Good afternoon. My name is Sarah Councell Turner. I am 36 years old and have been sick for three years.

My illness started with what I thought was the flu. I went to a doctor who ran various tests on me for about two months. All that time I tried to keep working full-time, thinking I would be better soon. Finally, after using up all my sick days, I tried to apply for short-term disability. But the doctor refused to sign the papers because she still didn't have a diagnosis. She blamed me, saying there must be something I wasn't telling her, and said if I really felt that bad I should go to the emergency room.

Thankfully, my next doctor was very different. She helped me file the disability claim by listing my symptoms and noting that she was still running tests to find the cause. She tested me for Epstein-Barr Virus and diagnosed me with mononucleosis. Putting a name to my illness helped put my mind at ease, even though there was no medicine for it. I went on leave from my job and fully expected to be well in no more than a few months.

Three months later, I went back to work. The plan was to start part-time and gradually ramp up to full-time over six weeks. Instead, that process took a full year. Every time I tried to increase my hours I suffered a setback. Finally, I did start back full-time. I was able to keep it up for six months. Then I had a relapse. I went on leave again for another three months. Up to this point I had been calling my illness "Chronic Epstein-Barr Virus" and thought of it as a lingering form of mono. But last October my doctor changed my diagnosis to Chronic Fatigue Syndrome.

When I came back in January of this year I really tried to get back to full-time again, but just couldn't do it. Finally, in June, my job was officially changed to part-time status. I now work three days a week. Sometimes even that's too much. Sometimes I have to work from home. But thanks to the patience and good faith of my employer, the arrangement is working out for now.

The most difficult part about living with CFS for me is that it's so unpredictable. I don't know when my symptoms will flare up and when they will subside. Every morning I guess how much I'll be able to do that day. Sometimes it's hard to tell, and I have to make tough choices. Should I go to work, hoping to be able put in a whole day? Or should I stay home, hoping the rest I get will be worth the cost of being out again?

The other big challenge has been negotiating with doctors and insurance companies. My doctor is sympathetic, and she believes that my illness is real. But she knows of no treatment beyond rest and gentle exercise. She's not curious about diet or alternative healing methods. So I've had to do my own research and try things myself. I've found some results with yoga, integrative manual therapy and a gluten-free diet. But trying these things is always a shot in the dark.

Until recently, I would have had nothing bad to say about my disability insurance. The system worked well for me, and the benefits helped pay the bills. However, my claim was suddenly closed at the end of August and I'm now in the process of filing an appeal. This has been particularly frustrating because the reason they gave for closing the claim is that they say my doctor has provided <u>no</u> <u>medical</u> <u>evidence</u> that supports my not being able to work full-time.

On a daily basis, I try to avoid wasting energy on what could have been if I weren't sick. But the fact is, this illness is taking away a big chunk of my life at a time when I expected to be moving ahead in my career and starting a family. It's not easy to face the possibility of losing my job or, worse, of never getting well enough to be a mother.

So, here's what I've got. I have faith in God's goodness. I have a wonderful husband, a solid network of friends and family, a very helpful CFS support group, and an employer who is willing to work with me. I have some limited relief for my symptoms through a healthy diet, meditation and relaxation, light exercise and other non-medical interventions. So I have resources to deal with being sick right now.

What I don't have, and what I'm asking from you, is a way through this illness and back to health. Please make research, leading to objective diagnosis and treatment of CFS, your highest priority. Please do all that you can to fix the way private disability companies deal with CFS in their policies and handling of claims. And please continue to educate doctors so patients won't be blamed for their illness when they try to get help. Thank you for your time.