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on behalf of myself and
approximately 500 total members of the CFS Facts support group
and CFS Facts Facebook page

As you know, the earth-shattering XMRV research was published in Science magazine almost exactly a year ago. Hopes reached an all-time high, this research was supposed to be the game changer.

But down here at the patient level, we're still getting the same old, same old, that we're psych cases, not physically ill. For all the excitement in the CFS community about this proof of something physically wrong, the news still is not filtering down to the front lines: the doctors who actually treat patients. Many of us are still being fobbed off with false psych diagnoses and a handful of useless anti-depressants, rather than being referred for proper viral testing.

A precious year of our lives has been wasted. Why?

And that's on top of the quarter-century that some of us have already wasted on being ill, waiting for politics and psychobabble to subside and science to come to the fore.

In deciding to prescribe AZT for herself and her daughter, Dr. Jamie Deckoff Jones said something about not having the time to wait while the science shakes itself out, they need treatment NOW. And the results of that treatment have been nothing short of remarkable.

Meanwhile, for the many patients who don't have health insurance – don't have an employed spouse who gets insurance at work and/or don't have a spouse at all as a result of the devastating nature of this disease – AZT remains out of reach, not only because doctors won't prescribe it but because we couldn't afford it if they did. Most patients have been denied Disability benefits on grounds that we're "not disabled enough" or "could work if we wanted" or "just need psychotherapy"; we're barely managing to keep a roof over our heads and food on the table.

If and when I am ever approved for SSDI – I applied exactly 10 years ago this week – the check I receive will be less than the cost of the AZT, leaving nothing for food, housing and utilities. I have no spouse, no siblings, no children to assist with the bills, and my elderly parents have their own substantial medical bills to deal with. The only relative who keeps in touch with me is a single parent, barely making ends meet on her secretarial salary, so I can't ask her for help, either.

In a country with such a strong "Protestant Work Ethic", it would behoove the government to get every CFS patient tested for retroviruses, bootstrap us to a few years of AZT, and get us back to the good jobs we had before, which would not only allow us to pay for our own AZT, but would have us paying taxes again, too. Instead, the prevailing attitude seems to be that only those of independent means are entitled to the expensive test and the expensive drugs, and those of us

who've already exhausted our savings in the words of Mr. Scrooge, should "die quickly and decrease the surplus population."

We need regional Centers of Excellence – such as the privately-funded Whittemore-Peterson Institute – to provide accurate diagnosis and cutting-edge treatment to patients. And we need them now, while patients are still able to be healed enough to return to work, not 5 or 10 or 20 years down the road when too much physical damage has been done by the ravages of the disease. I've been told that as a result of medical incompetence and medical neglect, I'll never work full-time again; with enough time and proper treatment, I might eventually be able to work half-time.

For this one patient alone, the lifetime loss to the economy is roughly a million and a half dollars. Multiply that by an estimated one million patients in the US, and the number is larger than my calculator can handle. Suffice it to say that we could make a big dent in the deficit by getting that million people back to taxpayer status. But the patients cannot do it alone; we need doctors who are trained to treat us and assistance in paying for proper medications. Knowing AZT is available does me no good if (a) there have not been clinical trials proving that it works, meaning that (b) my doctor is unwilling to prescribe it, and (c) I'm expected to pay for it myself.

Yes, under health care reform, in 2014 my individual Blue Cross policy will be required to provide certain minimum benefits, which might cover AZT, but by then I'll have four more years of viral damage to my body, making it even LESS likely that I'll ever recuperate enough to return to gainful employment. Treatment needs to be made available NOW, not some mythical day in the future.

For more than 18 years I've heard that "Ampligen is 18 months from FDA approval". At least they're consistent! But that doesn't help the patients who aren't in the clinical trial, who just keep getting sicker, and dying, because there's no FDA-approved treatment for the actual disease, just palliative symptomatic relief. (If you can get even that much – it took me SEVEN YEARS of begging before someone prescribed pain pills.)

One of the easiest things this Committee can do for us patients right now is to back legislation at the Federal level and in every state making it illegal for anyone other than a licensed psych professional to place a psych diagnosis in a patient's medical record. I have a number of such amateur diagnoses in my file, placed there by people who took the same Psych 101 class I did, and those inaccurate diagnoses have wreaked havoc with my life and my ability to win Disability benefits.

I've lost count of how many psych professionals I've seen over the past quarter-century, all of whom sent me back to the PCP with a clean bill of mental health, and the MD, not wanting to be proven wrong, insists that I need to see another and another until I finally find one who agrees with him. Unfortunately, no licensed professional ever will, because the emotional and/or irrational components required to validate his amateur diagnosis are missing.

