

Testimony

Rachel

To the CFS advisory committee, Personal Testimony
April 18th 2011

I am twenty-five years old and I have had ME/CFIDS for more than a fifth of my life. What began as a flu-like illness unfolded into a devastatingly, debilitating disease, which has robbed me of much more than my health.

There are likely fifty names for this poorly understood illness that I share with at least one million Americans, but it has been documented across the world. It is characterized by extreme exhaustion and pain in every part of our bodies. We have many symptoms, perhaps as many as forty, and each of us may have different combinations, but we share a basic pattern.

We are not malingerers, though we are maligned by being called such. Without a clear, measurable abnormality to define this disorder, and a medical system reluctant to admit its ignorance, we are often left to wander this bewildering medical maze with few allies.

Abnormalities are most certainly present, but they are subtle, and in the reliance on inadequate technology, an entire population is being marginalized. These are numerous parallels in the annals of medical history, of disorders such as AIDS or multiple sclerosis, where until an identifiable marker was found, patients were deemed neurotic.

Though some of the myriad of symptoms I experience daily are “commonplace”- who hasn’t been exhausted, nauseated or had a headache?- the unrelenting intensity with which they occur are far from commonplace. An avid student, I can no longer read more than a few pages before the pain of holding the book, the throbbing of my head, or the sheer exhaustion of the effort overtakes me. I cannot bend from my waist, or tip my head back without my visual world swirling. I am shackled to the plastic bags I carry everywhere, lest I find myself moments from vomiting with no toilet (or the energy to reach one) nearby. I am not, like an AIDS patient, dying from my disease, but ME/CFIDS has whittled my life to a bare bones existence- one in which I quite literally feel the blade marks.

I know that good research takes time and people, but foremost, it takes money. It is only with proper research funding that experts in such diverse fields as immunology, neurology, sleep physiology and others will be able to begin projects that may help to answer some of the questions about ME/CFIDS. Research takes patience, but for patients like me, who struggle daily to perform even the basic activities of daily living, we do not have the time to wait.

So, on behalf of myself, and all the others directly and indirectly afflicted by CFIDS/ME, I implore you to allocate resources **RIGHT NOW** to look towards a better understanding of this incapacitating disease. It is without a doubt a threat to public health and productivity.

Sincerely, Rachel