Our Future as Defined by the NIH, CFS State of Knowledge Workshop

NeuroEndocrineImmune Illness Awareness Day – May 12, 2011

Burlington, VT

Kenneth J. Friedman, Ph.D.

Introduction:

On the occasion of NeuroEndocrineImmune Illness Day, celebrated globally, I have been asked to summarize and remark upon the NIH "State of Knowledge ME/CFS Workshop" held April 7 & 8, 2011. The site of the Workshop was the NIH campus in Bethesda, MD. It brought together leading experts in the field of ME/CFS research, patient care, education, and patient advocacy. Its primary focus, however, was research. I was asked to serve on the Steering Committee which planned the workshop, and subsequently asked to be a workshop participant.

Brief Overview of the Workshop's Content:

The Agenda of the Workshop, as established by the Planning Committee, was fairly straightforward. The first session of **Day 1** started was an **overview** of the workshop and consisted of two presentations. **Anthony Komaroff** gave an overview of the C***linical Presentation of CFS*** and **Leonard Jason** reminded us of the ***Diagnostic Criteria For, and Case Definition of, CFS*****.**

The overview was followed by five, themed sessions to complete the first day:

Session 1 dealt with **CFS as an Infectious Disease** with three presentations**: Ron Glaser** spoke about ***Epstein Barr***, **John Chia** spoke about ***Enteroviruses***, **Judy Mikovitz** spoke about ***XMRV***, and **John Coffin** spoke about XMRV being a contaminant rather than a true infectious agent found in CFS patients. My personal opinion is that: although many are convinced that there is a link between CFS and viral infections, we are no closer to understanding that relationship than we were many years ago.

Session 2 was called **Systems Biology** with three presenters. **Gordon Broderick** spoke about the use of ***"Network Biology"*** to detect metabolic pathway imbalances/abnormalities in CFS, **Mangalathu Rajeevan** spoke about ***Genomic Studies***, and **Keith Kelly** discussed the evidence demonstrating that ***Systemic Inflammation Alters Brain Behavior***.

Session 3 was devoted to **Immunology** with two presentations. **Mary Ann Fletcher** spoke of the ***Immunological Alterations Found in CFS Patients and Gulf War Syndrome*** and the possibility of correcting immune system imbalances clinically. **Ben Natelson** spoke of the ***Similarities in Inflammatory Cytokines in CFS and FM*** but of unique proteins found in CFS.

Session 4 was devoted to **Neurology** with four presenters. **Kathleen Light** compared ***Gene Expression in CFS Patients*** to that of MS, FM, and healthy controls. She found up-regulation in alphanergic genes in CFS patients. **Roy Freeman** spoke about ***Autonomic Nervous System***

Abnormalities (orthostatic hypotension, neurally mediated syncope, and postural tachycardia). **James Baraniuk** spoke about ***Neuroimmunology and CFS***.

Session 5, the final session of the first day, dealt with **Exercise Physiology and Energy Metabolism.** There were three presenters. **Jane Kent Brown** provided a literature review of ***Muscle Function and Fatigue in CFS.*** **Christopher Snell** spoke of the use of ***Cardiovascular Exercise Testing*** to assess CFS patients, and **Peter Rowe** spoke about ***Orthostatic Intolerance*** contributing to the symptoms of CFS.

Day two consisted of three themed sessions followed by a summary session.

Session 1 of Day 2 was devoted to **Diagnosis and Biomarkers**. There were three presentations: **Nancy Klimas** spoke about ***Immune-based Biomarkers*** – markers that define a person's risk for CFS and the severity of illness. **Dane Cook** spoke about using ***Brain Imaging Techniques*** to detect brain abnormalities in CFS, and to test functional differences in the brains of CFS patients in comparison to control subjects. **Michael Dean** spoke of identifying ***Genes and Genetic Risk Factors for Complex Diseases.***

Session 2 of the second day dealt with **Treatment**. There were four presentations: **Fred Friedberg** spoke about ***Patient Self-Management*** – he emphasized how the reduction of stress, through a variety of techniques, enhanced the patients' sense of well-being. **Italo Biaggioni** spoke about the ***Postural Tachycardia*** frequently found in CFS patients correlating with higher sympathetic activity, and being able to treat the postural tachycardia with beta blockers. **Theroharis Theoharides** spoke about the ***Role of Substance P, Mast Cells, and Possible Mitochondrial Involvement in CFS***. And **Cindy Bateman** outlined the ***Supportive Care*** that can be given to address the symptoms that alter function in CFS patients. Treatment of symptoms reduces illness severity. Cindy recommends treating symptoms by treating the *presumed* mechanisms and the *physiology* of the symptoms.

Session 3 was entitled entitled **Opportunities for Communication.** There were five presentations: **Kim McCleary** made a plea on behalf of the CFIDS Association for ***Better Communication Between the Federal Government and*** what she termed ***Research Stakeholders***, I (**Ken Friedman**) spoke about the ***Prejudice and Contempt for CFS Research, Education, and Patient Care*** exhibited within the scientific, healthcare provider and academic communities, while **Pat Fero** and **Mary Schweitzer** spoke of their ***Personal Experiences with CFS***. **John Burklow,** of the NIH, described the ***Efforts Currently Being Taken by the NIH to Communicate CFS Information*** to both the professional and general public under a revitalized initiative of transparency and employing new electronic and social media.

The **final session** of the workshop was devoted to the Session Chairs giving ***Summaries of the Workshop Presentations*** made in their respective sessions followed by a ***Workshop Summary*** delivered by **Suzanne Vernon**.

