

Symphony in a Cell

Nobody saw it coming. Least of all me, but once it was here, there was no getting rid of it. Dermatologists said it was eczema. A nuisance, a tad uncomfortable, but nothing life changing. They were so clueless. I could already see and feel my body morphing into a bizarre silhouette of crusty, scaly flesh that itched and burned.

At first my skin was just very dry and flaky—erupting in white flurries that came and went quietly without causing much disruption. But after a year, the flakes grew to near blizzard-level conditions—covering most of my body—arms, legs, back, even my face. And when I scratched, the itching and burning became even more intense—almost intolerable.

I was finally diagnosed with a rare and aggressive blood cancer called Sezary Syndrome. It happens when a particular white blood cell called a T cell goes bat shit crazy—multiplying and mutating uncontrollably. Your T-cells normally boost the immune system and fight infections. But Sezary cells do just the opposite. Sezary cells live in the blood but its true colors show on your skin. Colors that screech in dissonant harmonies, turning what was once delicate and smooth terrain into a thick and matted carpet of redness and distress.

The red discoloration is called erythroderma and if Sezary is left untreated, you can count on your skin developing lots of scales, plaques, even tumors on your martian red epidermis. Eventually, the mutant T cells will move beyond the blood and hit the lymph nodes and then vital organs. Two to five years later, your afterlife comes knocking. Well, that's better than 6 months and of course better treatments have improved the prognosis for many patients.

There's no medicine cabinet miracle for Sezary Syndrome. The disease is chronic and there's no cure. At best, you can expect a lifelong repertoire of systemic and targeted therapies to control the beast. I am currently playing the ECP movement of my Sezary Symphony. ECP (that's extracorporeal photopheresis) is an infusion procedure in which the blood is removed, treated with a light-activated drug, exposed to UV light, and then returned to the body. The movement is about 1 ½ hours—long enough to wish you were somewhere else, but short enough to be thankful it isn't worse.

For me, the disease has me trapped in my skin 24/7. I am forced into an endless regimen of anti-itch moisturizing treatments, just to maintain some semblance of my earthly origin. I often dream of being a gecko or a frog, and I could just molt my way to a fresh new skin in less than a week. Oh, but even if that were possible, the new skin would still be affected by the Sezary cells because they are still living in the blood.

So I keep myself sane with distractions—doodling in cool colors like blue and green instead of red and orange, and listening myself to sleep with Mozart's **A Little Night Music**. I suspect however my Sezary cells will never leave me cage free and my next movement will channel Bartok.