

Thank you for allowing me to present a patient's perspective to doctors and researchers who are working to create treatments and trials for the devastating illness of PML. I also want to thank my caregiver and any other caregivers who might access this webinar ... you are heroic life-savers!

My name is Suzanne Tobin, and I was born and still live in the Washington, DC area. December will mark 8 years since my PML diagnosis. That part of my story is a months-long one, so in the interest of time, I will refer you to The Washington Post "Medical Mystery" article link in my bio.

As with life in general, I have my share of good and bad days, but PML and ICL are ever-present clouds over my life.

On many days since my illness began, my sense of humor has sustained me and allowed me to laugh instead of cry. I once heard a woman who survived cancer say: "If you don't have a sense of humor, you might as well be dead anyway," and I **totally** agree with her.

Here's what I hope to impress upon you:

One: Continue to search for a proven drug to treat PML. We survivors need you to cast the widest net possible to find a treatment.

My yearly MRIs have been stable since 2015. The JC virus continues to show a presence in my yearly LPs, but it is negligible compared to when I was diagnosed.

Neuroplasticity will help survivors recover over the long-term, but we need to have a treatment that stops the virus from doing any more damage, so we can focus on our recovery.

I have regained many physical functions I lost to PML, which paralyzed my whole left side. The fine motor skills of my left hand and my short-term memory still pose challenges. As for my mental health, my NIH neurologist told me that some of the PML-caused lesions show significant permanent damage to the frontal lobe that controls mood, so it's difficult to manage my chronic clinical depression. I have **yet** to find medications that work as well as they did prior to PML.

In **my** case, Mefloquine, an anti-malarial drug, had an almost immediate positive impact. I believe the progression of my PML was halted within a day of starting it. My unclear speech, which had been my first symptom, improved overnight. While it was not validated in clinical trials, Johns Hopkins had had some success with Mefloquine killing JC virus in the lab. I believe it saved my life, and for that I am grateful. I have taken Mefloquine once a week since 2013. The experts don't know why I got sick or why I got better. But, as the saying goes, "If it ain't broke, don't fix it." So I continue to do what worked for me.

Two: We need more attention for PML, as it looks like more people will be at risk for PML with the continued development of immune-suppressing drugs. Even though PML may have declined with the progress that's been made with HIV/AIDS treatment, there are new therapies using immune-

suppressing drugs that are putting **more** people at risk. One person in our survivors' Facebook group said that "developers and prescribers of immune-modulating drugs like oncologists" need to realize that regular testing for the JC virus and CD4 counts should be routine procedure. Another patient comment was that if scientists could develop a vaccine for the JC virus, they could vaccinate all patients prior to any immune-modulating therapies. We aren't scientists, so we don't know if that's even possible.

Every time I see a TV advertisement for a drug that mentions PML as a possible side effect, I just want to scream "Don't take it!" at my television. Unless users are being actively monitored for PML, it's not worth risking the health of your brain--which is the very essence of who you are--for clearer skin or anything that is not immediately life-threatening. Obviously, transplant patients and MS patients are a different story.

Three: Spread the word about PML any way you can. Many of you specialize in PML, but the awareness of the disease is far from universal. The next speaker, Luca Isabella, will talk about using social media to spread awareness of the disease. Over the last 8 years, I've noticed that more doctors seem to at least **know** about PML. That's progress.

Four: Urge your colleagues to listen to their patients. We patients know our bodies better than you do. Use your clinical skills and do **not** rely on diagnostic tests to the exclusion of listening to your patient. Ask yourself whether the diagnostic test's default diagnosis is consistent with the progression of symptoms. Repeatedly, I raised the inconsistency of my symptom progression versus the original diagnosis of stroke and was repeatedly told that the MRI indicated stroke, period. End of discussion.

If you have 5 MRI snapshots of brain lesions, each, in isolation, may look a lot like a stroke but, taken together with progressive increases in the same lesions, they are not typical of a series of strokes, particularly if small lesions, spread widely across the brain, grow over time. I was getting incrementally worse each day rather than in the stepwise manner of a series of strokes.

If I would have had a lumbar puncture when I visited the Johns Hopkins ER in October, instead of telling the resident I had an LP scheduled the next month at my local hospital, I could have been diagnosed two months earlier. Having always been phobic about needles, I was terrified of the lumbar puncture. If I had known it was the key to the correct diagnosis and that all LPs are not created equal, I would have insisted on it. (When I had my scheduled LP at my local hospital, they didn't test for the JC virus; Once I was an inpatient at Johns Hopkins, they did.) When I saw my local neurologist after my hospital stay and told him of the PML diagnosis, he admitted that he had never even **heard** of the disease.

Five: Continue to develop ways to differentiate between PML lesions and other types of lesions. My NIH neurologist told me there is research on how to differentiate PML lesions from other types, and it's possible PML lesions may have an "iron ring" of sorts around them, but the data isn't conclusive yet. Keep up the good work! Early diagnosis would be a **huge** deal for someone like me, who doesn't fit the normal profile of someone at risk for PML.

My sixth and final idea is a far-fetched one, but I figure it never hurts to ask.

Since PML is so rare, is it possible to have some sort of mobile lab for clinical trials that could go to the survivor? Or is there some way to help defray travel costs for trial participants? I live within an hour's drive of two state-of-the-art medical institutions, NIH and Johns Hopkins. But how could you make it easier for others to get access to trials? This idea may not be feasible in the **entire** United States, but it might work in individual states or countries in Europe where the land mass is not so great. Depending on the severity of the patient's symptoms, travel may be difficult, if not impossible, particularly with the added challenge of Covid. Cost is another obstacle. I had private disability insurance that paid me two-thirds of my previous salary, but many people don't. During my worst phase, my whole left side was paralyzed. This made travel difficult and required an able-bodied person to drive and accompany me to appointments. Long-distance travel, by air or rail, would have been even more daunting. Defraying travel costs might help more survivors participate in clinical trials.

In closing, I want you to give you a gift -- the word "**yet.**" It has sustained me during the almost nine years of rehabilitation process. ("I can't walk without a cane **yet;**" "I can't drive **yet.**")

You haven't found a vaccine **yet.** A clinical trial hasn't produced a proven treatment **yet.** **Yet** is a hopeful word and has been a key to my continuing recovery.

Thank you again for your work to help us PML survivors. We are so grateful.