

Dear Committee, Government Entities, Medical Community, and Fellow Sufferers:

I have been experiencing the typical surges of brain fog that unfortunately come with this disease, although I don't believe fog is the word I would use. Perhaps "disenfranchisement from self" would be a better description, a wrenching and forced disconnect from the tools that should lay readily at my hands; tools such as the ability to maintain thoughts long enough to connect them and come to a conclusion.

Fortunately, when I have full access to my toolkit, I write. I write to others who suffer as I do. I write to government entities. I write to the medical profession. But mostly, I write for myself, so that I can burn a record of my thoughts on a platform that won't disappear as readily as the canvas of my own mind does from time to time.

And so, in the face of my current disenfranchisement, I want to share with you some things I have written before, but have not said to this particular gathering.

Not too long ago, I had pondered the question, "When did it become all about me? Not M.E. the disease, but me the person. When did I become the center of my universe? When did every waking moment become a devotion to the damned disease that has come to define my very being?"

It became all about me the first time I couldn't get out of bed when I wanted to. It became all about me when I could not get to the bathroom by myself.

It became all about me when I had to give up my career, my house, my cars, and my family life for the greedy and unwanted tyrant that has hijacked my life.

It became all about me when I realized that the government, my doctors, my family and my friends took no interest whatsoever in the history of my illness and how we got to be a tribe of disenfranchised sick people with a disease that might as well be leprosy.

It became all about me when I realized I was on my own. And then, my journey began.

All of my life I had been an upstanding citizen, a believer in the process, a truster of doctors and government agencies, and a stalwart bastion of "doing what's right". I always thought that the "moral code" was mostly universal with a few sad exceptions, and that policies that were driven by hidden agendas or studied ignorance were anomalies of human nature. I managed to get into my 40's without being disassociated from my delusions. Then I fell into the black hole called CFS.

As with any black hole, this one has an "event horizon", the boundary of a region of space/time where it is impossible to escape infinity, and beyond which no information, including light, can reach the distant observer. The CFS Event Horizon seems to consist of faux advocates and government agencies, quackologists and psychologizers, big pharma and snake oil peddlers...all of who have some sort of apparent vested interest in minimalizing this disease and at the same

time, keeping us from recovering from it. The event horizon is a paradox of strange behavior and anti-logic.

But once one has breached the Event Horizon and is inevitably and permanently sucked into the black hole, one's perception of reality changes forever. It's kind of like taking the red pill and disassociating from the Matrix, with a finality that is irreversible. One tries frantically to scream a warning to those still on the outside...those who are newly sick, or not inducted into the political abyss. But that same "event horizon" that kept you from seeing into the Black Hole in the first place...keeps those on the outside from seeing or hearing YOU.

After I got sucked into the wormhole of CFS and spent considerable time screaming at the unkind gods who would allow such a twisted charade, I started to notice that there were many others floating out here in space with me. Many others. In fact, vast numbers of others. Each and every one of these people had already been through what I'd just experienced. Each and every one was stripped of any illusions of what had happened to us. Each and every one was fighting a fight, alone but in the company of many. I finally realized that I may be alone, but I was alone with a lot of other people.

When Does It Become About "US"?

We had a vibrant end to 2009. The XMRV research and surrounding events brought a new life into an old fight. The last CFSAC meeting was stunning, driven by testimony from Dr. Peterson, Annette Whittemore, Dr. Coffin, and Dr. Bell.

Many of us, early on, voiced strong concern about riding the momentum and being prepared for history repeating itself in the face of pseudo-replication studies and a culling of X-positives from the herd. As it turns out, these concerns seem valid. We have had three very controversial pseudo-replication studies and a pursuant online firestorm of speculation and supposition about the validity of the WPI XMRV studies, addressed by Annette Whittemore in no uncertain terms in her publicized letter to Professor McClure.

Canada has recently taken the position that there is no point in waiting for the dust to settle, and recently halted allowing CFS patients to donate blood due to possible XMRV contamination. New Zealand has followed suit, and the Australian Red Cross is in the process of risk analysis.

To this committee, to the government entities involved, to the medical community, and most of all to my fellow sufferers, I say "Let the fight begin". If I were to issue a call to arms, it would co something like this:

Don't let your suffering be your cloak. Instead, let it be your shining spear of righteousness, your sword of justice. Use it without prejudice. Set your eye on the truth and do not waver.

The time for talk is over. It is time to DO. No matter how you fit into this puzzle, whether you are a sufferer or a committee representative, let's DO. Support the science. Donate to the WPI.

Clear the path for the WPI to receive funding. Actively pursue information and updates on XMRV. And if you won't, please get out of the way. We are sick and out of time, and no longer have the patience for "can't".

Thank you for allowing me to "speak".

Khaly Castle