Testimony

Erin Pressner

First I would like to thank you for accepting my statement.

President Obama, Sec., DHHS, Kathleen Sebelius, Dir. Collins, NIH, and CFS Committee Members,

My name is Erin Pressner. I am twenty-one years old and I've already been sick for most of my life. When I was a young child my immune system wasn't very strong and I spent a lot of my time fighting off colds and flues and various infections. I developed exercise- induced asthma at the age of twelve. I started having symptoms of Chronic Fatigue Syndrome, Fibromyalgia, Temporomandibular Joint Disorder and Primary Dysmenhorrea when I was just fifteen years old, maybe even before that. When I was sixteen I developed Irritable Bowel Syndrome and many food sensitivities and I developed Restless Leg Syndrome in my twenties. Throughout my adolescence and early adult life there is not one facet of my life these conditions haven't eaten into. They've taken my education, as I've been unable to go back to school; they've taken my job, I've been unemployed due to illness since the new year; they've taken my hobbies - dancing, painting; they've taken my social life, they've taken away physical intimacy with my spouse, they've delayed us indefinitely from starting a family. I am left mostly housebound and severely mobility challenged, having to use a cane or forearm crutches to walk. While my peers are in school or preparing to graduate or starting families I am left contemplating whether or not I should buy a wheelchair this summer. There is no doubt that these types of illnesses are devastating no matter whom they affect, but I feel the affects on young adults are even more traumatic. We're supposed to be out there creating ourselves and meeting people and leaning and working, but we're not able to do any of that. It's as if our whole lives have been put on hold and all we can do is try anything and everything and wait.

I'm tired of waiting.

Not one doctor my entire childhood and adolescence believed there was anything actually wrong with me, even though something clearly wasn't right, even though I constantly complained of feeling sick, exhausted, weak, sore, it didn't matter. No one advocated for me, and at that time I was too young to advocate for myself. The ignorance was astounding. My symptoms were always brushed off as being growing pains or strain from being a dancer, or just a flu. By the time I got my first adult doctor I had become so accustomed to not being taken seriously I didn't even fight when they wouldn't believe me either. Once I got married and moved away my new doctor was at least familiar with these conditions but had no inclination to diagnose me, claiming she didn't want me to 'wallow in it' or become obsessed. During this time and with every passing year my symptoms were getting worse and worse. After first becoming symptomatic it's taken me six years to find a doctor who finally acknowledges that

something is definitely wrong with me, and together we are finally working towards a diagnosis. I often wonder to myself, had someone taken me seriously back then and diagnosed me as a juvenile and put me on a treatment plan, would I be in the same unfortunate situation that I find myself in now? After having six years to try different things and find a treatment plan that worked, would I still be so disabled? I don't think so. Through utter negligence, the medical profession at large has cost me my youth.

For the past couple of months, my general practitioner has had a med student shadowing him. When he was sitting in on one of my appointments for the first time, he didn't know what 'Fibro' or 'CFS' stood for. When my doctor told him what they were, he said he wasn't familiar with either condition. This isn't twenty years ago, this is 2011! *And he wasn't familiar with either condition*. That is hundreds of thousands of people he might never learn how to properly diagnose or treat! Luckily he was paired with my doctor who has successfully treated patients with Fibromyalgia and Chronic Fatigue Syndrome; what about all those other new doctors who are never as luckily paired? This is perpetuating ignorance throughout another generation of doctors who will, like their forefathers in the medical profession, continue to ignore and misdiagnose us.

I find it difficult to put into words how desperately this needs to change.

I want an initial $75 million to be put into revising med school curricula to include more information on detection, diagnosis and long term treatment of Chronic Fatigue Syndrome and similar conditions. All doctors, specialists, general practitioners, (especially) pediatricians, need to acknowledge that these conditions as legitimate and 'life stealing' and they should all be educated on how to detect and treat them, as if they were any other potentially disabling conditions like Diabetes, Arthritis or Multiple Sclerosis.

I want an initial $150 million to be put into creating better resources and support for patients and caregivers. One thing I noticed right away is that there are hardly any resources for people with Fibromyalgia or Chronic Fatigue Syndrome, and the support systems that do exist are 'by us for us'. There is hardly any government interest in helping and supporting affected families, especially those with afflicted children. There should be financial support made available for families with lower incomes who have children who require expensive medications or special diets due to CFS/ME and related conditions.

I want $200 million in immediate (initial) funding given to intra/extramural research. I want any patient diagnosed with 'CFS' to be evaluated at Infectious Disease clinics to be evaluated for EBV, HHV 6A and 7 (CMV). Money and man hours needs to go into developing definitive tests to diagnose these conditions instead of the current 'process of elimination' approach.

<u>These amount are all initial investments</u>; let it be clear that they are good first steps but in order for more permanent changes to take place additional funds should continue to be allocated annually.

Thank you for your attention and consideration; I sincerely hope that you all want to see change as much as we do.