Testimony

Gabby Klein

I am a 56 year old wife, mother of three, grandmother of seven and have been suffering from ME/CFS for the past nine years. I used to work full time as a vice president of administration in an insurance company. In addition, I raised my children and took care of the household. All this came to a halt in February 2002 when I came down with a stomach virus that lasted for weeks. My condition kept deteriorating. I felt constantly ill and weak. I could not keep working and had to quit my job. Now I am so handicapped that I am mostly forced to stay housebound and when I crash, I am left bed bound for weeks or even months.

I suffer from insomnia, weakness, orthostatic intolerance. I am in constant pain. I feel pain in my joints, legs, sinuses and most severely, I suffer from headaches. When I crash, I have to lie still in a dark quiet room. Any noise or movement brings excruciating pain. I have had weeks at a time like that with relentless severe pain. Painkillers help a little but, certainly not enough.

In addition, I suffer from cognitive problems that are very disturbing. I have memory loss and word retrieval difficulties. At times when I crash because I have done too much which might be just trying to cook a simple meal, all my symptoms worsen including the cognitive problems. At those times, I cannot speak in comprehensible sentences. At times, only grunts are able to escape my mouth..

This past summer, I wrote these words in my journal.

There is something wrong when:

The one thing you look forward to is falling asleep.

The one thing in your life that you dread the most is waking up.

You stay in bed all day, every day.

You skip some meals because even though you are hungry, it hurts too much to go downstairs to the kitchen to get something.

You don't answer any phone calls, even from family members because it takes too much energy to talk.

You feel like pouring a bucket of water outside on the little children who are part of a backyard camp that your neighbor is running. The noise is just too much.

You feel like you have a sledgehammer in your head from the minute you wake up and painkillers don't help.

You watch TV on mute because you are so sensitive to noise.

You look forward for your husband to come home from work but, by the time he gets here, all you could do is mumble some words that don't make sense.

You don't answer you children's phone calls because you don't want them to know how sick you are but, if they don't call, you are upset at them for not caring.

You try to do as much advocacy as you can from bed but, it leads to nothing.

You read Toni Bernhard's book "How to be Sick" and it makes you feel guilty because you can't be as gracefully sick as her.

This illness is a very lonely, misunderstood and ill-treated disease. It does not follow the rules of other illnesses. It is invisible and people have a hard time grasping how ill you really are. It renders you completely restricted. You become so hyper sensitive to all kinds of senses, like noise, light, odors, foods and medications. Because of this, you can't attend events where there are many people around. You stop socializing and slowly but surely, your friends start disappearing.

I don't really fully blame them. They have no clue as to what's wrong with you. Yes, they hear the name "Chronic Fatigue Syndrome" but, in their mind, they are thinking "I'm also tired all the time. What woman today, working and raising children is not tired all the time".

Most GPs and Internists who are the first line of defense in the medical system are

also clueless about this illness.

When I first took ill with a stomach virus that didn't go away and my health kept declining, I went to my GP and explained to him how I felt . I told him I feel like I have the constant flu and am exhausted all the time as if I had just hiked up a mountain for two days in a row without any sleep. He took blood work from me. When all the tests came back negative he whispered to me "you know sometimes, we can be depressed yet not know it. I'm going to put you on some anti depressant, you will feel much better."

My body could not tolerate any of the anti depressants that he tried.. It took me two years to get out of the abyss created by these drugs. Of course it didn't help me. I was not depressed.

After two years of this where my symptoms just kept getting worse. I could not function. I could not sleep. I had to quit my job. The doctor finally said, "You know, it could be that you suffer from Chronic Fatigue Syndrome but, it doesn't matter because the treatment is the same as for depression."

I was finally referred to a CFS specialist who started to take my condition seriously. He put me on anti virals and supplements to strengthen my immune system. He also gave me medication for sleep since I had terrible insomnia. The ability to sleep helped my condition somewhat but, the anti virals didn't help. By the time I got to him, I was too sick. My viral load in my body was too strong and my immune system too weak for it to work.

Since that time, I have gone and tried so many treatments; conventional and alternative that I can write an entire book about it. In addition, I could have bought a house with the money I spent since most of the treatments are not covered by medical insurance. Some worked for a little while but nothing sustained for more than a couple of months.

Here I am nine years later sicker than ever. I had dreams of retiring and enjoying my grandchildren around me. I had dreams of enjoying my hobby of painting. I had dreams of socializing with my friends. I had dreams of going out to eat or to a movie with my husband. They are all simple dreams but, unattainable for me now.

My heart breaks that I can't enjoy the company of my grandchildren because it puts so much stress on my nervous system.

I think that this illness has been cursed because it has been given the name of Chronic Fatigue Syndrome which is really a joke. A very cruel joke because no one takes it seriously. It is insulting to the minds of the patients. Whenever I tell someone that this is what I suffer from, I see their eyes roll and they come up with the most inappropriate comments. For example "but you look fine" or "yes, I'm so tired all the time too"; the worst of the lot "all you need is just to get out more and exercise". Doctor's by the way who are not informed about what this illness really is about, are the worst culprits. Maybe, it's not their fault. They have not been taught about it and especially not about the latest studies that have come out recently. There is a tremendous need to educate the GP and the Internists about what this illness is and how greatly it affects the patients. They need guidance as to which tests to take and how to try to treat it.

There is also the issue of lack of funding for studies to come up with real biomarkers to help with the diagnosis of this illness and for possible treatments. This illness is estimated to affect 1.7 million people in the U.S., though the funding is a fraction of what the funding for MS is currently.

The CDC website still has the same antiquated information up which has been there for the past 20 years even though there is so much more that we know today. The ICC that came out a few months ago is a good place for them to start and follow their recommendations. This International Criteria was authored by the experts in the field coming from many different countries and the experience of studying and seeing thousands of patients. They recommend dropping the name of CFS and adopting the name of Myalgic Encephalomyelitis because it better describes the nature of the illness which is neuro-immune related.

There is also a great need to code this illness properly in the IC-10-CM coding system under "diseases of the nervous system" at G93.3, so that patients can get the medical care they need and deserve. In addition, they will be able to get proper disability coverage.

I am sure that you will hear many more testimonies of people. Some who were struck at a young age, where they don't even get a chance at a normal life like

getting married and having children? Others, who live alone and have no support system to rely on. Some are homeless and despondent with no help in sight. The only wish that I have is that you open your heart when you hear these stories. They are not just stories, it could be your daughter, wife, father or even yourself who God forbid could be struck by this illness. The numbers are growing at an alarming rate.

The thing that is most lacking with this disease is hope. On a forum I belong to with other patients who have this illness, someone posed a question as to when people thought there will be a treatment for us. I was struck by the fact that a majority of members answered; “not in my lifetime.”

“Hope is like peace. It is not a gift from God. It is a gift only we can give another.”
-Elie Wiesel

I did my part to come and testify. I hope you will do whatever is in your power to reconcile these problems and give back hope to 1.7 million Americans.

It is very hard to describe pain or suffering to anyone. It is an invisible feeling.