My Journey With Cutaneous Lymphoma

As shared by Charmagne and David

"It's not a sprint, but a marathon."

These are words spoken by Susan Thornton at every Cutaneous Lymphoma (CL) Foundation conference we have attended. While they didn't have much personal meaning at the Atlanta Patient Educational Forum (PEF) in the fall of 2012, the words rang true in Chicago 2016.

My husband, David, was diagnosed in June 2012. The phone call came about his biopsies approximately three weeks after they were performed. The doctor said the words, "T-cell lymphoma."

We researched online trying desperately to learn as much as we could about this cancer that was on the skin, but not skin cancer. We were assured this was a perfectly manageable cancer, although not curable. Well, it couldn't be too bad if we were simply rubbing creams on and going to a tanning bed, could it?

In August 2012, we attended a PEF in Atlanta, which I had found on the Foundation's website. We went with David "kicking and screaming" that this was just a waste of time. We have since attended three more conferences since that one, each without "kicking and screaming."

While at the Atlanta conference, we learned that he had folliculotropic mycosis fungoides (FMF), and that systemic treatments would work better on FMF, as opposed to the creams and light therapy he had since been prescribed; our doctor concurred. David started Targretin the next week. Because of Targretin, his thyroid quit working properly so he started on a medication for this. Itching became his constant companion so he began taking Gabapentin to relieve the itching. Although the medication often made him drowsy, life was still pretty good.

We attended a CL Foundation conference in Kansas City, and one in San Diego the following year. In Kansas City we learned about photopheresis. We returned and presented this suggestion to our doctor, who was receptive to the idea. This was June of 2014; by August of that year, we were traveling to two days a month for David's photopheresis treatments.

During the latter part of 2015, however, the outbreaks spread all over his body and the itching was life-altering. In the spring of 2016, we received our Forum Newsletter from the Foundation. There was an article about a study being conducted in Boston using full body low dose radiation. The results were mostly positive and patients participating in the study were having lengthy periods of remission. My husband spent a lot of time online researching this treatment and was determined it would help him.

We presented it to our treatment team and once again, they were receptive and optimistic. On June 1, 2016, he started radiation; he completed it on June 15. We added a very capable radiation oncologist to our treatment team. David was able to attend the Foundation's conference in Chicago at the end of June. I was skeptical, but this time HE insisted on attending.

Since radiation, he has lost his hair, but he has gained restful nights, alertness, and a body without sores. For the first time in four years, he was able to shave with a razor. We are currently doing photopheresis two days a month to strengthen his immune system. We know this is not a cure. However, we have had two months of no itching and no harsh systemic drugs. The Cutaneous Lymphoma Foundation's website, publications, and conferences have provided us with the tools and information we needed and has allowed us to help direct David's treatment. In addition, networking at the conferences has been invaluable. We have taken time for "us" more than ever before. We have traveled; we have celebrated the marriage of our eldest son; we have welcomed his first child into our family. Was it difficult at times? Yes. Have we been scared? Yes.

My advice to others on this journey would be to educate, advocate, and live. Don't just exist but live. Take time for what you need to feed your soul; then you will have the mental and physical strength that your partner needs you to have.

This disease has definitely changed our lives, but we have always found advocates in our healthcare team and in the Cutaneous Lymphoma Foundation. They have propped us up when we needed it.

It is a journey we didn’t plan, but it is one that we now feel equipped to navigate. Slow down and breathe. Remember a wise woman once said, “It is a marathon.”