

May 12, 2015 International Awareness Day

Introduction:

30 years ago, 30 years, there was an outbreak of an unexplained flu in Incline Village Nevada. Incline Village is a world class tourist destination on the shores of Lake Tahoe. Hundreds of patients streamed into the office's of Dr. Dan Peterson and Dr. Paul Cheney with flu-like symptoms unusual in their severity: crushing fatigue, fever, flu, memory loss, sore throats, exacerbated symptoms after exercise, muscle aches, headaches. It was such a profound "outbreak" that it was reported to the CDC and they investigated. Activated Epstein Barr Virus was a common denominator, EBV. Because Incline Village is such an exclusive town, the media called it "Yuppie Flu". The local Chamber of Commerce did not want an "epidemic" and a state health officer said these people would just as soon have EBV as a BMW and labeled them as neurotics, difficult personalities and malingerers. The doctors were treated as a pariah on the town, were refused service at local restaurants and their children were taunted at school. 30 years ago.

The CDC studied the cases and because there was no known cause, determined it to be a mass fantasy, a coordinated social hysteria and those patients in particular to be a "sub-culture of invalids".

Physicians who claimed it to be valid were openly ridiculed. Researchers were denied grants, insurance companies denied claims for Chronic Epstein Barr and medical reimbursements for drug treatments and therapies were denied. The numbers were growing and now across the country tens of thousands were ill. It wasn't going away. The CDC had to act. Some called it Neurasthenia, in Japan and Europe, Myalgic Encephalomyelitis, here in the States, maybe a post viral syndrome or a chronic viral syndrome. They chose the name chronic fatigue syndrome. CFS because it sounded benign and gave plenty of wiggle room for physicians and insurance companies to explore the psychiatric definition which they did.

Dr. Robert Gallo worked for the NIH and was credited with discovering the HIV virus. He also discovered Human Herpes Virus VI, or HHV-6 and most patients from the Peterson/Cheney clinic tested positive for this virus. At that time the theory went like this: If you were positive for both HIV and HHV-6 it was bad news, your immune system was under-active and that usually lead to pneumonia. However, if you tested positive for HIV but not HHV-6, you could live with it, see Magic Johnson. Now, if you tested positive for HHV-6, but not HIV, you presented the symptoms of CFS, because your immune system was overactive. They called it the mirror image of AIDS. You would have thought that to gather more attention. 30 years ago.

20 years ago it became personal. I got the flu and it never went away. My story is in the book and the film. And the history of this organization is on our web site.

As patients, we are Type A Personalities. We work long hours. We work hard. We work smart. We attack projects with the grip of a pit bull. We attract a following because we lead the way. As expected, we respond to disease with the same fervor and passion that we do all of life. There is no other option but success, and in this case, success means full recovery.

So why is it that after 30 years, it's such a hideous struggle? Why is it that such a significant portion of our population is so terribly misunderstood, maligned, and belittled?

I'll tell you why.

First, because it's mostly women and we all know that women are helpless, weak, and prone to whining. It's a pervasive attitude. I'm sorry.

Second, it's the name. A real disease has a real name, a name that casts fear: Cancer, Typhus, Malaria, Polio, AIDS.

When I got sick, I knew it was bad. I knew that it had such a grasp on my body that I might never recover. When you spend years flat on your face, drained of any strength, dumb as a bucket of rocks, watching your life's assets being dismantled through a distant fog, you suspect the worst.

It was made clear to me by a true and insightful friend, that every time we use those three words (cfs) we lose. Every time. To convert those three words into the ghastly lifelong disease they represent is impossible. Just by saying them, we lose. We're disregarded as whiners, malingerers, looney-bins. Case closed.

What about Fibromyalgia? Multiple Chemical Sensitivities? Lyme Disease?

Third, it's the insurance companies. They're not prepared for an inflammation of the brain or an obscure virus that disables for decades with no cure in sight. They're not prepared for people who stay sick. Not on their watch. They will never understand that money well spent could reverse the billions evaporated in lost productivity. They will never understand that doing the right thing can be profitable. The world is soiled by greed. As long as we are given the psychiatric misdiagnosis, they think they win, and that's all that matters. (Deny claims and stall, this week, this month, this year, until I get my pension.) Graft within the political structure is not uncommon. Disease is business, but don't get me started.

And finally, we lose because we're fractured. The more groups there are for whatever variation of this disease we choose, CFS, Fibro, MCS, Lyme, the more diminished our message. When I see single flashes of activism, a card table in the Mall, or that fantastic banner at HHS, it breaks my heart because I know the price they paid to be "active" and how that activism gets turned against them. Organizations like this one teeter on the edge because those at the helm have involved health issues. The Coalition4ME/CFS is on the right track, while

the IACFS/ME and their newly released ME/CFS Primer for Clinical Practitioners and Consensus Manual gives more power to patients and their providers than ever before. Kudos. The ME/CFS Human Subject Pilot Project at the University of Vermont needs to be funded. Research we can do at our own University can have global impact.

But first on the list of needs is respect, which we lose because of those three awful words, don't say them. The blatant lack of respect, the sneers, the jokes on radio and TV, all make any semblance of recovery infinitely harder. I refer to Al Franken, who, in his previous life wrote a really thoughtless, book, and smeared our population on Letterman and again on the Today Show or to how cruelly Laura Hillenbrand was treated on Imus in the Morning, when they laughed at her, scoffed behind her back. And just like that we're back to the name thing and we lose. Lose, lose, lose. Until we have a name that strikes fear in our heart, we'll run in circles til we're exhausted and die. Insurance companies know this.

That we need help is an understatement. This organization has been held together with a song and a prayer for 20 years. We have an august group of brilliant, talented, and passionate medical professionals at our core. *Dr. Maughan, Dr. Naumann, and Dr. Friedman are the best you'll ever find in this field.* Vermont should be proud.

So,... please,

Log in to our web site. See our scholarships, our book, our film, our manuals for patients, for families, for physicians, for school nurses, watch one of our many videos, share this as you can, with those you know who need help. Everyone knows someone. Let us know how you can help. Let us know which project deserves your support.

Rik Carlson