Testimony submitted to CFSAC Meeting October 13, 2010

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[You have my permission to use my name with my testimony in public.]

Thank you for giving me time to speak in person.

Who am I?

I have been involved with this disease and politics since 1985. In 1991 I co-founded the international organization Medical Professionals with CFIDS/ME, an international organization which showed that people from the medical field are at risk for this disease. This statistic is very similar to the higher risk health care workers have of getting MS. Because of the strains of the illness, our organization has been inactive since 2003. However, we maintain a website. We are still here, listening and contributing to the education of the "Mis-diagnosis" of diseases by using the name Chronic Fatigue Syndrome, or even worse, "Chronic Fatigue."

I have a diagnosis of Immune Deficiency and Post Polio Syndrome. My sister and I both caught the polio virus in 1956. My older sister had mild paralysis of lower body. **Blood work that I had done in 1984 and 1990** from UCSD HIV/AIDS specialist Allen McCutchen **showed T-Cell alterations similar to HIV patients**. Dr. James Sinclair, a cancer specialist at Scripps Hospital in La Jolla and Encinitas did a bone marrow test on me in 1995 that showed the same T-Cell alteration. Dr. James Sinclair put a "Port" in for IV fluid infusions. I carry a letter from him with my diagnosis and he states clearly, "patient sufferes from severe constitutional decline. Do NOT give Normal Saline, give Lactated Ringers solution. According to my medical records I have an immune deficiency. According to my family medical history (**see my second suggestion**), my **Father died of Non Hodgkin's Lymphoma and my Grandfather died from Chronic Lymphatic Leukemia**. Acute Leukemia and Chronic Lymphatic Leukemia and Non Hodgkin's Lymphoma "run" in my immediate family. **Could it be that the MLVs and XMRV** is directly responsible for why I was so vulnerable to the Adenoviral Outbreak at Children's hospital?

*Could I have been helped in early 1990's with Dr. Elaine DeFrietas's discovery of HTLV-II like ...**in nearly 70% of CFS patient Population? Probabably.***

In April 1996 at the Official CFSCC meeting run by Dr. Philip R. Lee, I called for the removal of the late Stephen Strauss, Dr. William Reeves Junior and Dr. James Jones from all work that dealt with ME, CFS/CFIDS due to their bias against this "new" disease.

CDC still has on their Web Site WRONG information and continues to deny a retro virus today, just like they did in 1990 with Dr. Elaine DeFrietas and Dr. H.

Kropowski/Director of Wistar Institute. (**See my first suggestion for DHHS and CFSAC)

The trigger that started me down this long road of many different diagnoses (ARC/AIDS related complex, CFIDS, PPS and now Immune Deficiency) **was an infection with a "run away" virus** during a tragic outbreak at Children's Hospital, San Diego from 1980-1983. It was Adenovirus #2, and the outbreak is well documented, but CDC never came. At least six children died in 1980, and 2-3 children every year after that. I was a Respiratory Therapist working with the children when I became severely ill. The director of neo-natology died and so did an intensive care nurse. Most of the staff was affected during the high peak seasons of the virus, Fall and Spring.

My Twin sister had "mono" when we were 17 at University. She still has high titers for EBV and is WELL. I do not show even exposure level to EBV!!

I have two suggestions that are doable for the DHHSand CFSAC to implement:

Suggestion One: Create a DHHS CFSAC website directed by knowledgeable physicians and Researchers.

It was recommended to the Secretary of HHS in May 2010 that "*CFS [should be] part of any efforts to train or educate health care providers under health reform*".

I suggest a way to implement this directly. **Create a WEBSITE directed at physicians who treat CFS patients or those interested in the disease.** Focus on the fiction of "Medically Unexplained Symptoms." Dr. Lange spoke of this in her excellent presentation to you on October 12th. Let us come to 2010 and use the Internet. Remove the incorrect information that CDC has on their website. Doctors need to access to accurate information NOW. If this website were under the HHS "brand," physicians would certainly become better informed about CFS from a reputable source - the DHHS.