As was explained by the very first I consulted, a professor of counseling, decades ago, there are symptoms of depression which overlap with symptoms of the flu, and while the doctor might be

correct that I had “at least 3 of 8” on his women’s magazine-style quick quiz, the ones that I had were all symptomatic of physical illness – of COURSE someone with a fever is going to feel sluggish, sleep a lot, and have difficulty concentrating! The PCP never learned that there has to be some emotional component before diagnosing a psychiatric illness, and thus insists that his “3-of-8” diagnosis is correct, and it’s written in my medical record, where it comes to carry the same weight as if it came from someone who is qualified to make the diagnosis, even though it is clearly erroneous.

Nonetheless, because there was nothing to prevent the PCP from doing so, he wrote his inaccurate opinion in my file, and it haunts me to this day. The Disability judge cannot understand, if that’s what’s wrong with me, why I cannot go back to work after a little counseling and a prescription for psychotropic drugs. When I state honestly that anti-depressants make me sicker, I’ve had extreme adverse reactions to most of those I agreed to try, the judge does not conclude that I was prescribed the wrong thing, but that I don’t want to take the pills because I don’t want to go back to work, because those are the correct pills to prescribe for someone with the incorrect diagnosis written in my file by someone unqualified to make that diagnosis.

And, with a psych diagnosis in the file – even though it’s false and inaccurate – MDs consider it unnecessary to seek out any physical cause for my symptoms. I have three fractured vertebrae which were not discovered for a decade because the “easy answer” was that all my symptoms were caused by my marital status, and therefore, the constant pain was written off to “depression hurts” and x-rays were deemed unnecessary. Thank God that I did not become paralyzed from this untreated spine fracture! Living with a chronic pain condition as a result of the medical malpractice is bad enough. Those are the realistic dangers of amateurs placing psych diagnoses in the medical record without the input of a qualified psych professional.

And, in fact, many of my fellow patients tell similar stories of very real physical problems going untreated because they have an amateur psych diagnosis in the file which is then used to falsely explain away everything that ever goes wrong in the future, even simple things that someone with basic Red Cross First Aid training would recognize as a physical condition rather than a psychiatric problem – one friend shattered her wrist in a fall and was denied x-rays at the first ER, which had access to old medical records stating she was depressed. Her hand was swollen and turning colors, but the depression diagnosis caused doctors to ignore what was right in front of their eyes. Thankfully, she had someone willing to drive her to another ER on the other side of the county, where a correct diagnosis was made immediately because they weren’t blinded by the assumption that she was just depressed. This happens time and again in medical offices throughout the country – some doctor unqualified to make a psych diagnosis writes one in the file anyway, and ever after it’s presumed to be accurate, to the patient’s detriment; she can never again get anyone to listen objectively to her physical symptoms.

One of my doctors told me “nothing you said made sense”, which is true – he was listening for the symptoms of chronic depression and I was intentionally telling him the symptoms that differentiate CFS from depression. When I told him that I physically could not perform simple tasks because I lacked the strength to do something as basic as operate a stapler, he gave me a pep talk that I’d be surprised how much I could do if I’d try. Maybe he missed the part where I

already did “try, try again” and failed each time? In looking over the medical records after the fact, the only symptom that was written down was “fatigue” – the rash, the fever, the sore throat, the swollen glands, the fainting and constant lightheadedness that required me to spend 23½ hours a day lying down so I wouldn’t pass out, the paralytic muscle weakness, even the bronchitis for which he gave me an antibiotic, were nowhere to be found. If he’d acknowledged those symptoms, he’d have had to think about what additional tests should be done, but by creating a fictional lifelong history of depression, he absolved himself from having to do anything more than lecture me with inappropriate platitudes trying to build up my self-esteem enough to believe that I would succeed if I just tried to work, rather than looking for a medical treatment to build up my body enough to go back to the career I dearly loved.

Something needs to be done to help patients NOW!!! Now, before more people get sick, before more people become permanently disabled, before more people die waiting for treatment.

After a quarter-century, it’s time the cost of researching this disease is paid by the government, rather than by impoverished patients and their families. The Whittemores, God bless them, put the seed money in, but we have patients living below the poverty level scraping pennies together to send monthly donations to the Institute to further the research, while the government allocates a dollar or two per patient, then wastes most of that studying things that have nothing to do with post-viral CFS.

CFS patients have been described by Dr. Loveless as sicker than AIDS patients, and by Dr. Klimas as more impaired than cancer patients. So why is it that cancer receives \$650 per patient in research funding and this retrovirus receives less than 1% of that amount? This is not a “rare disease” affecting just a few dozen patients worldwide – it affects millions.

And those millions of patients deserve the same level of funding that’s allocated for similar diseases, such as MS, with the same goal of finding a treatment that gets us back on our feet, rather than being expected to be happy with the inadequate pittance which is then frittered away studying everything BUT what it’s supposed to be used for.

To reiterate:

- we need research funding
- we need Centers for Excellence
- we need doctors trained to give appropriate treatment
- we need legislation to prevent inaccurate psych diagnoses which are later used to deny treatment

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Founder, www.CFSFacts.org -- dispelling the myths and providing the facts