Testimony

Janelle Wiley

Hello, and thanks for the opportunity to share my story with you all today. My name is Janelle Wiley. As counting by the number of years from my birth, I am 32 years old. I was struck with ME at the age of 19.

At that time, I was a sophomore in a university. I had just completed my first semester in my new, harder—and already beloved—major of biology, making a 4.0 GPA for the semester. I was learning to play soccer, taking beginning violin class, keeping up my piano skills, and doing volunteer work. Why do I mention all this? Not to pat myself on the back, but to burst some stereotypes. I was *not* deconditioned, disillusioned, or unfulfilled, as the popular myths go. I was far too young to be burned out or for overwork to have caught up to me. I was having the time of my life, ready to take on the world.

Then I got sick.

I effectively went from 19 to 70 years old. Instead of flying up and down staircases without a thought, I wished I lived on the first instead of third floor. Instead of having great balance and special perception, I felt floaty, dizzy, and was often on the verge of fainting or collapsing. In fact, I now have more in common with my grandmother and great aunts than I have with my classmates from college. Except that my elderly relatives are much more active than I'm able to be. And I was forced to skip the whole part where one goes to grad school, gets married, buys a house, starts a family, has a career, saves for retirement… the whole nine yards. I did, by much perseverance and the grace of God, and with the support of family & friends, and because of the incredible patience and understanding of my alma mater, eventually complete my Baccalaureate in Biology.

That training has helped me research my disease. But I'm getting ahead of myself. It was a long time before I got a diagnosis that gave me a disease name to research. Nine years, in fact.

For the first three years, no one would help me at all. The MD's wouldn't even try. They didn't care. Fatigue patients matter *that little*. I went to the doctor for medical help, and I explained that I could not even do many basic activities of daily living. I was treated as if I came in because I was bored or lonely, not because I was ill. I was too young to be sick, too female to have heart problems (it didn't seem to matter that my heart rate was high, my blood pressure low, and I complained of dizziness and chest pains—including with exertion), and too ready with a smile to be depressed (this third item was the only true part of their cursory assessment), so they ordered the exact same tests they would for a perfectly healthy patient with no complaints of any kind, told me I was healthy, and sent me away.

In the second year, my back and neck were sprained in a motor vehicle accident. As a result, I also developed myofascial pain syndrome (as they called it in my charts then) or fibromyalgia (as my current rheumatologist calls it, even though I think I still have not been properly assessed for tender points). In the third year, even after lots of physical therapy, I was still in too much pain. I went to a specialist, who turned out to be an orthopedic surgeon. He said there was nothing he could do for my pain, but he thought my hands were too shiny and he recommended testing for a connective tissue disease. That was when they found the positive ANA.

I instantly achieved Real Patient Status. I got referrals to rheumatology and neurology. They did testing to check for medical conditions. This did not reveal much further of significance. The neurologist noted in my chart I had "no neurological disease, though symptoms referable to neurological causes," told me I was healthy, and sent me away. The rheumatologist also thought she was giving me good news by not finding a disease. Nothing could have been farther from the truth. I needed answers, not for them to run through a checklist of Top Expected Diseases and then stop looking for my Answer when it wasn't on the checklist.

After a while when I failed to develop Lupus or Rheumatoid Arthritis, my Real Patient Status dissolved. I was once again treated like a hypochondriac, merely because my illness was not on the list of Top Expected Diseases In Young Females and therefore remained undiscovered. This cavalier dismissal of me by my physicians—dismissal not merely as a patient, but even as a person—was not quite universal. One exception was my rheumatologist, who had come to know me and knew I wasn't making things up. But she still didn't have the faintest idea what was wrong with me or what to do to help.

I learned to limit asking for help. I saw various doctors, by switching primary care doctors a few times as well as visiting urgent care, so I also learned that doctor shopping probably wasn't going to help. I didn't stop seeking help altogether because I still very much needed answers and medical assistance, but one can only take a certain amount of being rejected and patronized, so I didn't ask very often.

My disease was relapsing and remitting, and I did do better sometimes, but I was never actually well enough to lead a normal life, carry a typical workload, support myself—much less keep up with what my old self (my real self) could do. Other times, I could barely manage a minimum of personal care, and that is not an exaggeration. I found both ends of this spectrum frustrating, but no approach: not common sense good health choices, not ignoring my limitations, and not seeing an ND, could cure me, and I still could not find any MD assistance.

In the seventh year during one of those better times, I felt reasonably strong and decided I was going to move on with my life. I would either get a full-time job or go back to school. I enrolled in a local community college and then transferred back to my four-

year university. I took a relatively low number of credits, since I knew I wasn't very strong. I was determined to get stronger. It didn't happen. Long story short, I had to sit out some, and get a lot of help and accommodations. I got a lot worse instead of better, and was having trouble with balance, migraines, breathing, walking, and so on… at one point, I couldn't even read my texts because I couldn't focus my eyes… but I eventually finished, and earned my diploma thirteen years after beginning a four-year degree.

In the eighth year of my ME misadventures, I got a small bull's eye rash, but didn't realize what it meant. Back at school, I was even sicker than usual, and my mom flew out to drive me to the doctor. The doctor said anyone with as many symptoms as I had, must be somatizing. However he did run a lot of tests, presumably to prove to me that nothing was wrong (and to check for multiple sclerosis, just in case). Two tests came back positive, one for Lyme disease and one for acetylcholine antibodies. I was told to have them rechecked at home. The doctors at home claimed there was no Lyme pathogen in the Pacific Northwest (not true), nor anywhere else I had ever visited, except in upstate New York but that it wasn't possible for me to get bitten by a tick in the backyard of a *deer hunter*. They also refused to retest me for Myasthenia Gravis because I don't have a droopy eye—not actually a requirement for MG.

