

I'm a 63 year old woman who has been a prisoner of this illness since January 2000. I was bed bound for a year. Currently I can go out into my years only after dark due to reaction to light. Prior to that I had two successful careers. I have a BA, an MLS and a JD. The last degree I got in the hope that I'd be able to work from home as my body was failing at a rapid pace. What I did not know at the time was that my mind would fail also.

I love to travel and did so frequently. I love to visit California where my son lives in Manhattan Beach. I would walk along the strand or the water's edge, then sit on a bench and enjoy the ocean breeze. I have not been there in ten years. I was active with social issues in my community. For me, the most difficult adjustment has been my inability to do for others. If I could only get one part of my life back that would be my wish. I was a backpacker, river rafter, horse rider and I love to rappelle (though I could not do technical climbing due to weak arms, but I would find a way up the mountain to be able to rappelle down the face).

I am not an atypical sufferer of this disease. It is taking out people who are making contributions to society. That should not matter as a matter of decency, but I realize that we are in a mode where money is the issue. Instead of paying taxes on my salary these past ten years, I have been on disability. I have spent nearly one hundred thousand dollars of my own money on medical issues in those years. That is money that I will not have to take care of myself in my "old age".

The amount spent on me by medicare is huge. There have been tests and appointments that I knew were useless, but if I did not follow the doctors instructions I would be labeled a non-compliant patient. I am a former academic researcher, have lived with my body for 63 years and have spent every possible moment researching my problem. I still dream of getting some degree of function back. Yet a doctor who spend 15 minutes with me total dismisses anything I have to say and acts on medical information that is usually at least ten years old.

Eight years ago I became so certain that I had a virus that I took the organ donor designation off my driver's license. I could not live knowing that I might put someone else in the hell I have known. Now Canada, Australia and New Zealand are asking ME victims not to donate blood.

This country has already lost billions in tax revenue do to this illness. Even if you choose to dismiss all other arguments, please err on the side of caution and do not allow this virus to spread.

I am sorry my statement is not what I wish it could be, but even this has been done with great difficulty.

Sincerely,  
Jami Hotsinpiller

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