

My Journey With Cutaneous Lymphoma

As shared by Brittany B.



My journey with mycosis fungoides (MF) began in 2005. I was just a normal teenager striving to be at the top of my high school class and juggling multiple extracurricular activities. I led a healthy, active lifestyle, surrounded by great friends and a supportive family.

One day, my mother noticed a light patch about the size of an orange on the back of my right thigh, which prompted us to make a dermatologist appointment. My dermatologist could not provide us with much information at first glance, so she insisted that she perform a biopsy. As weeks passed as we awaited results, I was not worried much, and kept to my usual routine, but it was hard to avoid my mother's uneasiness about it all. We finally got a call to come in to discuss my results. The dermatologist stated that after circulating the specimen to multiple sources, she found that my cells were consistent with a form of cutaneous T-cell lymphoma called mycosis fungoides. Much could not be answered, and we were extremely frustrated with the lack of information. Apparently the condition was extremely rare, and the resources simply weren't there to answer our questions upfront.

I was first prescribed topical steroid cream to use. After weeks of use, my light spot hadn't cleared up a bit. I was then prescribed UVB light therapy. The idea of standing in a "tanning booth" for a couple of minutes a week didn't faze me at first, but after a while, it began to invade my daily routine. The closest treatment center was 45 minutes away, and required me to depart school 1-2 hours early, and also caused me to be late to my after-school extracurricular activities. It was difficult to explain what was going on to my friends, so negative thoughts began to set in - Why me? Why do I have to do these stupid treatments? When will it end?

My UVB treatments went on for about two years without much of an effect on my initial spot, and certainly was not helping to prevent new spots. In 2008, my sophomore year of college, another biopsy was taken, which further confirmed the diagnosis of MF, but with some progression, which prompted my doctor to heighten the level of treatment to PUVA. My frustration that had only loomed once in a while took a turn. Not only did the Psoralen pills make me feel weak, lethargic and sick to my stomach, but I was also forced to wear sunglasses and fully cover my body for 48 hours following treatment, which obviously came off a bit strange among my college peers and professors. Beyond the classroom, I also had to explain to my dance teammates why I was constantly wearing sunglasses, and often had to sit out at practice.

As much as I detested the PUVA treatments, my body quickly took a liking, and my spots were cleared within weeks of first starting. I remember calling my mother with such excitement to report that I was nearly spot-free. Seven years later, I am still in remission, and have simply made treatment a part of my weekly routine. I no longer wrestle with the idea of skipping treatment, question my worth or internally complain about why I was chosen to carry MF. I know that I was chosen because God equipped me with the skills to carry the fight and advocate for those who may not be strong enough.

My (now) husband was there with me from the very beginning when I was first diagnosed in 2005, providing emotional support and helping me to keep up with treatments. In carrying the fight, my husband and I recently decided to use our wedding as a fundraising platform for two non-profit organizations, one of which was the Cutaneous Lymphoma Foundation. We asked all guests to provide donations in lieu of gifts as the foundation has greatly helped me get through my journey with MF, specifically along the lines of patient education, and most important, easing the idea of simply not being alone. We managed to raise over \$3300, which we equally split between the two non-profit organizations. Our family and friends were happy to support, and equally open to enlightenment on a silent condition that all should be made aware of.

