSAC for your service and commitment to the CFS/ME community. All of us recognize the sacrifices you make to serve on this Committee and we appreciate your efforts on our behalf. Nothing I say here should be construed as criticism of the CFSAC.

I write this testimony with a heavy heart, a great deal of frustration, and considerable outrage at the CDC, the DHHS and the NIH for failing us for so long by not making this illness a public health priority.

I came down with what I thought was the flu in January of 1986 (23 years ago) and it has never gone away. It took six excruciating years, with visits to numerous specialists, before I found Dr. Nancy Klimas who officially diagnosed me with CFS/ME because there were no other physicians who knew anything about CFS/ME and most had never even heard of it.

This lack of knowledge is the fault of the CDC who knew this illness existed because it supposedly had investigated the outbreak in Incline Village in the mid-eighties. Unfortunately, the CDC did not take it seriously enough to follow proper protocols to find a causative agent or even warn the public about the possible infectious nature of a potential new virus. Very few of us ever recover and, as a result of the continued negligence of the CDC all these years, there are now well over a million of us who have essentially been sentenced to a lifetime of misery.

The suggestion by the CDC that CFS/ME is not a disease but actually a state of "unwellness" that could lead to disease is patently false and reinforces the claim that the CDC is trying to push this illness into a classification of emotional disorders. I test positive for CMV, HHV6 and EBV and my titers remain high. Emotional disorders don't cause someone to test positive for acute mono for 20 years!

II. LACK OF COLLABORATION BY THE CDC

By the CDC's own admission, a person with CFS/ME is as disabled as someone undergoing chemotherapy or someone in the last stages of HIV-AIDS, yet the CDC has done nothing to alleviate the suffering of those of us who have lived with this disease for decades. After 25 years of so-called study by the CDC, there are no tangible results to show for all those years, partly because of the paltry amount of funding and the misuse and mismanagement of the funding that was made available, but also because

the CDC has failed to form any real partnerships with national and international scientific CFS/ME experts.

The CDC has also failed to give credence to the thousands of scientific papers published on CFS/ME. Instead of moving forward with the knowledge now available to it, it has moved backwards by adopting its Empirical Definition which is overly broad and not recognized by the extramural scientific community which uses the 1994/2003 international consensus CFS case definition.

My criticisms regarding the use of an incorrect Empirical Definition, the lack of cooperation and collaboration, and the paucity of funding, are particularly relevant given the Science journal publication on October 8th, of the highly significant association between the XMRV retrovirus and CFS/ME discovered by the Whittemore-Peterson Institute (WPI), Cleveland Clinic, and National Cancer Institute. These study results have generated great excitement in the CFS/ME community, not only because they represent a possible breakthrough in the treatment and cure of CFS/ME, but also because they provide further proof that CFS/ME is a disease and not just a state of "unwellness" as expressed by Dr. Reeves.

Dr. Reeves' response, according to Lizzie Bucken in an article published in Nature News, was that the findings are "unexpected and surprising" and that it is "almost unheard of to find an association of this magnitude between an infectious agent and a well-defined chronic disease, much less an illness like CFS." He goes on to say that "the report represents a single pilot study" and the CDC is already trying to replicate the findings. The CDC can't possibly replicate the findings if it continues to use a different definition of CFS/ME. These examples clearly demonstrate the importance of instituting the reforms I and many others have been urging.

ACTIONS REQUESTED:

- Publicly announce that the CDC will no longer use the Empirical Definition but will use the 1994/2003 International Consensus CFS Case Definition
- Form partnerships with the Whittemore-Peterson Institute, CFIDS Association of America (CAA), International Association of CFS/ME (IACFS/ME) and the newly formed International Ambassador Program and CFS Clinicians Network
- Network to collaborate and share worldwide CFS/ME information by sending representatives to attend national and international conferences
- Establish a worldwide database to gather and share information on CFS/ME studies

- Stop relying on the limited Georgia patient group as its base for information and expand the patient base to include the multitude of CFS/ME patients currently under the care of established CFS clinicians and researchers

III. LACK OF TRAINING AND EDUCATION BY THE CDC

Research shows that early diagnosis and symptom care can greatly improve long-term health consequences, and yet only about 20% of people who have CFS/ME have actually been diagnosed because of the lack of physicians who are trained in the diagnosis and treatment of CFS/ME. The CFS CME on the CDC website has had only about 1,000 continuing education hours on its site while the Medscape CFS CME, partnered with the CAA and Dr. Lucinda Bateman and Dr. Charles Lapp, had 28,000 CME hours in 2008. This indicates that physicians lack confidence in the CDC site.

