

I am writing on behalf of myself and approximately 250 members of the CFS Facts online support group.

We have group members who are fairly functional (and may be misdiagnosed); at the other end of the spectrum, we have a member who is caregiver to a bedridden patient who cannot even chew and survives on small amounts of beef broth spoonfed by the caregiver, a few spoonful per hour, round the clock.

When Whittemore Peterson Institute announced the discovery of the XMRV virus 7 months ago, we thought our world had changed. It has not. We still get no respect. In fact, after that announcement there was a stepped-up effort in some quarters to discredit patients and researchers who refused to hew to the party line that CFS is purely psychiatric.

Doctors in the CFS community are aware of XMRV; doctors who are not CFS specialists remain oblivious. Still the same old story that the research is not getting down to the front-line doctors who actually treat patients. And if they do not recognize what they are seeing, they will not refer a patient to a specialist; despite a long-standing CFS diagnosis from a virologist, I dealt with a PCP who insisted that I did not need to see any medical specialist, just a psychiatrist, and every attempt to see a rheumatologist, neurologist, or CFS specialist was rebuffed. When I attempted to go directly to a specialist, I was told a written referral from my PCP was required; as long as he refused to accept that I had a physical illness, I could not see a specialist.

Even decades after the Incline Village and Lyndonville epidemics, even after 5000+ research papers, he - - and many others -- remain oblivious to the existence of any objective physical symptoms and continue to view CFS as a term chosen by patients to avoid the stigma of admitting to a mental illness. When the patient brings up these physical symptoms that prove it's not depression, she is accused of lying/exaggerating or, in the words of my PCP, told she's "not making any sense". Some of my obvious physical symptoms were never noted in my medical records, others were attributed to anything else but the CFS -- it was repeatedly assumed that I was too stupid to know what I was talking about when I said that certain symptoms were not a result of what the doctor said they were and offered my factual evidence.

By my own efforts, and over the objections of my doctors, I enrolled in clinical trials to get the correct medications that they refused to prescribe. They intended to prescribe every one of the hundreds of anti-depressants on the market, in hopes of finding one that would work, before they would admit that the smiling, giggling, joking woman in their office was not depressed and give me the medications I requested. The anti-depressants did nothing but make me sicker, so I was not looking forward to spending 20 years proving that none of them worked before a doctor would finally give me what the experts were recommending.

In one of those clinical trials, I was given a C-Reactive Protein test, which the doctor described to me as "off the charts". No one else had ever ordered that test, which would have proven that this was not something that was all in my head, there was objective evidence of something physically very wrong. But it would have proven that I was right in saying it was not depression, so it's easy to see how the doctors' egos were at stake if they ordered a test that would prove them wrong.

CFSAC and IACFS meetings are a good thing, but they're preaching to the choir. We desperately need to get this information out to the rest of the medical community.

On another note, most patients are either too sick or too geographically distant to attend CFSAC meetings. Video live-streaming of meetings has recently been added, which is a boon to some, but many of us who are disabled can barely afford dialup internet service, so we can't watch video. And, no, we can't go to a library or coffee shop like healthy people -- we're bedridden, or homebound, or simply cannot sit upright for that long. A low quality audio-only feed of the meetings would provide access to many more patients.

In closing, I'd like to thank CFSAC for the things they've accomplished to date, and urge you to do more to get the word out to the larger community that our disease has more in common with multiple sclerosis than it does with depression. If we can get it taken more seriously as a physical illness -- neurology, not psychology -- more patients can be helped. A PR campaign that shows something more severe than a woman holding her head is called for, as are presentations to doctors and medical students.

Karen M. Campbell