

**To: The CFSAC**

**Subject: Testimony for the next meeting**

**I don't know how to do double spacing so I will make this brief and use lots of paragraphs and large fonts.**

**I got sick in 1984. There were no doctors who believed I was sick – just an anxious over-worked female that needed more rest.**

**They disregarded my dizziness, low-grade fevers, loss of memory, lack of coordination, chronic sore throats and bronchitis, and the ever present horrible, horrible profound fatigue that seemed like a combo of jet lag, the world's worse hangover, and sleep deprivation.**

**I now have either Dr. Lapp or a now convinced PCP to take care of me. But I talk to many, many people as a result of writing/editing an e-newsletter in the Charlotte area. They have the same issues with doctors that I had 25 years ago.**

**This is unacceptable. Mine was not the most serious type where I was housebound or bedbound. However, I forced myself to work only to sleep the rest of my life away with no energy for anything else. Eventually, after 8 years of that, my absenteeism kept increasing (note...I loved my job) to the point where human resources advocated early retirement. I took it and cried all the way home on my last day.**

**The ironic thing is that with what I know today, I could have been kept healthy enough to work if doctors just took care of me appropriately from the getgo and the same is true today. Doctors lollygag in caring for today's CFS patients allowing them to get sicker and sicker.**

**And why is this? It is because they have not been informed about how serious this is. Ryan Baldwin in Asheville, NC is a good example of this.**

**People die from this worst case. People get cancer and heart disease. I don't want to hear that they didn't have CFS because it can't be proven one way or another.**

**This takes research and the CDC/NIH conglomerate has done nothing in that regard. They focus only on psychological aspects.**

**In later years I developed neuropathy and dysphonia, both neurological disorders that I think stem from having ME/CFS. My neurologist concurs. However, it can't be proven due to lack of research. Again too much focus on psychological issues.**

**Psychological issues do not start suddenly one morning after being perfecting fine the day before and then get sicker and sicker never to be the same again.**

**Would you want that for your child, sister, mother, wife, son, husband, brother or father?**

**My research dollars are going to go to the Whittemore Clinic where I think they are going to accomplish something. I remain a member of the CFIDS Association as well.**

**The CDC should be investigated thoroughly for abuse of power. My life was totally abused by lack of medical care. My son has a lesser form of CFS and it affects his life to a degree. If my grandchildren end up with this, you will hear from me more and more and more.**

**I want to see a change and I want to see a dramatic change NOW. We've waited long enough.**

**Nancy Henson, Patient and Advocate for 25 Years  
Editor, Charlotte ME/CFS/FM Support Group E-Newsletter**