

## TESTIMONY TO THE CFS ADVISORY COMMITTEE

October 29-30, 2009

DHHS/ Hubert Humphrey Building /Washington DC

My testimony is presented on behalf of Dr. Chuck Lapp. This is his statement: Many of you know me as a former member of the CFD Advisory Committee, and also know that I have specialized in Chronic Fatigue Syndrome since 1985. Only a handful of doctors have provided diagnosis and management to as many patients as I have.

My patients complain that their illness is not accepted by either the public or their providers. They feel humiliated, ridiculed, discredited, and frustrated. Friends and family dismiss their illness, and doctors are whether unwilling to or incapable of managing their problems.

On the other side of the coin, my fellow practitioners are frustrated by an illness that is complicated, has no visible signs, no diagnostic marker, and has long been regarded as psychiatric in nature.

Treatment guidelines are published for many illnesses. The CDC has published a provider toolkit. However, the toolkit guidelines are too simplistic, non-specific, and outdated. Some recommendations, such as Cognitive Behavioral Therapy, are downright impractical. Exercise advice is spotty and incomplete. Only 1704 providers an alarmingly small number have requested copies of this printed material. Specific and practical guidelines for management of CFS need to be developed, updated regularly, and made widely available in print and web based formats.

I was honored to be on of the authors of the Provider Project sponsored by HRSA, the CDC, and the CFIDS Association. From 1997 to 2007 we developed a course that Lenny, Jason and I taught to primary providers. We educated 77 providers, who in turn taught 2300 other colleagues. This self taught module was requested by 8800 additional providers. This was a costly way to reach a relatively small number of practitioners.

In contrast, Dr. Cindy Bateman and I wrote a web based program with the staff of the CFIDS Association that was promoted on MedScape. In the first 6 months alone, over 28,000 providers earned certification through this course. Why the difference? The MedScape course was brief, straight forward, and provided simple tools for diagnosis and treatment. More important, it was promoted professionally on a site that doctors frequently use to obtain CME credits. In other words, a good program, professionally promoted, can reach thousands of potential CFS providers.

This year the CDC requested public input to their 5 year strategic plan. Results indicated that the public wanted the CDC to emphasize:

- Diagnosics
- Pharmacologic studies
- Treatment and management
- Provider education, and

## CFS in children

Despite this mandate, the CDC plans to revisit the same old dogged paths. At the 2009 IACFS Meetings in Reno, at least six new potential markers were suggested, none of which are being explored by the CDC.

While the CDC is busy still with epidemiology and sociological studies that have little potential for improving the lifestyle of CFS patients, there are a half dozen reasonable theories that could be tested including the RNaseL Theory, the Nitrous Oxide Theory, the Hydrogen Sulfide Theory, and Glutathione Depletion.

The CDC's current leadership goals are old-fashioned, out-dated, and unproductive. They are not serving doctors who need practical help, nor patients who need relief from a debilitation condition. And unless a credible agency boldly states that CFS is a real illness, and a credible agency provides simple guidelines, today's skeptical, evidence driven providers will not deal with this illness.

This is why I advocate a change of leadership at the CDC. The CFSAC has spoken the public has spoken and it is time for the DHHS to make necessary changes in these programs. We need an aggressive, highly motivated team that will, seek a marker for this illness, promulgate clear guidelines for the diagnosis and management of adult and pediatric CFS, educate practitioners, and increase public awareness of the devastating illness.

Thank you for your attention.

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