

Testimony

Gina Bettor

April 18, 2011

Dear Dr Jones,

My name is Gina Bettor and I suffer from ME/CFS since 6/16/93. Severe sudden onset. Never ever a day without that sick feeling.

I planned on sending a much more detailed testimony but due to poor health the past 2 weeks (bad flare up after taking my son to opening day Marlin's game and additional activities) I can only write I would like to be included in phone testimony. I heard Mary Schweiter at the SOK hearings and I feel as if I could be her clone. 2 percent NK function upregulated immune system as dx in Miami by one on Dr Nancy Klimas' studies. CMV, Cosackie 1 2 3 5? Positive Epstein Barr had mersa, shingles etc. I am mostly concerned and advocate for pain relief.

I would like to share more on this subject in the next few days as health permits but because of the deadline I wanted to at least drop you a note and be included in phone testimony.

If there is such a thing I am a textbook case with all the symptoms from day one. I share information on my facebook page by posting as many articles as health permits and am very very happy you and Dennis Magnan are involved. I mean sincerely appreciative of BOTH of your efforts.

As hope is the one thing Dr. Klimas always wants us to keep: I am hoping for centers of excellence where others can be helped much earlier and in better terms. It was just last November I had a pain doctor tell me CFS doesn't cause pain. **WAS HE KIDDING ME?** Sadly, he wasn't; he just was clueless from lack of information about our very sick community. I am one of the lucky ones as my primary physician was **AMAZING**. He had to cut back care of complicated cases as he himself became ill. I don't think I will be able to find another doctor just as caring about CFS because they aren't being trained. HHS and CDC can correct the years of neglect by acting swiftly to our requests for research, clinical trials, education for doctors and medical students, but mostly funding **CENTERS of EXCELLENCE** where this can be accomplished. Lastly as this is one of my personal (not funny but my mind just went totally blank; the cognitive difficulties

are awful) crusades to use the word pain medications including oxycodone.....etc instead of over the counter ie., Motrin, Advil as is listed in treatments in the CDC. What part of severe doesn't our CDC understand? Look at the number of suicides with our illness. I must speak up and say if you don't need them great but make sure patients that need them receive them! I know how completely bedridden I was before taking them. At this point I went on so long and went past the midnight deadline I may as well finish. I never once got high from my oxycodone, but at least was able to somewhat function because of them. If we have to live with this for life at least teach the doctors to make us comfortable.

The personal story I was going to share at the beginning is I was in bed curled up in pain when on a Sunday afternoon my husband said here please take one of these and please get up and make some sauce. I was prescribed Percocet for a pulled back earlier in my illness and they gave them to me in the ER. I thought I was better and wanted to sign up to go back to work as an insurance agent (I worked for a great company and was moving up from sales when I got sick. One day at work as I said 6/16/93 3pm, I said to my friend Ruth I sick I'm getting sick and you know the story) after taking them for a few days as I really loved my job. I even made a joke to my doctor "look it took a stupid back injury to get rid of that flu!" NOT then NOT now. Anyway after he took me off them right away the pain of course was still there it was being masked. So the next day Monday after making a Sunday dinner I went to my doctor and said you have to let me have that medication at least I can function. He gave me 1 pill a day and now after almost 18 years I am up to six but a higher dose. Many times we would discuss the medication and I even asked am I a drug addict and he said no you are drug tolerant. I couldn't even imagine how I would have cared for my children if I didn't have such a knowledgeable caring doctor. My advocacy is for the others that haven't.

God Bless and thank you for really trying to understand our illness.

Very Truly Yours,

Gina Giarrusso Bettor