

Testimony

Matthew Fairman

My name is Matthew Fairman. I am 23. I became sick with ME/CFS nearly a year ago. I count myself as extremely lucky for reaching a diagnosis so quickly and for having loved ones so supportive. Many are not so fortunate. Yet, as important as these factors are, they barely mitigate the tragic and shameful reality that, after thirty years, adequate medical treatment is not available to those with ME/CFS, never mind a cure. So, in the continued absence of real commitment by the NIH and CDC to solve this illness, we drift, lives stolen, financially in ruin, and with little hope for the future.

In submitting this letter, I hope to focus attention on those falling ill with ME/CFS today and to make clear three simple, concrete changes that would make a significant difference in their lives, even if government agencies continue to commit desperately needed research funds disproportionately to other illnesses.

.

To family and friends, I describe my experience navigating our medical system with an analogy. I say: “I feel as though I have a giant rock on my chest. I’m unable to move; I’m trapped. And the more I struggle against it, the more I realize, “Holy &#%#@ . . . there’s a huge rock on my chest.” I tell them that when I first went to my general practitioner (“GP”), he said, “Hmm, I’m not sure about that rock. I’ll refer you to an infectious disease (“ID”) specialist and a gastroenterologist.” The ID specialist ran tests and said, “I don’t see a rock. Start exercising again. Don’t sleep more than nine hours. Be active. It’ll go away soon enough.” The gastroenterologist ran tests and said, “I only see a pebble; it’s Irritable Bowel Syndrome. It will go away . . . And if there is a rock, I can’t help you. It’s not my area.” When I finally diagnosed myself, my ID specialist and gastroenterologist were unyielding. “It’s not a rock. It’s a pebble.” When I returned to my GP, he said, “Hmm, maybe you just think there’s a rock. Fill this prescription and call me in a few months.” And there I was left, with a rock on my chest that no one would acknowledge, starting to think, “Maybe it’s not a rock . . .”

Left adrift, but convinced that I was not crazy, I turned to the internet. I created a list of possible illnesses and crossed off the most unlikely. Chronic Fatigue Syndrome matched my symptoms, but seemed like a “wastebasket diagnosis.” I resisted it, refusing to settle on what seemed a diagnosis created only to give sick people a label when no answer could be found. But eventually settling

on the diagnosis, I learned as much as I could and approached my doctors, who again told me there was no rock. I was left to drift. But a self-diagnosis at least gave me a place to start. The obvious sources – the CDC, WebMD, the Mayo Clinic, and Wikipedia – gave me no context about the disease and provided no real path forward. In fact, they provided information about treatments, like Graded Exercise Therapy, that I had already discovered to be harmful. So I scoured the internet daily, sorting through mountains of conflicting treatment recommendations piece by painful piece, till my eyes burned, my head ached, and I could take no more, feeling all the while like I was trying to assemble an elaborate puzzle all by myself, from pieces scattered across a field and without the picture on the outside of the box. Names of doctors, supplements, medicine, and treatment protocols flew by me.

My search put me on a roller coaster of alternating optimism and despair. One day I would feel driven and optimistic, occasionally even jubilant at the thought of a solution; the next I felt shattered . . . frustrated, angry, and abandoned . . . hopeless. But I gradually began to pull together the pieces. I crafted a treatment program of my own, learning about pacing from one source, interval exercise from another, sleep hygiene from still others, approaches to orthostatic intolerance from forums, and the potential value of supplements from innumerable other sources. I eventually reached a workable understanding of the illness and began to devise a bare-bones treatment program. From my research, I was able to find two specialists knowledgeable about CFS, who expanded on my bare-bones treatment program and gave me some hope through encouraging words. Most importantly, even though they could not provide me with a cure or a definitive treatment plan, they validated my illness. They gave me my first official confirmation that I was not crazy, that there was indeed a rock on my chest.

