14 Oct 09

Subj: Chronic Fatigue Syndrome Advisory Committee (CFSAC)
Meeting of 28-29 Oct 2009, Pre-meeting Comments

Dear Sirs:

The recent announcement by the Whittmore-Peterson Institute (WPI), National Cancer Institute (NCI), and Cleveland Clinic has stirred the CFS/ME patient community worldwide. If nothing else, XMRV is further proof that we are physically sick and severely immune-compromised. We are also optimistic that the CFSAC, CFIDS Association of America (CAA), and International Association for CFS/Myalgic Encephalomyelitis (IACFS/ME) had already reached the consensus that current obstacles to progress must be removed.

The public videotaping of the last CFSAC meeting was a first. For this we are most grateful to Dr. Wanda Jones. We also applaud the bold honesty of Drs. James Oleske and Leonard Jason in laying out unpleasant truths. Many of our handful of medical experts have struggled in vain at the CFSAC and its predecessor panel, facing opposition from the very agencies Americans and their physicians count on to advance medicine and protect the public health. This meeting will be the first litmus test of which parties are ready to embrace the necessary change and can be trusted.

CDC Leadership

Only recently, CDC web pages stated that nothing of epidemiological consequence happened at Lake Tahoe in the mid-80s, and all "CFS" clinical findings to date (which collectively comprise a disease biomarker) are "experimental." Yet the *raison d'être* for WPI and the Nevada state legislature's funding of their new research center largely stems from the normally-rare cancers which quickly emerged at Lake Tahoe. In addition to noting Dr. Jason's report on early morbidity[1], I recall one advocate breaking into tears at the last CFSAC meeting while reading a list of patient names; it was unspoken but reasonable to assume that at least some names belonged to the deceased if not critically ill.

The CDC publicly, belatedly admitted the existence of "CFS" in 2006. Yet it has pursued what it affirms as an organic, multi-system disease a mass-psychosocial phenomenon. Another late conclusion by the Research Advisory Committee on Gulf War Veterans' Illnesses is notable:

"Studies whose principal focus is on psychiatric disorders such as posttraumatic stress disorder or effects of psychological stressors are not directly relevant to Gulf War illness and should not be considered Gulf War illness research." [2]

It's likewise time the CDC's psychiatric population studies broadening its useless definition-by-symptoms be discontinued. The same holds for studies done by a university attempting to pin a debilitating illness affecting one million Americans - at minimum, including children as young as five - on childhood abuse and trauma. Only the CDC-Emory "CFS" cabal views our disease as a life extension program. It's time to cut the funding for this nonsense, and place responsibility with those who will get on board with the NCI/NIH and put the public welfare first. This is really no longer a matter of if but when and how. Until it happens, though, CDC cannot be trusted as a player in CFS/ME research, care, or education, and any CDC 5-year plan for "CFS" is worthy not of consideration but cancellation. It follows that confidence in DHHS degrades the longer this status quo remains.

Light- vs. Heavyweight

That said, the CFSAC, IACFS/ME, and patient advocates must judge their own proposals by the potential cost in time and lives. Some of the nominations for upcoming CFSAC slots were themselves disconcerting. On one hand, the finding that CFS/ME requires the brain to work harder for executing tasks is hardly novel; that researcher could pursue more promising studies, but his position on a steering committee seems unwarranted at this point. Far worse was the inclusion of a physician whose unusually public reputation rests far more on health store books, supplement sales, and media appearances than the results of his "landmark," "gold standard" study with 66 patients. It would have been far better to re-nominate the likes of Drs. Cheney, Bell, and Komaroff, which the bylaws would have allowed. This is hardly amateur hour.

Whether or not XMVR is the final answer, WPI-NCI is forming an impressive, credible, and growing alliance; they are posed to be a significant contributor, and their new building a true "center of excellence" conducive to treatment studies. I believe Dr. Mikovits, Peterson, or another WPI-NCI representative should join the committee. This would help connect the CFSAC directly to their cutting-edge technology and methods, and empower CFSAC to ensure other research efforts will dovetail and converge. (Somehow, I feel compelled to add that the direction of the sled is more important than which dog is pulling lead, and that successful teams embrace this idealism with far less at stake.)

