

International Association for
IACFS/ME
Chronic Fatigue Syndrome

Dedicated to Promotion of Scientific Research and Improved Patient Care

BOARD OF DIRECTORS

PRESIDENT

Fred Friedberg, Ph.D.
Stony Brook University
Stony Brook, NY

TREASURER

Kenneth Friedman, Ph.D.
UMDNJ - New Jersey
Medical School
Newark, NJ

SECRETARY

Staci R. Stevens, M.A.
University of the Pacific
Stockton, CA

Jonathan R. Kerr, M.D., Ph.D.
St. George University of London
London, U.K.

Nancy G. Klimas, M.D.
University of Miami School of
Medicine
Miami, FL

Gudrun Lange, Ph.D.
UMDNJ-New Jersey
Medical School
Newark, NJ

Lee B. Meisel, M.D., J.D.
Epiphany Biosciences
San Francisco, CA

Teruhisa Miike, M.D., Ph.D.
Kohbe, Japan

Rosamund Vallings, M.B., B.S.
Papakura, New Zealand

Suzanne D. Vernon, Ph.D.
Charlotte, NC

May 10, 2010

TO: CFS Advisory Committee

**FROM: Fred Friedberg, PhD
President
IACFS/ME**

RE: Written testimony

As president of the International Association for Chronic Fatigue Syndrome, representing over 500 biomedical and behavioral professionals, I thank the CFSAC for allowing me to submit this written testimony.

First I would like to endorse in the strongest terms the renewal of the CFSAC charter. The CFSAC is the sole government-sponsored group to provide a national forum for scientific and public policy discussions related to CFS. Over the past year, the committee has proven its value by airing issues critical to the CFS community. This included a thoughtful review and well-articulated recommendations for the CFS program at the Centers for Disease Control. As such, I would like to thank committee members for their commendable efforts to advance the science and recognition of CFS, an illness that continues to be stigmatized and medically under-served.

Second, this committee is uniquely suited to serve as an independent voice for the important concerns of the medical and research communities. One major concern is the definition of the illness--a topic referred to in the CFSAC Charter as "current and proposed diagnosis." The 2003 Canadian Case Definition offers substantive improvements over currently used definitions: It better identifies the symptom constellation of CFS and provides a cleaner differentiation with psychiatric disorder and less severe forms of chronic fatigue. Without a well-focused definition, many non-CFS patients are erroneously folded into study samples. This impedes our efforts to advance the understanding of the illness. I ask that the CFSAC consider opening up a regular session for

research presentations and ongoing discussion focused on the Canadian criteria. I believe that scientific progress in this difficult domain will be furthered by this effort.

In addition, the regularly scheduled public forum of CFSAC is well-suited to present recent developments in the critically important search for etiology. Inviting leading experts to report on etiology provides timely input to the committee and the CFS community in general. Informed by current data, the committee can evaluate the impact of current evidence on diagnosis, treatment, and clinical care and then formulate recommendations for research and public policy goals. One long-standing issue is the stigmatization and even ridicule that is a fact of life for many patients with CFS/ME. The CFSAC can work with all appropriate agencies, particularly the Centers for Disease Control, to encourage new public initiatives that convey a message of legitimacy for this illness. Without legitimacy, the ability of this field to attract new scientists and clinicians is limited.

Finally, we request that the CFSAC meeting be restored to its full 2 day schedule. The productivity of the past year emerged from the 2 day meetings which allowed time for scientific presentations, public testimony, and useful interactions among committee members. The committee rose to the challenges of the past year by writing bold and important policy recommendations --recommendations informed by current evidence, patient concerns, and the immediacy of public comment and discussion.

I'd like to thank the committee once again for its service to the CFS community. Please know that your efforts are appreciated.

Thank you.

Fred Friedberg

Fred Friedberg, PhD
President
IACFS/ME