Testimony
Anonymous 2

I am a CSF patient. I have been ill for more than 15 years.

I am here today to talk about treatments for CFS. I have been treating my illness symptomatically with the help of my CFS Specialist, Internist, Allergist, Endocrinologist, Pain Specialist, and Neurologist. Generally I am at a doctor 3 times a month. My annual visits include my CFS Specialist and the Neurologist who follows the growth of my acoustic neuroma, a benign brain tumor that is a cakewalk compared to this disease. I seem my Allergist, Endocrinologist and Internist 4 times yearly and my Pain Specialist monthly.

In my case my CFS began as Myofascial Syndrome which became Fibromyalgia and as the associated sleep disorder grew worse I developed CFS. I rapidly became acutely ill with CFS and it was associated with constant upper Respiratory Infections and severe asthma and seasonal allergies. I have the typical medical history of Endometriosis, Hashimotos, Spinal Meningitis and various autoimmune disorders.

The first 5 years I was extremely ill and frequently missed my monthly appointment with my CFS Specialist. On most days I could not elevate my head without feeling like I was going to pass out. I lived alone in my bedroom. I could not tolerate light, sounds, odors, or touch. My meals were delivered and a nurse friend administered IV's to me 2-3 times a week. I did not experience even one "good" day for nearly 2 years. In my case, the "killer flu" lasted many years.

CFS patients are desperate for treatment. In the beginning we are too ill to do any thing for ourselves yet we want to be left alone, unable to tolerate the excitement of having someone else in the room. A phone call can leave us exhausted for days.

My CFS specialist sent me to Columbia Presbyterian in NYC for endocrine tests. My husband would take me into the department head's office and I would put my head down on his desk and fall asleep. My thyroid and HGH were abnormal and my cortisol was low normal. My thyroid medication was changed to Thyrolar and I began daily Humatrope injections. The growth hormone made me feel even worse and it was a challenge to continue it, particularly when the dose was increased every 90 days. But I stayed on it because I had seen my sister, who had similar symptoms, improve on the injections. I believe that growth hormone eventually helped me to get out of bed. Today I also take Armour Thyroid and Cortisol.

I have asthma and allergies that preceded my CFS. I have experienced episodes of shortness of breath since 2005 when I started an exercise program while in my only CFS remission. I am treated with QVAR, Singulair and Xopenex.

Because my CFS began as traumatic Fibromyalgia, I have significant pain that is treated by a Pain Specialist at a Pain Clinic and requires a monthly visit. I believe that had I been

treated for pain early on I might not suffer from chronic pain. But it took 9 years before I was treated for pain. I have severe disc injuries with spinal cord compression. I have had one episode of paralysis of my left arm. Once MRI technology caught up with my injuries I finally received treatment. Prior to that, it was just one more symptom that doctors refused to believe or treat.

Since my CFS diagnosis I have had my Herpes viral loads checked each year as well as my NK cells. My viral loads are always high and my NK cells have always been low. This year I faithfully followed a supplement routine hoping to improve my energy level and for the first time I had an increase in my NK cells. The supplements are expensive and difficult to take but I will continue them as long as I see improvement.

I believe that my symptomatic treatment of CFS has allowed me to be here today. But regiments like mine are expensive - my medications and supplements alone cost $25,000 a year.

Even with the improvement in my health, I am generally housebound in order to have any quality of life. I am out of bed only 2-3 hours daily and I have had to practice "active resting" for days prior to this meeting. I will still be punished with multiple days in bed recovering from this trip.

I am very aware that I am one of the few "active" CFS patients.

We need treatments to help us improve our quality of life.
We need doctors that are CFS qualified.
We need regional CFS Hospitals like the WPI in Nevada.
We need Clinical Trials that lead to drug treatments and we need them completed in our lifetime!
I would like to see Ampligen and AIDS drugs made available to us.

I do not want to lose another decade waiting for doctors and scientists to stop fighting each other while destroying the lives of millions of CFS patients. We are very sick people and we should not be left to figure this out on our own. It is outrageous that I live in the city that is home to the CDC and I cannot find even one doctor who believes CFS is a real disease. I blame the CDC for wasting the lives of millions of CFS patients.