Syndrome Names and Definitions

I believe prior decisions not to push for a name change have been due more to political pressure than any wisdom in waiting for the cause(s) to be identified. By this point, CDC's differentiation of "CFS" from ME or any true neuro-immune disorder mandates a change. The CFSAC should:

(1) follow the lead of the IACFS/ME, and integrate "ME" into its own name;
(2) renew the push for American adoption of the Canadian Consensus Definition of CFS/ME;
(3) amend that definition for adults with the pediatric qualifications proposed by Dr. Jason.

This is the best we can do while groups are sub-typed, which test and genetic advancements have made imminent. If nothing else, (1) would show that Americans refuse to be re-colonized by Britain through its increasingly defunct, psychiatric-based health care system.

Sub-typing, however, must soon be approached from a broader perspective. The clinical distinction for fibromyalgia hinges mostly on tender points. In many cases, "Post-Lyme Disease Syndrome" is certainly chronic Lyme, while Gulf War Illness has a unique set of triggers. Yet symptomatically these are difficult to distinguish from CFS/ME, and provide for a set of wastebasket definitions which plagues patients, doctors, and insurance companies alike. This means the following:

(4) Any education efforts as to what CFS/ME is should include the similarities and differences from FM, Lyme, and GWI, not only in terms of symptoms but neurotransmitter alterations, lymphocyte profiles, RNaseL, gene expression, etc. Yes, this would appear beyond the current CFSAC charter. However, until this is being done officially – at the federal, state, or institute level – patients and physicians will remain at the mercy of "facts" offered otherwise.

(5) This level of detail requires that the diagnostic footprint I mentioned be laid out. There may never be a *single* test for CFS/ME, but to keep repeating the mantra that no test or biomarker exists is misleading. The strength of the Canadian Definition, when added to many of the tests which CDC labeled "experimental," is that it allows for ruling in as well as ruling out. Even Social Security has allowed for certain heterogeneous findings in establishing "CFS" disability.[3]

(6) Deliberate efforts should be made to enroll patients with rheumatologist-diagnosed FM, GWI, and "confirmed" Lyme in CFS/ME blood and genetic studies. As poor as the Lyme ELISA-Western Blot is, this may require a patient without a photographed rash registering positive on both portions. However, the payoff in finding and validating a Lyme-specific cytokine, genetic, or other such profile could be immense.

Summary

Like other patients writing for and speaking at this meeting, I have lost much of the best years of my life, a career, friends, and nearly my family over this illness while almost going bankrupt seeking diagnosis, benefits, and treatment. For 25 years, meanwhile, some in my government have fostered a veil of public ignorance about what we face, while we are only growing in number with new generations.

That veil, ever-slowly lifting, now stands to be removed altogether. This presents a new opportunity for sorting out and re-educating the victims of vague diagnoses and our physicians, and for obliterating the notion of CFS/ME as the result of mere overexertion or a mental manifestation. It calls for utilizing our best and brightest in medicine to the fullest, and a firm, vocal stance against those who wish the status quo to continue.

We expect our medical and patient advocates at this CFSAC meeting to boldly seize the moment, and those entrusted with the public health to do what is right.

Sincerely,
Chris Niestepski
Age 40, male, CFS/ME since 1998

[1] Jason, et. al. (2006). Causes of Death Among Patients With Chronic Fatigue Syndrome. *Health Care for Women International*, 27:615–626.

[2] Binns, et. al. (Nov 2008). Gulf War Illness and the Health of Gulf War Veterans: Scientific Findings and Recommendations. GPO.

[3] SSA (1999). Social Security Ruling, SSR 99-2p.; Titles II and XVI: Evaluating Cases Involving Chronic Fatigue Syndrome (CFS). Online at: http://www.ssa.gov/OP_Home/rulings/di/01/SSR99-02-di-01.html.