Treating for Lyme early on would have had an 80% chance of curing me of Lyme disease. There isn't a cure for MG, but I'm certain there are treatments which could make some impact on my health-related quality of life, had they pursued this and been able to confirm it as a comorbid (or alternate) diagnosis. And while there do not seem to be treatments that get at the (as yet undetermined) ultimate cause of ME/CFS, there are supportive treatments available, but these are largely unacknowledged. As it was, I continued to have no interventions at all, eight years into a debilitating and possibly degenerative disease—except the NSAIDs I'd recently put myself on with the approval of my rheumatologist (and an asthma medicine I eventually had to stop when I realized its side effects were causing the bone pain I was experiencing and contributing to my eye blurriness).

In the ninth year, I was diagnosed with CFS. *Nine years* it took to get a diagnosis. But that didn't lead to treatment. All I was offered was stimulants. When I tried this, I found it gave me a terrible headache (in a chronic pain patient, unbearable pain is saying a lot), so I couldn't use that treatment. I tried to research the disease I'd been diagnosed with, and was discouraged by conflicting information.

In the tenth year, I checked on CFS research again. I had a breakthrough when I discovered that there were various definitions and much of the "conflicting" information came about by comparing differing patient populations. I began to research in earnest. I found that problems with heat shock proteins (which, among other things, have a cellular repair function), were associated with ME/CFS and I wondered if this could account for my failure to heal after the MVA. I also learned about the Th2 shift and I wondered if

this might account for my inability to run a fever and my failure to have many signs and symptoms of infection when I get a respiratory infection or something like that. I learned about low NK cell function and that this abnormality has been consistently found since 1987, ironically around the time the confusing and disparaging name of Chronic Fatigue Syndrome was invented. Of course I've never been tested for anything related to any of this.

I haven't been tested because doctors don't know about the things I've researched. They aren't told in medical school. They don't hear about these things from their normal sources like CDC, Medline, Mayo Clinic, continuing education classes, and professional conferences. Those few who look at the literature (most don't since they don't have time) will find a very confusing picture. One group finds an abnormality, another group doesn't, a third group reproduces it, a review article and the health authorities proclaim the evidence "inconclusive" and the test for that abnormality "experimental." If you have the patience to look further, you will often find that the group(s) who found the abnormality are using the Fukuda inclusion (the CDC's official criteria), while the group(s) who didn't find it are using the Oxford inclusion (the UK criteria).

Fukuda, when used exactly as written, includes a lot of the people the CFS name was coined for who had low NK cell function, neurological problems, exercise intolerance, and chronic infections, (we'll call this group ME/CFS), but it does not have any requirements to specifically select this group, so also includes some patients with other unrelated conditions. Oxford identifies what we would, in the USA, call Chronic Fatigue, or longlasting fatigue which *does not* meet the criteria for CFS. Sometimes Oxford studies include a few people with ME/CFS, but sometimes patients with neurological and immune manifestations (i.e. ME/CFS patients) are specifically excluded from Oxford studies. And the CDC has begun using an inclusion rubric called the "Empirical" criteria, which considers patients to meet various requirements of the Fukuda criteria when they, in fact, do not. The "Empirical" inclusion does not include many, if any, ME/CFS patients.

Thus patients with completely different diseases are being compared under the same disease title and it is on this basis that information is being considered inconclusive and experimental. And the CDC is using primarily Oxford and "Empirical" studies to make decisions and not their own official Fukuda criteria.

This all is not only terribly unscientific; it is also unethical. Patients are being denied the most basic of medical care: proper diagnosis and assessment, not to mention medical interventions.

In the eleventh year I finally got some treatments—for my migraines and for my positive ANA. And there was a little more medical investigation into my difficulty breathing, which is not well-explained by my mild asthma. This came about because I made a big

fuss on the phone with my rheumatologist's assistant, and my rheumatologist knew I didn't fuss without a good reason. My primary care doctor insisted the shortness of breath was caused by deconditioning, and I insisted any deconditioning was secondary to a serious medical condition. I began to shop for doctors again, particularly for a new primary care practitioner.

I found a supportive primary care doctor and a kind and brilliant pulmonologist who—a research physician—does not use the Checklist Method of diagnosis. However, neither of them could act as treatment physicians for a complex neuro-immune condition, even though they are interested in the research about it.

In the twelfth year—this year—I could find no one in my area who knew anything about ME/CFS, so I flew across the country to see a CFS specialist. He diagnosed my supraventricular tachycardia and my goiter, which all my doctors had been ignoring for 12 and 9 years, respectively. He also found reactivated HHV-6 infection, something that goes with ME/CFS (and is also found in other serious diseases like MS and cancer), and suggested treatment for chronic Lyme disease. He said that, by this time, the Lyme microbe is hiding in my tissues and cannot be found with blood testing, although the blood tests may become positive after treatment begins.

The point of this story, ladies and gentlemen, is that diagnosis and treatment of fatigue patients in general and ME/CFS patients in particular, are in shambles. My story is representative of two populations: chronic fatigue patients who are not being assessed for their various diagnosable, treatable conditions (especially my first three years are representative of this group)… and ME/CFS patients like me, who are not being assessed, much less treated, for a disease the health authorities and medical schools have long ignored. Doctors—even specialists—have no idea what to look for beyond their standard checklist, what tests they can run to support a diagnosis of ME/CFS, what treatable conditions might be comorbid. Indeed, CDC specifically says *not* to run any of the tests that could support a diagnosis of ME/CFS or discover treatable comorbid conditions such as infections. This is a grave human rights abuse which deserves the most urgent attention of the Committee, Secretary Sebelius, Congress, and DHHS.

Thank you.

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