

Testimony to the CFS Advisory Committee

October 29-30, 2009

DHHS / Hubert Humphrey Building / Washington DC

As a healthcare provider dedicated to the treatment of Chronic Fatigue Syndrome, Fibromyalgia and similar chronic and all too often disabling illnesses, I would like to thank the CFSAC for the opportunity to speak today.

Over the last 25 years, the CDC has been funded with over \$100million by the department of Health and Human Services.

Why is it, then, that, to date, there has been no attempt on the part of the CDC to further explore the many abnormal findings associated with Chronic Fatigue Syndrome which have been discovered by researchers outside of the CDC such as:

- DNA alterations
- Suspect viral infections or co-infections
 - o Herpesvirus family (HSV I, II, CMV, HHV-6, 8)
 - o Enterovirus
 - o XMRV

What does the CDC have to show for our taxpayer dollars and 25years lost to illness for a million or more Americans?

Attempts to revise the original diagnostic criteria by relying solely on self reported symptoms have grossly overgeneralized the affected patient population and fueled controversy in the minds of many as to whether Chronic Fatigue Syndrome is in fact truly, the physiologic and debilitating illness that it is. Although to this point, there is no "gold standard," of diagnosis, there are enough physiologic biomarkers which have not even come into consideration with the revision of diagnostic criteria. Criteria need to be more specific and objective and might include requirements for a certain number of abnormalities, such as are evaluated by the department of Social Security for determination of disability according to regulation 99-2p. Some of these include:

- o Laboratory abnormalities such as:
 - High levels antibody titers
 - Abnormal RNase -L
 - Low NK cell function and
 - Other immune system and
 - Endocrine abnormalities

As well as

- o Abnormalities on other studies, such as:
 - Low maximal oxygen consumption and
 - Early onset anaerobic threshold on cardiopulmonary exercise testing
 - Orthostatic changes on tilt table testing
 - Low total blood volume as determined by nuclear medicine studies
 - Increased cerebrospinal fluid (CSF) pressure on Lumbar Puncture (LP)
 - Decreased cerebral blood flow on SPECT scanning
 - Abnormalities on overnight sleep studies, such as decreased or absent slow wave sleep, alpha-delta complexes, frequent arousals, among others
 - Impaired cognitive function as shown by cognitive testing and quantitative EEG

Several therapies have shown potential in the treatment of Chronic Fatigue Syndrome, empirically, by clinical experience and small studies which have not have the funding \$\$\$ that have been available to the CDC over the last 25 years.

- Antivirals
- Neuroleptics
- Volume expansion
- Other

The fact that after 25years, we still do not have a single specific medical therapy approved by the FDA for treatment of Chronic Fatigue Syndrome is unconscionable.

Only 1,000 hours of continuing medical education have been provided by the CDC to healthcare professionals according to their website. To my knowledge, CFS still isn't even spoken of in medical schools or residency programs. Why such lack in this area? Without education of new generations of healthcare providers, scientists and the general population, how can we expect to move forward? Our healthcare providers, scientists and communities must be educated in order to rise above

- The lack of awareness and professional understanding of this illness, the lack of healthcare provider support of the patient and their families, the ignorance which results in discrimination by communities and healthcare providers
- verbally accusatory and abusive healthcare behaviors
- unwillingness to treat or see patients
- Inability of healthcare providers (general practioners and cardiologists alike) to interpret or understand the implications of objectively abnormal cardiopulmonary function testing

All of which exacerbate the very problem which medicine aims to abolish. The mistreatment of patients and lack of appropriate, even adequate, healthcare is an embarrassment to my profession. We must first do no harm.

We cannot continue to sit by and do nothing while this as of yet undefined public health priority goes unchecked and continues to exert an estimated \$9.1 billion annual economic impact. The financial burden is large, but, the even larger loss, which cannot be well characterized by figures, is the social impact: loss of productivity, public image, social responsibility and leadership of citizens, many of whom previously had made great contributions to society, now, not only sick, but, angry, too.

The psychological damage resulting from abusive healthcare providers who tell patients that "there is no such thing as CFS," or "it is all in your head," and push them to exercise past their limitations, can't or won't help, or worse creates undo psychological burden to patient, family *and* community and contributes to physiological and emotional stress, exacerbation of symptoms and propagation of misunderstanding and misinformation. Yet, there is no public health policy program at the CDC to counteract the ongoing stigmatization.

This is why leadership must change. The absence of senior leadership from the CDC CFS research program at the March 2009 IACFS/ME international conference is a prominent example of how insular and uninvolved this program has been with the larger scientific and patient communities. Leadership must recognize the urgent need to attend to the crisis, the "public health priority," the epidemic that is Chronic Fatigue Syndrome.

I ask that the CFSAC reaffirm its recommendation that leadership of the CDC program for Chronic Fatigue Syndrome be changed. Only with new leadership will this disabling illness become the public health priority that it deserves to be. Thank you.