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To: OS OPHS CFSAC (HHS/OPHS)
Subject: written testimony

My name is Sarah Goodwin, 25 years old, of Harveys Lake Pennsylvania, formerly of Farmington Maine. Thank you for allowing me to offer this input. This is a compilation of things I previously wrote, as I am unable to think clearly enough to express an intelligent thought right now. There are thousands of CFS patients across the country that would probably like to offer their opinions as well, but are unable to due to their poor health. Much of this had to be heavily edited to sound as coherent as I hope it does.

Ask yourself if in an industrialized nation, someone should have to go through the following for a correct diagnosis, so treatment can at least be attempted. How can we change this situation so that others must not?
April 2nd 2007. around 6 at night... it just happened so suddenly. I remember standing up from the couch where I was reading and promptly falling down, unable to stand up again, and that was the moment that everything changed. I managed to reach for the phone and called my (then) boyfriend and begged him to come home from work. I remember saying-"Please, I really mean it, I've never felt so sick in all my life" My eyes couldn't focus, everything looked so bright and blurry, my head was pounding I was doubling over in abdominal pain and I couldn't get up off the floor. It took all the strength I had to reach the phone. My muscles felt like I had the worst flu imaginable. I just laid there curled up in a ball and that's how he found me. I could hardly speak or remember who or where I was.

He decided that maybe I needed a bath. He got out our washtub, placed it next to the woodstove and filled it with hot water from the pots on the stove. (at the time I lived in a house with no running water) He picked me up and put me in it, and I just laid there, unable to even lift my arms to do anything to wash. I remember that it was hard to keep my head supported on the back of the washtub because I couldn't lift my head. My eyes couldn't focus. I just stared up at the very blurry and bright light above me, thinking, "there's something wrong with my brain" He put me to bed. I slept for probably 15 hours or more, and when I woke we had to find a doctor. I graduated just months before, so I hadn't established a doctor outside the student health center. This was a challenge in a remote town of 6,500 people with a physician shortage. It meant quite a drive to another town to see one of the only doctors in the region taking new patients. I could hardly stand up on my own or produce a sentence, they told me I had a bladder infection (though these tests were negative) and suggested that I was somehow sick from living in an off the grid house. (if anything I was healthier for it because I got a lot of exercise= chores and, we were scrupulous about sanitation) 2 days of antibiotics and I was getting worse, not better. My blood tests showed signs of a massive infection of some sort, so they sent me to our rural hospital

for a very expensive ultrasound and because of inflammation in my uterus and left ovary, decided that it was Pelvic Inflammatory Disease. I was sent to the emergency room to have my IUD removed, and due to lack of an available bed with stirrups, (not joking) they put a bedpan under my butt and ripped out my IUD. I was put on a one month course of 2 very strong very pricey antibiotics. These did nothing, but ruined my digestive system. The cultures for Pelvic inflammatory disease came out negative. My condition continued to deteriorate. They sent me to a gynecologist who tested repeatedly for the same STDs in one visit, despite my protests that I was in a monogamous relationship, had been tested a week ago and didn't think I could make it to the bathroom anymore without falling. I did fall in the bathroom and in the waiting room on the way out, and had to be held up to get to the car. He was just so convinced I had an STD (which all tests showed I did not, and I paid for all of them)

They then suggested that I had mono, because it seemed like a viral infection on blood tests, but the tests for mono were negative. I now know that I had a horrible virus, just not one they tested for or could identify. I still experience many of the same symptoms I had at this time and I have never felt healthy or normal since. It goes on and on like this with a comical series of increasingly awful doctors. In a few months I was diagnosed with and treated for endometriosis, which had probably started much earlier. It was almost a year before a doctor, Dr. Deborah Hamilton of Wilton, Maine (thank you Dr. Hamilton) got to the root of the problem- I have something that is called, almost as a joke, chronic fatigue syndrome. It only took EIGHT doctors to figure out what all of my disabling symptoms added up to. Ive come far since then, but I am still unable to work and often unable to even cook, drive, travel, and clean myself or my house.

I wrote this excerpt once when I was bedbound, and my arms hurt and were extremely weak for days after to the point where I could not use them for anything. I just want to take care of myself. I want to not need help so badly. I want to walk without feeling like I will collapse at any second. I want to carry heavy things and throw them. Wait tables, dance, bang hammers, hike, run, and spin around in circles. I just feel like a zombie made of jello. I hate having to ask for stuff that's so humiliating. It makes it more humiliating to see that no one will do it anyway. I cant take care of myself. No one should have to. I don't like to ask. I wish there were a volunteer program for this.

I have stumbled into a class of unknown and ignored people. I always knew there were people like this orphans of unpopular diseases. Right now I don't have the strength to get out of bed. I don't usually write when I feel like this. Its embarrassing. There is no charity for me, or the thousands upon thousands of other people just like me who cant even get out of bed to fill out the stupid disability forms that they'll get denied anyway.

