

Testimony

Michele

To Dr. Wanda Jones and CFSAC members

Hello, I have Chronic Fatigue Syndrome and need help desperately. I have spent the last 5 years in my bed without the strength to cook or do housework. I stayed in bed trying to save what little energy I had in order to go to work 2 days a week. For every day I worked I was unable to get out of bed for 24 hours. Now I am unable to do even that much. It is hard to explain, after a couple of hours at work I feel as if I am carrying a heavy weight on shoulders and in my shoes, I feel dizzy, and I have trouble staying awake. Now for every day I work I am unable to get out of bed for 48-72 hours. I pass these days full of pain all over my body, sometimes I feel short of breath. I have not been able to continue working. I don't know how I will support myself. For years I have gone to different doctors and they all said that I was healthy. No one at my job(which is in a hospital) believes me when I tell them that I am ill. I found out about Dr. Klimas at the University of Miami about 2 years ago. I had to get on a waiting list until Dr. Rey came on board. I don't know what would have happened to me if I didn't get to see Dr. Rey as my condition has deteriorated so much combined with the fact that most doctors and medical professionals are not aware of this illness. In light of the immense suffering caused by CFS and the discovery of a possible link to XMRV/MLV viruses I am asking for an immediate increase in research and immediate clinical trials of medications for this disease. Also needed is the establishment and funding for 5 centers of excellence, as well as increased education for healthcare providers about this illness.

Sincerely,

Michele

(I am available to read this letter by telephone on the 10/13/10 meeting)