Public Comment
Fred Friedberg

On behalf of the International Association for CFS/ME, I would like to thank you for including our recently released CFS/ME clinical guidelines, "Chronic Fatigue Syndrome Myalgic Encephalomyelitis : A Primer for Clinical Practitioners," in the information packet distributed to official and ex-officio members of CFSAC for this meeting.

As you know, CFS/ME affects at least one million people in the US but up to 80% may not yet have been diagnosed. Medical providers are often uncomfortable diagnosing and treating these patients and patients tell us that they frequently have difficulty finding a knowledgeable physician. We hope that the Primer will help to solve these problems by providing the information necessary for clinicians to understand, diagnose, and manage the symptoms of CFS/ME. The text was developed over two years by an 11-member Primer Committee composed of experienced clinicians and researchers who have seen thousands of CFS/ME patients cumulatively. Afterwards, it was externally reviewed by a number of international CFS/ME specialists and advocates.

Highlights of the Primer include:

• A summary of pathophysiological effects

• A user-friendly diagnostic worksheet utilizing the Canadian Consensus Criteria for CFS/ME

• Treatment suggestions covering an array of symptoms

• Post-exertional malaise, a symptom unique to CFS/ME, and activity management

• Sections on special populations/ situations (e.g. severely affected patients, pediatric CFS/ME, pregnancy, pre-operative care, etc.)

The document can be also be accessed at http://www.iacfsme.org/Home/Primer/tabid/509/Default.aspx.

We would be happy to discuss the Primer and answer any questions from governmental agencies and officials at the next CFSAC meeting in Fall or in an alternate setting. As the largest organization of CFS/ME clinicians and researchers in the world, we believe that a concerted effort by all stakeholders (government, private industry, academia, patients, advocacy groups, etc.) is needed to solve this illness and we would be honored to serve the US government in any scientific/ clinical capacity possible.

Sincerely,

Fred Friedberg, PhD

IACFS/ME President