Feeling that I understood ME/CFS as best as I could, I next worked to convey to family members and friends just what it was that was crushing me, what was stealing my life in ways they could not see. This was equally challenging, and perhaps more dispiriting. With such poor awareness of this illness and with popular sources of medical information so grossly inadequate, I lacked clear and comprehensive sources of information to which I could point my family and friends. The task of conveying the nature and seriousness of my illness was (and is) on my shoulders alone. But with an illness popularly named Chronic Fatigue Syndrome, I found it nearly impossible to convey the severity of my illness to others. I found myself constantly apologizing: “I know it doesn’t sound that bad, but it’s actually quite severe;” “Yes, I am *really* sick;” “No, it’s not depression and I’m not simply tired.” Someone close to me said early on, “Oh, Chronic Fatigue

Syndrome, I think I had that once. I was really exhausted at work. I changed my diet and started to exercise and felt better.” With those around me, I face persistent doubt and misunderstanding, and that doubt creates an elephant in the room: that my illness is not real, is not severe, or is simply depression. With such a complex illness, such poor public awareness, such inadequate popular information sources, and a name that suggests I am simply tired, how am I to convey to family members and friends that I suffer from a serious illness? How am I to convey that I am trapped beneath a rock that gets heavier the harder I struggle, and that, although they cannot see it, I am sapped by an illness that is stealing my life and vitality at 23?

It is imperative that the NIH and CDC reevaluate whether the distribution of funds to ME/CFS research is equitable when compared to other illnesses of similar severity. Funds for biomedical research in search of a cure for ME/CFS are desperately needed. And by continuing to provide only token sums for ME/CFS research, these agencies not only commit a gross injustice, but abdicate their responsibility as drivers of scientific research advancing the national health.

While finding better treatments and discovering a cure will take time, even with adequate funding, much can be done *right now* to improve the lives of those with ME/CFS. For the sake of those who have just woken up exhausted this morning, with a headache, feeling spacey and mentally clouded, and are not yet aware of how their lives have changed, I ask that the Committee work to *immediately* effect three changes.

1. We need to educate the medical community and ensure that students graduating from medical universities next year have at least a basic understanding of this illness. Those patients falling ill today and next month should not have to experience what I and every other ME/CFS patient has experienced: being bounced around from doctor to doctor; being told they’re not ill, but may be depressed; being prescribed “treatments” often permanently harmful to their health; and being forced to learn about an incredibly complex illness and craft a treatment program all on their own because the medical community has failed them.
2. The CDC and NIH must revamp their pages on Chronic Fatigue Syndrome and work with other healthcare information providers and research institutes to ensure that information on ME/CFS is clear, comprehensive, and provides patients with a definitive path forward. Doing both would not only ensure that these soon-to-be patients do not

experience the painful and arduous process of self-diagnosis and treatment that I experienced, but would also enable them to educate their family and friends. Their emotional health demands it. Their physical health demands it. People with ME/CFS need to know as soon as possible how to modify their lifestyle in order to avoid the push-crash cycle that leads to deteriorating health.

3. Lastly, thousands have said it, but CFS needs a new name. Chronic Fatigue Syndrome is a grossly inadequate name for such a complex and devastating illness. In so poorly describing only one of a myriad of severe symptoms, “Chronic Fatigue Syndrome” delegitimizes patients’ horrendous experience. For soon-to-be patients, this label will not only make it more difficult to obtain appropriate medical attention, but will also make it very difficult for them to convey the nature and seriousness of their illness to loved ones. The alienation and stress of being unable to describe a serious illness to family members, friends, co-workers, and even healthcare providers can be lessened simply by changing the name. If the public and medical community remain unaware, if popular sources of information remain inadequate, if the NIH and CDC continue to abandon patients, if nothing else changes, a name change will, at the very least, make a significant difference to people who have not yet realized their lives have changed.

These three simple and concrete changes do not require much funding; they require only political will and initiative. Patients with ME/CFS have waited 30 years for that initiative. They cannot wait any longer.

Thank you for allowing me to submit this letter.

Sincerely,

Matthew Fairman