

**WRITTEN TESTIMONY BEFORE  
THE CHRONIC FATIGUE SYNDROME ADVISORY COMMITTEE**

**MAY 10, 2010**

My name is Sister Sandra Duma and I have been ill with ME/CFS for over 30 years. My disease progressed to the point that, since 1996, I have been homebound and at times bedbound. I applaud the many courageous and dedicated men and women who have served on the Committee since its inception as the Chronic Fatigue Syndrome Coordinating Committee in the late 1990's and, since September 2003, when it became known as the Chronic Fatigue Syndrome Advisory Committee. Not only does this Committee serve as an important information source and exchange of ideas with ME/CFS experts to those charged with protecting the health, safety and well-being of the people in this country, it is also an invaluable source of hope for those of us suffering from a very tragic illness.

I am concerned that to date the charter for this Committee, which will expire on September 5, 2010, has not been renewed. I am concerned that the terms of prior members which have expired have not as yet been filled, even though The CFIDS Association of America has submitted as candidates the names of several very prominent specialists who would provide invaluable input on various aspects of this disease. This disease is so complex that it will take a team of specialists working from different aspects and coordinating their work to unlock the mechanisms of its etiology and pathophysiology. Only then could there be the hope of effective treatments being developed. I believe that government scientists are locked into their comfortable little boxes of old ways of doing things and perceiving disease -- especially this disease -- that they cannot or will not move beyond that. I believe that ME/CFS calls for a new paradigm, a new way of thinking. That is why the existence of this Committee is essential. The work this Committee does is crucial to the health and well-being of over 1 million Americans, not to mention the estimated 17 to 27 million people world-wide whose lives have been turned upside down by ME/CFS. Who knows how many more there will be in the future. Besides the great personal losses experienced by individuals and families affected by ME/CFS, there is also the collective economic impact this disease has on our country, now estimated to be \$20 billion each year.

This could be a very exciting time for ME/CFS research. To date there have been several thousand papers published by independent researchers, many with minuscule budgets, highlighting various important physical abnormalities found in numerous body systems in ME/CFS patients. These findings have been largely ignored by government scientists. Now is the time for the Department of Health and Human Services to have the will to pursue this and to provide the necessary resources to begin to put together the complete picture of this disease. The CFSAC has repeatedly made many pertinent recommendations to the Department of Health and Human Services that would go a long way to understanding ME/CFS, if only they would be acted upon. I cite as examples recommendations from their last meeting held on October 29-30, 2009:

- 1) Establish Regional Centers funded by DHHS for clinical care, research, and education on CFS. *(Look at what the Whittemore-Peterson Institute has accomplished in such a short time with much less funds supplied by a frustrated and hurting patient population. How much more progress could have already been made if only the government had adopted this recommendation when it was first proposed some time ago.)*
- 2) Complete a review of the state of knowledge of CFS and communicate this to medical education personnel, etc. A Surgeon General's letter should be disseminated to inform clinicians and other health professionals throughout the US and its territories on the impact of CFS on the health of US adults and children. *(Does this not imply that what is currently out there is outdated, one-sided, incomplete and inadequate?)*
- 3) Multiple case definitions are currently in use for CFS. There is a need for a national effort to arrive at a consensus definition of CFS that is accurate, standardized, and REFLECTIVE OF THE TRUE DISEASE. *(The Canadians did it. Why can't we? Or why can't we just adopt their excellent work and the progress they have made in understanding the many facets of this disease? To any rational person, isn't this basic before any real progress can be made? Also, reading between the lines, does this not point to great dissatisfaction with the stance government agencies have taken thus far toward this disease?)*
- 4) Provide adequate funding to the CDC to effectively carry out a detailed 5-year plan. The Committee stated the need for immediate progress in these priority areas:
  - a) identification of biomarkers, with an increasing effort in viral etiology of CFS;
  - b) creation of UPDATED guidelines for CFS management IN FULL PARTNERSHIP WITH ORGANIZATIONS REPRESENTING CFS SCIENTIFIC AND CLINICAL EXPERTISE;
  - c) provision of UPDATED web-based guidelines for CFS management given our CURRENT STATE OF KNOWLEDGE AND EXPERT OPINION;
  - d) provision of COMPREHENSIVE information about CFS in PARTNERSHIP WITH CFS EXPERTS to the scientific community, medical and mental health providers, educational institutions and the public through DHHS resources. *(Again, it implies that things have been very one-sided and that critical, valuable information has been ignored as independent researcher and clinicians outside the*

*realm of the government's position have been disregarded. Time and again, worthy grant proposals made to the NIH by these independent researchers to investigate some aspect of ME/CFS have been turned down. ME/CFS ranks near last in government funding.)*

There is SO MUCH work to be done. This Committee has set excellent goals and an excellent direction to accomplish this work. I request the following:

- A) that the Committee's charter be renewed;
- B) that the Committee meet two to four times a year;
- C) that the replacements for outgoing Committee members be filled in a timely fashion;
- D) that the agenda for upcoming meetings be posted in a timely fashion;
- E) that the video live-streaming of the meetings be embedded in the charter;
- F) that the CFSAC's recommendations be acted upon; and
- G) that the status of the CFSAC's recommendations be posted.

This Committee has my sincere gratitude for all that it has accomplished and has tried to accomplish. I ask that the Department of Health and Human Services keep this Committee in existence and seriously consider accepting and adopting its expert recommendations so that true progress can be made on the devastating disease.

Thank you.