In sum:

- There were 29 presenters at the Workshop; 28 from the United States and 1 from Canada. This State of Knowledge Workshop was North-America centric. A more worldly State of Knowledge will hopefully emerge from the IACFS/ME International Conference to be held September 22 - 25 in Ottawa, Canada.

- As of now, the only method of retrieving the content of the Workshop is by accessing the archived webcast via the internet at: http://videocast.nih.gov/PastEvents.asp and searching for the dates of the meeting.
- According to Dennis Mangan, the Chair of the Trans-NIH ME/CFS Working Group, and organizer of the Workshop, formal writing of the Workshop Report/Suumary/Recommendations will start in a week or so, and he expects the report to be released in a few months.
- The IACFS/ME Conference will have a printed program, distributed at the beginning of the meeting, which will contain abstracts of all papers to be presented at the meeting. (My guess is that the Conference Program will be in print before the Workshop Report.)

Personal comments on this Workshop:

- ***The most exciting and promising presentation*** at the Workshop was Gordon Broderick's "Network Biology" presentation. Gordon presented a new way of looking at, quantifying and graphing, the expression of gene products of CFS patients vs. other study groups. He is able to show differences in the clusters of gene products for CFS patients when compared to other groups, which should eventually indicate differences, if not abnormalities, in physiology and metabolic pathways.
- ***The most disappointing presentation*** was that of John Coffin. John believes, and presented data, that the presence of XMRV in humans is an artifact; a contaminant of cell lines and reagents. While John's belief may turn out to be true, his lack of willingness to acknowledge that further investigation is necessary and warranted, is unsettling.
- ***This event was billed as a workshop; not a symposium.*** There is a difference: In a symposium, a large volume of many researchers' work is presented with little time devoted to discussion. In a workshop, less of researchers' work is presented and more time is devoted to discussion amongst the researchers. Despite its name, *this* event was *more* of a *symposium* and *less* like a *workshop*. Discussion time was consumed by presentations and, at the end, when we were to have been writing our report at the workshop, we were out of time.
- It was on the afternoon of the second day, when the two patient advocates made their presentations. Subsequent to their presentations, the researcher ***Workshop participants expressed their desires for more information, and greater detail, of the plight of patients***. The researchers were asking for a translation of patient symptoms back into research projects. In my opinion, this was what should have happened throughout the Workshop and *vice versa.*
- Suzanne Vernon captured the frustration of the researchers in her summary. But she might as well have been voicing the frustration of the patients as well: She spoke of CFS research being conducted in "silos," of researchers working in these "silos," and ***the need for communication amongst the silos.*** Essentially, it is a matter of the right hand not knowing what the left is doing, and, as a corollary, the right hand not benefitting from what the left hand is doing!

- From my viewpoint, as an educator, if the researchers concede that there is a lack of communication and a lack of knowledge of each other's work, what hope is there for this information to be promulgated to healthcare providers and their patients? ***How is this information going to be translated into effective treatment protocols?***

Our Future As Defined by the Workshop

The State of Knowledge Workshop was, in my opinion, **a partial** fulfillment of the mission of the NIH which is: *to seek fundamental knowledge about the nature and behavior of living systems and the* ***application of that knowledge to enhance health, lengthen life, and reduce the burdens of illness and disability***.

How does the NIH complete its mission of applying the currently scant knowledge of CFS to the enhancement of the health of CFS patients and the reduction of their burdens of illness and disability? I encourage you to seek the answer to that question!

I agreed to serve on the Steering Committee of this Workshop to address the issue of the translation of research into education and patient care. Of all the workshop participants, I was the only individual with an expressed interest or presentation that dealt with healthcare provider education. Cut from a 20-minute, to ***a 10-minute, presentation***, I did my best to convey the urgency of ***addressing the impediments to the dissemination of knowledge concerning CFS.*** I sincerely hope that it was oversight or neglect that these concerns were not mentioned in the meeting's summary delivered by Suzanne Vernon.

As this NIH State of Knowledge Workshop shows us, if there is going to be a translation of research findings into the knowledge and practice of healthcare providers, the stimulus for it will need to come from outside of the NIH. For 30 years, the NIH has not provided leadership in this area. ***It is the CFS Community that must compel the NIH to fulfill its complete mission for CFS patients.***

In the state of Vermont, patients are fortunate to have a collective voice with which to speak: the Vermont CFIDS Association. ***A collective voice is more effective than our individual voices; particularly when speaking to the federal government***. With your support and encouragement, **the VT CFIDS Association** can speak effectively *with* our federal delegation; advocate for, and hopefully achieve the *fulfillment* of the NIH mission.

Further, this organization can join with other CFS patient advocate organizations to create an even stronger collective voice: ***a coalition of CFS advocacy organizations has been proposed.*** The coalition would be a sounding board and mechanism of communication for CFS patient organizations. Matters brought to the coalition for consideration would be aired. Those coalition members who wished to participate in that project, whatever it might be, would sign on. Those organizations which decided not to participate in that project would simply decline. There would be no stigma for not participating in a particular project.

The advantage of having the coalition is to generate as large a collective voice as possible, on any and all issues that affect our Community. By furthering the agenda of the CFS Community to a greater extent than can be achieved by individual organizations, the coalition can bring us closer to the day of a better quality of life for all CFS patients.

In conclusion, we must confront the challenges before us. We must confront them with honesty and integrity. Recognize that there is strength in our numbers. May we be one Community, with one cause. ***And may we speak with one voice***. Thank-you!