CFIDS is insidious in that it takes away your ability to stand up for yourself. I never thought that was something I could lose. I have worked since before I was of legal age to work, and gone to school full time. I have occasionally held down more than one job and gone to school. I got amazing grades (3.7 GPA) and did all the extracurricular stuff youre supposed to do. I loved volunteering whenever I had time. I worked crappy jobs for next to no money. I was happy to be working, it always made me feel good about myself. Just to be a worker, working hard, being proud of what I did. I went to college to help people, my basic goal was to get a job that would make me feel like I was volunteering every day- doing something to make a concrete difference in peoples live.

If ever get well enough, I would spend the rest of my life making sure no one ever has to go through the humiliation, starvation, red tape, helplessness, public stupidity, degradation, hopelessness and poverty that I have gone through in the past two years. I want everyone to know this robs people of their dignity and life. I want people to take this seriously and not just think that people with CFIDS are just depressed, lazy, or just taking too many pills. I don't want people to say, Yeah, I think I had that, I get tired too. Right now Im in bed and my hand and my arm hurt so much from this rant that I went on- I don't think I can sit up and Im angry at the world, but maybe someday it will be different than this. This is no way to live.

This is adapted from written testimony that I sent to the CDC for their recent planning input. I would like to ask you the same questions that I asked the CDC. I am sorry if it still sounds geared towards them, I am getting worn out by this and you'll have to go along with it. The things I want to add are: there needs to be a thorough, independent investigation into spending and the relationship and effectiveness of ABT associates with the CDC. You should ask yourselves if after 20 odd years of failure at CDC, another agency should take over. It should go without saying that the government needs to radically increase funding for this disease to be effectively researched. Six dollars per patient per year is an absolute joke. There should be a congressional caucus or other body for CFS that is permanent, so that there is oversight on all government agencies (SSA, NIH, CDC, DHS, insurance regulation, etc.) in their decisions about and spending on CFS. This has been done successfully with other chronic diseases. Although, without being paired with increased public awareness of the physical basis of CFS, to join this caucus may be to risk political suicide for many legislators. Be Brave! And educate! If you or someone you loved suffered this much, wouldn't you want more than anything to find a cure for your/their devastating condition? Why is the government not spending every single research dollar on research that will move towards a cure? It is an absolute waste of time and money to do expensive studies about stress that are probably true for nearly every chronic disease. Trauma messes with your immune system, and the way you handle stress, your endocrinology, the way your brain processes information. Anyone could figure that out, much research has already been done on it. Do research that will make me healthy! Imagine what we could know now that we don't because of how research money has been used. Why has funding been given for research that has never been completed? Will you continue to use the contracting company (ABT) involved in this scandal? Also, why is Dr. William Reeves still in charge of this program considering this, his lack of direction towards finding a cure, and isolation from other researchers? He seems to be on a wild goose chase to prove his assumptions and that is not true science. He is dismissive and insensitive to the needs of both the patient community and doctors trying to treat them.

Why does the CDC definition of my illness keep expanding?—bringing in populations that do not have CFS, making government research incomparable to research done by other entities, skewing the results of your research so that the results are useless? What a waste of money! I have an illness brought on by viral onset, are you helping me be cured by expanding the definition to potentially include people with other conditions, such as depression? Why isn't post-exertional malaise considered a required symptom when many researchers consider it the hallmark of CFS? Why isn't the government doing any research involving subgroups?

Why are you funding so little of the studies proposed to you, even when money is available? It costs a lot for researchers to write proposals. If they are nearly certain you will not approve them, why should they bother applying? Why aren't researchers or doctors with experience in this disease heavily represented on the panel to choose which studies to fund? If you will fund more proposals to use the funding that you have available, how will you let researchers know this has changed so they send you studies? Why can't there be more collaboration with private research? There is so much to work with. Why not share data or samples with other researchers?

When will the name of CFS change to something more appropriate? The name means that patients are submitted to constant belittlement from doctors, family, friends and even strangers. Imagine how it feels to have a terribly debilitating disease and to have people respond by laughing at you. We do not deserve this. It is often humiliating for me to try to explain what is wrong with me. Public perception regarding this disease must change, it seems you choose not help change it. How will you educate the

public that this is a serious and debilitating condition, often lifelong? Will you disseminate information that shows this to be a disease of the immune, endocrine, and central nervous system, and a malfunction in the mitochondria, with a real physical basis?

When will you have reliable information to provide to physicians and medical schools about this disease? Nearly all of my doctors have had to do their own research or give me inappropriate information. Doctors deserve to have accurate information to treat their patients.

I feel as though I am a person who tried to do everything right, got good grades, stayed out of trouble and intended to devote my life to public service. Today I fell and laid on my kitchen floor for over an hour because I could not muster the energy to get to the sink for a glass of water, and many of my days include similar indignations. This is not how I wanted my life to turn out. If you can help me get my life back or prevent others from the same fate, what is holding you back from doing all that you can to help me and others like me?

I hope this is not too long. Thank you again for this opportunity