

## Testimony

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### MAY 12 IS CFS/FIBROMYALGIA AWARENESS DAY

And, unfortunately, too many doctors are still unaware that CFS≠depression. I showed one of my doctors a number of objective symptoms (rash, fever, etc.) which proved it was not depression, and not only did he continue to diagnose “post divorce depression”, but he also later lied to SSDI by stating there was “NO objective evidence” (emphasis his) of any physical ailment.

Our big focus needs to be communicating to the medical community that there ARE objective tests that will show abnormalities (although I’ve not yet been able to be tested for XMRV, I have a series of “sky-high” C-Reactive Protein tests showing some sort of rampant infection/inflammation, from which it can be inferred that I’m telling the truth about having a virus).

A cortisol test will unequivocally differentiate between CFS and depression ... if the doctor is willing to see the proof that he’s wrong, which mine was not.

The best research in the world is no good if it doesn’t get down to the front lines where it’s actually used on patients.

Some of our activists (including me) had gold-plated medical insurance when they first got sick ... but the best insurance in the world won’t help you if your doctor doesn’t know what to do for you. And too many doctors don’t know, because they haven’t been taught what to do for CFS. Their first line of defense against anyone who complains of being tired is anti-depressants (which were proven useless against CFS decades ago!), if the first anti-depressant doesn’t work they prescribe another, and another, and eventually verbally abuse patients about “not wanting to get well because then you’ll have to go back to work!”, when, in fact, the patient wants nothing more than to get well and go back to work.

Dr. Nancy Klimas observed she’s seen patients who “came to a doctor with Chronic Fatigue Syndrome; they left the doctor with Post Traumatic Stress Disorder”; research shows 77% of CFS patients have had a bad experience with doctors. Certainly most of those I’ve talked to have been insulted at least once by a doctor who doesn’t believe they’re really sick. **THAT HAS TO CHANGE!**

And that CAN change right now. It doesn't matter whether the cause is the XMRV virus or the XYZ virus; it's clear that the symptoms are neurological in nature, and doctors can be educated the same way they are about MS – they still don't know the cause of MS, but doctors do believe that it's a real disease and not just a figment of the patient's imagination or an attempt to avoid work.

Had the doctor I saw first in the current relapse listened to the medical advice I passed on from the specialist who diagnosed me more than a decade earlier, I could've been back to work in a couple months. Instead, he insisted it was depression, not medical, so it's been 11 years, and I'm nowhere near sufficiently recuperated to return to work even half-time. His ignorance will cost me over a million dollars in paychecks/pension/retirement savings – which costs the system a goodly chunk in taxes that I'm not paying.

It's been estimated that CFS costs the US economy over \$20 billion a year in productivity. Yet, not even 1% of that is invested in getting us back to work. Not even a tenth of a percent of that is invested in the research that would get us back to work. The blame for patients not getting well and returning to work shouldn't be placed on patients “not wanting to get well” but on the system that thinks a virus can be cured with talk therapy and anti-depressants.

Ampligen – an anti-viral – has been shown to work since the 1980s, but is still not FDA approved (though it is available in other countries). Dr. Montoya at Stanford is having good results with other anti-virals. AZT – an anti-retroviral – has shown promise in off-label use. Yet that information doesn't get to the doctors who treat us; they're left with the impression that anti-depressants are best, and any patient who dares to dispute that research has shown anti-depressants are useless gets written off as a Problem Patient rather than a knowledgeable one.

Truly, even if all that can be done pending final resolution of the XMRV issue is to impress upon doctors that CFS is neurological not psychiatric, that would be a big first step, and an important one toward patients being able to get treatment that might get them back to work, rather than inappropriate treatment that leaves them sick and makes them sicker.

On behalf of the 250 members of the CFS Facts e-group and the nearly 600 members of our Facebook page, I urge you to start a physician education campaign to stress that there are more parallels between the symptoms of CFS and MS than there are between the symptoms of CFS and depression. The lives of millions of people depend on it.