

## Testimony

### Anonymous #3

To the Members of the Chronic Fatigue Syndrome Advisory Committee:

Thank you for your service and for the recommendations you made at your meeting last May. In particular, I thank you for recommending that “chronic fatigue syndrome” be moved out of the wastebasket R codes of the United States’ next version of the International Classification of Diseases, the ICD-10-CM.

In my testimony in May, I described my daily life as a severely ill ME patient. I got sick at age 20 and have been ill for more than 17 years; seven of them spent essentially bedbound. I’m sorry to report that I have lost more function since your May meeting. Now I often can’t lift a pillow from the floor to my bed, and I can no longer swing my laptop computer from my bedside table onto my bed. In order for me to lie on my back and type this testimony, one of my parents, who are my caregivers, had to lift and position my computer for each writing session.

Today I would like to tell you about my last doctor’s appointment--the only time I have been able to go downstairs, outside, and leave my home in the past year.

For severe ME patients, leaving one’s home is an extraordinary undertaking that requires weeks of preparation and months of recovery. A week before the appointment, my parents began to fill our van, which they have converted into an improvised ambulance, with items I would need for the trip. The day before the appointment, I struggled through my monthly bath in the tub and my mother washed my hair. Ordinarily, I bathe in my bed and change my nightgown twice a week, with help. Due to my extreme orthostatic intolerance, I can’t sit long enough to shower, even with the aid of a shower chair.

The morning of my appointment I put on street clothes for the first time in several months. This activity so exhausted me that I could not carry a lightweight purse. I tackled the stairs, which are next to my bedroom, by slowly walking down three steps on rubbery legs, then sitting and resting for a couple minutes, then wobbling down three more with support from the railing. From the foot of the stairs I was pushed in my wheelchair out to our

porch, where my father had backed up our van to a loading platform he had constructed.

The bright colors of the outdoors dazzled me. After six months mainly spent lying on this mattress in my small bedroom with one window, I wanted to linger on the porch and take in the vast, arching sky, the touch of breeze against my skin, the hum of insects in the sunlit fir trees. But I had to lower my body onto the bed in the back of our van and rest with eyes closed, wearing earplugs to block the noise of traffic, so that I would have enough energy to get through my appointment.

At the hospital, I had to transfer five times. I heaved my leaden body from the van to my wheelchair, then to a bench in the waiting room where I lay motionless as 85-year-olds hurried past me, then back to my wheelchair, and finally to the table in the exam room.

All of this extra movement and sitting upright took so much of my energy that by the time I reached the paper-covered table, I could barely lift my arms. I lay there blinking at the harsh fluorescent light and wincing at the hospital noises: distant machines beeping, conversations, doors opening. I was glad my doctor was 20 minutes late, because the effort of changing from my street clothes into the hospital gown weakened me so much that it was a while before I could speak again.

And what was the result of my enormous effort in getting myself to the doctor? Essentially, nothing. My doctor renewed my prescriptions for thyroid medication and B12 shots, ordered a few routine blood tests--which came back normal--and did a cursory physical exam. Then she told me to come back in a year and walked out. She had no treatment whatsoever to offer for the sickness that has destroyed my life. Can you imagine HIV or MS patients getting minimal medical care only once a year?

At least she didn't mock me like past doctors who have said such things as, "It must be nice to get so much attention" and "You'll have a lot more opportunities in your life if you leave your home." And in fairness, my doctor has been very good about completing paperwork related to my illness.

Back at home, my parents called a young woman from our local emergency squad and asked her to bring a special carry chair with handles so I could be carried up our stairs. While we waited for her, I lay on the futon in my mother's office downstairs, a room I had not even seen for more than a year.

Many of my old college textbooks were on her shelves, and I stared at their spines, remembering my active life before I got sick. I took a full course-load, worked part-time, jogged daily, volunteered, and happily partied with my friends. Now I can no longer read books. Now I spend up to ten hours per day resting with eyes closed, about six hours sleeping, and only short periods here and there listening to audiobooks or checking my email.

It took three people to carry me up the stairs in the chair, though my weight is normal. A few times, as they strained and sweated, I thought we would all go tumbling down the stairs. I clung to the banister, remembering how I used to run up and down those stairs all day as a teenager. Even when my ME was more moderate, I could walk up and down them whenever I wanted to.

Finally, I was back in my room, so depleted I could barely turn my head. And here I have remained for the past six months. A few times a day I walk to the bathroom, but mainly I just lie here, listening to the whoosh of my air cleaner. On my computer I see photos of my old friends, who have gone on to careers, marriage, children and beautiful homes. Outside my window, another year goes by.

