My Journey with Cutaneous Lymphoma

As shared by Susan S.

My journey with cutaneous lymphoma began as a mystery when my symptoms initially presented. In the Spring of 2009, I developed a rash around my neck and upper chest area. It was reddish and itchy. I tried to ignore it, but my Mom noticed it during a visit home (I lived in Chicago and she lived in Michigan). My Mom suggested that I see a dermatologist, but I thought she was overreacting to what I believed was an allergic breakout. I switched shampoo, laundry detergent, and tried numerous over-the-counter remedies rather than see a dermatologist - which seems ridiculous in hindsight.

By mid-August, I couldn't sleep because my skin was itching so badly. I would use a hairbrush to scratch my back. Finally, during another night of insomnia and itching, I saw a TV commercial for a cancer treatment center that featured a man describing a symptom of his lymphoma as "horrendous itching." Alarm bells went off; that was it!!! Around the same time, I noted two lumps on the back of my neck. They were roughly the size of rounded quarters and it was as if they had grown overnight. My doctor wrote an order for a CT scan to investigate the lumps on my neck. The other skin issues were left unaddressed.

I consulted "Dr. Google" and became convinced that I had some type of lymphoma. Since I worked at a medical center, I was fortunate to have access to managers who helped expedite the CT scan. The radiologist who read my scan reported that there was no apparent reason to believe I had lymphoma, though the scan confirmed the existence of two "masses" on my neck. While somewhat relieved, I had reached my wit's end with the itching and next contacted dermatology. The dermatologist examined my red arms, back, and torso, which would appear - to the untrained eye - to be a sunburn. The kind, experienced dermatologist calmly told me, "Your body is trying to tell you something, and it is very good that you are here." Skin biopsies were taken.

Two weeks later, I was informed that I had a rare type of cancer - cutaneous T-cell lymphoma (CTCL) - and was scheduled to see the Medical Director of Dermatology, as well as a doctor specializing in CTCL. I had an inkling that it could be serious, so I called my family and closest friends. My Mom packed her bags and drove from Michigan to Chicago. (She stayed with me for years and was a rock of support.) During my next appointment, several rounds of blood work were run and I was promptly scheduled for surgery to determine whether the cancer had spread to my lymph nodes.

While staging of my diagnosis was pending, the tops of both of my hands developed a pattern of growth that was foreign to me and could not be hidden from others in the workplace. I later learned that they were "plaques." Many people at work were compassionate, but the business reality was that I retained responsibility for a heavy workload while dealing with matters related to CTCL.

By mid-September 2009, I had my diagnosis: cutaneous T-cell lymphoma, Sézary syndrome, Stage IVA. The cancer had indeed spread to my lymph nodes. My case was referred to oncology and a treatment plan was developed.

I learned that Sézary syndrome is an extremely rare type of cancer, even within the CTCL world. Blood tests revealed a significant number of "Sézary cells" - cloned, aggressive cancerous cells - in my bloodstream. I understood it to be the CTCL version of leukemia.

In the early weeks of my diagnosis, I received light therapy several times a week, which was like standing in a tanning booth with goggles on - though I emerged red, not tanned. I sought additional medical opinions and continued to report to work as able.

For many patients with Sézary syndrome, the treatment of photopheresis is generally prescribed. In this treatment, blood is extracted through an IV in the arm, is exposed to UV light to treat cancer cells, and is then returned to the body. This treatment was recommended by two of the three opinions I had sought. Based on the advanced stage of my disease, the oncology group I selected did not recommend photopheresis. Instead, I was prescribed continued light therapy,

along with interferon shots to self-administer three times a week. Mercifully, I was also prescribed hydroxyzine to help relieve itching. Immediately, I became a weekly patient at the CTCL clinic and a regular in oncology blood draw; it was all surreal. By October 2009, I was too ill to work.

The lumps on my neck grew and interferon shots were increased. However, a batch of interferon I received from my pharmacy was tainted and therefore recalled. Interferon was discontinued from my treatment plan.

As a "what do we have to lose" next step, I ultimately tried photopheresis - also ineffective, as my team initially determined. Close to the end of treatment options at that time, I was advised that a bone marrow transplant/stem cell transplant (BMT/SCT) was necessary to save my life. No one in my family was a potential donor, so the Be The Match Registry was contacted to find an anonymous donor, an unrelated "allogeneic" donor. In the meantime, I was prescribed Campath® (altemtuzumab), a drug that was injected into my arm daily - by my Mom. Campath® brought me to a temporary remission while we awaited availability of a donor.

While awaiting transplant, my Mom, brother and I attended a workshop in Chicago sponsored by the Cutaneous Lymphoma Foundation. Many medical experts gave presentations, and Susan Thornton shared her journey with the disease. She injected humor and shared that her Mom - much like mine - had attended virtually every appointment with her. I was new to the disease and was comforted by the receipt of an informational binder, as well as the opportunity to meet Susan and others afflicted with various stages of the disease. It helped to know I was not alone in this journey.

As my oncology team predicted, Campath® was only a temporary remedy and Sézary cells aggressively began to re-invade my bloodstream. I developed plaques under both of my armpits. They seemed to "bloom" as swollen layers of skin - uncomfortable and unsightly. The disease also attacked my inner thighs. These changes reminded me of Susan Thornton's comment at the Foundation's event - that the disease had no respect for the body.

My transplant was scheduled for May 12, 2010, and I checked into the hospital on May 5, 2010 for a series of intensive chemotherapy treatments. My basic understanding was that the chemo would kill the "good" and "bad" cells, and I would receive my donor's cells to grow a new immune system to fight the Sézary cells. I will not elaborate on the transplant process, as I hope that most of you reading this will not reach that point of treatment. I will say, however, that having a BMT/SCT is not an overnight cure.

My life leading up to CTCL diagnosis and throughout treatment has been a physical and emotional rollercoaster. I've had many complications from the transplant and high doses of steroids that were prescribed. Fast-forward - I have now survived over eight years post-CTCL diagnosis and seven years post-transplant. I can't emphasize enough the importance of the incredible support I received from my family and friends. I received phone calls, books, videos, cards, letters, pictures drawn by children, prayers, food, flowers, clothing, balloons - from those close to me, from people I barely knew, as well as people I did not anticipate reaching out to me. All of it helped.

If you know someone touched by any illness, please know that all gestures matter - even a smile in a waiting room. This support in no way minimizes the critical expertise of the compassionate medical professionals who oversaw my care at all levels. I will never forget them.

I have come to realize that survivorship is not an end, but remains a continual challenge - as life in general. I have had periods of relative normalcy and the enjoyment of social activities, in between episodes of frustrating setbacks.

There are scars that are apparent, but other scars that no one sees - or at least that I try to hide. I am grateful for the gift of a second chance at life, while sometimes struggling with how to use my gift. One of the most difficult challenges for me has been the inability to return to work. Last year, I moved from Chicago to be closer to family in Michigan. I live near my Mom and see her often. I keep in close touch with my friends, spend quality time with family, and have a two-year-old dog - Coco. I'm taking piano lessons, collaborating with independent composers to write songs, and trying to live each day without obsessing about tomorrow - not always easy for me.

I hope that sharing my story will help people to perhaps recognize warning signs earlier than I did. Remember to reach out to resources, such as the Cutaneous Lymphoma Foundation and other support groups, and to be grateful for life. We can take nothing for granted. The cliche' of a "new normal" continues to be an evolving reality, yet also a life worth exploring and living