Research offers the greatest prospect of returning people with CFS/ME to healthy productive lives and preventing people from contracting this disease to begin with and yet, in 2008, the CDC and NIH combined spent less than \$9 million on CFS/ME research, which is hardly adequate given the magnitude of this disease.

ACTIONS REQUESTED:

- Update the CDC CFS continuing education site to make the information more relevant and reliable
- Provide adequate funding for education, research and treatment

IV. THE TIME FOR CHANGE IS URGENT

The time for change is now and it is urgent. Dr. Reeves should be removed from his position and replaced with new leadership more experienced in studying chronic diseases and capable of moving the CFS/ME program in the right direction by embracing and collaborating with the extramural scientific and medical CFS/ME community. The most current information should be disseminated to the scientific community, health care providers, educational facilities, and the public at large, and adequate resources and funding must be provided to bring about these changes.

ACTIONS REQUESTED:

- Remove Dr. Reeves from his current position and replace him with a leader who will collaborate with experienced extramural CFS/ME scientists and clinicians
- Disseminate information promptly
- Provide adequate funding

V. DHHS SHOULD ENACT CFSAC RECOMMENDATIONS

For years the Chronic Fatigue Syndrome Advisory Committee (CFSAC) has been recommending to the DHHS that five regional treatment centers of excellence be established to provide clinical care, research and education, and yet this recommendation (along with others) continues to be ignored.

The accomplishments of the Whittemore-Peterson Institute during the short period of its existence, gives us a glimpse of the possibilities that exist if we had the five regional treatment centers. If those centers had been established when initially recommended by the CFSAC, we might already have treatments or even a cure for this illness and years of needless suffering could have been prevented. The discovery of the XMRV live virus in CFS/ME patients makes the establishment of these centers even more crucial.

We are reaching a critical stage when some of our best and brightest researchers and clinicians are retiring and, because of the lack of urgency in training people to replace them, our nation is going to find itself in a crisis situation as the patient numbers continue to grow and the clinician numbers continue to decline.

ACTIONS REQUESTED:

- Designate CFS/ME as a public health priority
- Establish and provide funding for five regional treatment centers of excellence
- Provide CFS/ME clinicians with the means necessary to immediately begin testing patients for XMRV

VI. CONCLUSION

If the American public knew the true facts about CFS/ME – that it affects over a million people in the United States and the numbers are continuing to climb, that it costs the U.S. taxpayers \$17-25 billion in medical expenses and lost productivity each year, that it's likely to be infectious at some point in time, that there are very few physicians trained to diagnose or treat CFS/ME patients, that the effects are so devastating that people not only lose their physical and cognitive abilities but also lose their jobs, homes and, in many cases, their family and friends, etc. - people would be demonstrating in the streets demanding answers about this epidemic that's been concealed from them.

One can't pick up a newspaper or turn on the radio or TV without hearing about H1N1 these days, but the CDC probably doesn't even have a plan in place to track the numbers of people who come down with H1N1 and then go on to develop CFS/ME. In contrast to the attention given to H1N1, the silence is deafening when it comes to

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CFS/ME unless there is a major breakthrough like the announcement of the XMRV study results this week.

CFS/ME patients have played by the rules for 25 years and yet the lack of progress made in the field of CFS/ME by our government agencies has been appalling. The DHHS, NIH and the CDC should be held accountable for this lack of action. Someone needs to step up to the plate and do what's right. There must be leadership from the DHHS, NIH and CDC to stop the suffering of so many people. As long as I have breath, I will continue to fight for myself and for those who are too weak to speak for themselves. One way or another, change will come. The American people expect the DHHS, NIH and CDC to be that force for change. It is their duty and their professional responsibility.

Thank you,

PAT SONNETT