Members of CFSAC, my doctor can do nothing for me, but you can. You can influence the Secretary of Health and Human Services, and in turn, the government and public at large. I ask you to please pass strong recommendations on the following issues:

**1. Promote the study and awareness of severely ill ME patients--those who score below 10 on the Bell Disability Scale.**

**A. Count them.** No one knows how many American ME patients function at my level or below because no one--including the CDC and the CFIDS Association of America--has ever studied us. The CAA, which promotes psychotherapy and exercise as treatments, has chastised severely ill patients for supposed “kinesiophobia” (fear of movement) and advocates mainly for people with mild fatigue or “unwellness.”

**B. Study them.** Encourage several research studies composed entirely of severe patients, those who function below 10 on the Bell Disability Scale or who require a nursing home level of care, like me. I’m not a scientist, but it’s logical that the underlying pathology(-ies) of ME should be more pronounced in severe patients and therefore easier to detect

in their bodies. Testing severe patients will have “trickle up” benefits for mild and moderate patients.

**C. Include them.** Severe patients should comprise half the cohort of all research studies to avoid skewing results toward mild patients. In order to include the severely ill, researchers will have to make accommodations such as sending phlebotomists into patients’ homes. I was able to participate in a Whittemore Peterson Institute study, in which I tested positive for HGRVs, because the WPI--under the leadership of Dr. Judy Mikovits--hired a phlebotomist to come into my bedroom and draw my blood. We may not be able to undergo invasive procedures such as spinal taps in our homes, but there’s no reason why we can’t provide blood, stool, saliva and urine samples to researchers. Stop excluding from your studies the very people whose bodies are most likely to yield answers for all ME patients!

**D. Publicize them.** Making severe patients the public face of ME is an efficient way to get medical professionals, lay people, and government agencies to take this disease seriously. Rather than being seen as an asterisk, afterthought, or anomaly, severe patients should be the focus of newspaper articles, advocacy materials, and the CDC website. As long as high-energy patients--those who can care for themselves and their families and even hold jobs--are seen as typical, the government will continue to starve ME research of funds. This is a disabling disease, and the severely afflicted are the most capable of showing that!

**E. Make teachers of them.** Medical school students should be required to make house calls to severe ME patients. Most doctors and researchers have no idea how disabling ME can be because virtually all the patients they see have mild/moderate ME. Why? Because severe patients have extreme difficulty traveling to doctors, or can’t travel at all. Even many ME experts have never met a severe patient in person. After seeing us up close, perhaps future doctors won’t dismiss us with “I’m tired too.”

**F. Form a CFSAC task force devoted to severe patients.** The Secretary of Health and Human Services has repeatedly ignored your resolutions, but there’s no reason why the CFSAC itself can’t create a committee to actualize the above recommendations for these most overlooked and underserved of patients.

**2. Ask for a vast increase in funding.** As I wrote in May, if our government believes in equal rights for equal disabilities, it must increase funding for ME research by twenty-fold. Even a private endeavor, the

poorly named Chronic Fatigue Initiative, is spending \$10 million on research--twice what our government outlays for ME or CFS each year. Ask Secretary Sebelius how she can justify spending on Multiple Sclerosis 100 times, per capita, what she spends on ME or CFS, when I am more disabled than anyone I know with MS. Why has our government left us to decompose in our beds?

**3. Adopt and promote the new International Consensus Criteria (ICC) for ME**, which were published recently in the *Journal of Internal Medicine* by a panel of 26 respected clinicians and scientists from 13 countries. Researchers must closely adhere to these strict guidelines to create homogeneous cohorts. Note that to receive an ME diagnosis defined by the ICC, a person must function below 50% of normal activity. While this requirement may be too restrictive for diagnosis, it should be observed for research. Doing so will keep the focus on more disabled patients and facilitate the search for biomarkers and treatments.

**4. The term “chronic fatigue syndrome” should be phased out.** In particular, research using the Empirical Definition--which was co-authored by Bill Reeves, Beth Unger and Suzanne Vernon--should not receive government funding. Research based on this definition is virtually meaningless because it does not correspond to any disease entity but to a hodgepodge of psychiatric conditions, simple tiredness and unwellness. Any research on “chronic fatigue syndrome” must be based on the Canadian Consensus Criteria, which, like the ICC, defines a distinct neuro-immune disease and requires patients to function below 50% of normal activity.

Patients who don't fulfill the ICC or CCC should not be admitted to studies of either ME or CFS because they confound research results.

Thank you for reading my testimony, which took me five weeks to write because I can concentrate for only short periods.