Ask respected scientists to provide descriptions of their published & ongoing CFS research for the website.

Reading about Dr Klimas's immune markers, Dr Light's metabolic & genomic markers, & the presence of pathogenic viruses by scientists such as Drs. Mikovits, Glaser, & Ablashi, would enhance the physician's ability to diagnosis and treat the symptoms of CFS.

****Access to this accurate and current information at DHHS and CFSAC should empower CFS patients and physicians to get the best possible care for this illness and improve quality of life.****

Dr. Leonard Jason stated the need for accurate medical information. However, Centers for Excellence will take a long time to get up and running, and they will cost a lot of money. The DHHS web site will cost very little money and get the information out there faster to the medical community. **Let the CFSAC and DHHS come to 2010 and use the very valuable tool of the Internet.** Physicians around the USA need this information NOW.

Suggestion TWO: Design an epidemiologic study to determine the prevalence and incidence of CFS in the USA, including the collection of health statistics by household contacts.

Prevalence and incidence are different measures of a disease's occurrence. The "prevalence" of a condition means the number of people who currently have the condition, whereas "incidence" refers to the annual number of people who have a case of the condition. These two measures are very different. A chronic incurable disease like MS can have a low incidence but high prevalence, because the prevalence is the cumulative sum of past incidence rates. A short-duration curable condition such as the common cold can have a high incidence but low prevalence rate, because many people get a cold each year, but few people actually have a cold at any given time. Analysis of good epidemiological data could support what patients have believed for years: that CFS can be contagious.
It is important to **know who has the disease and who doesn't within families.**
It is important to **protect the blood supply**
It is important to **protect the public from a serious disease**
In conclusion, I would like to point out that Multiple Sclerosis does not have an etiological agent that science has yet come up with, yet MS is diagnosed every day in doctors' offices using the signs and symptoms of the disease along with the results of MRIs. Why can't that be done with ME/CFS? Many people who are misdiagnosed with CFS have MRI results that are similar to people with MS. I am one of them.

I have appended official papers to be included in the minutes:

1. **CDC writes in 1990'S: DON'T GIVE BLOOD.**

In the early 1990s, Joan Irvine, a patient who believed she had contracted the disease from a blood infusion, received letters from Reeves and another CDC official telling her not to give blood. Joan, who died in 1996, called these her "blood letters" and waned them in the public record. Please enter them into the minutes.

2. **BBC reports ME blood donation ban on main TV news**
   The UK recently announced that it would ban blood donations from patients who had ever been diagnosed with M.E. or CFS. According to the ME Association of the UK, the only reason for suddenly banning blood donation from anyone who has ever had a diagnosis of ME or CFS can only be the threat of possible infection from viruses or retroviruses in the blood system. This has already occurred in Canada and Australia.
3. **Letter by the late Leslie Macowicz regarding ERISA and her UNUM case.** This letter was in response to Dr. Lee's CFSCC request. It is dated 1997. Leslie died two years later. Leslie won her LTD in Federal court and lost it 2 years later to a Magistrate. Leslie died due to ERISA and UNUM.
4. As of early October 2010, according to Dr. Derek Enlander of New York City, **Blue Cross/Blue Shield is suddenly refusing to pay for visits to doctors by CFS patients**, when they have paid for them in the past.

5. **Dr. Philip R. Lee's** speech regarding the Name from 1998 when he received the Rudy Peprich award from the AACFS.
6. **Social Security Disability Administration** official letter regarding the various ways patients receive benefits for "medically Un-explained disease processes" and CFS.

I want to thank Dr. Jones and Dr. Schnell, the CFSAC committee, and all of the patients around the world for working on this serious, misnamed disease.

I would also like to thank Jean Harrison pt. activist MAME for working so hard to get this meeting on the Web. Dr. Wanda Jones for making it happen. This is truly a medical and public crisis.

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Co-Founder of North Coast San Diego CFIDS Support 'group, 1985

Co-Founder of MPWC/ME, now known as MPWME-C, 1991