My Cutaneous Lymphoma Experience...Thus Far

As shared by Joe P.

I'll mention a quick caveat for those who may have missed the Friday evening session at this year's Virtual Patient Conference: my disease trajectory is even more rare than the cancers we're fighting. If my math is correct, a situation similar to the one I'm experiencing arises in roughly half a percent of cutaneous lymphoma cases. In other words, please don't think your disease will follow suit.

Mystery Bumps

A little over five years ago, I noticed odd bumps on my scalp; they looked similar enough to zits that I assumed they were, so I went on with life as usual, expecting the bumps to go away. But they didn't! Instead, they started to spread. Concerned, I made an appointment to see my primary care physician (PCP).

My PCP thought the "rash" was likely shingles. She gave me a round of antivirals. When the spots on my head kept spreading, she referred me to a dermatologist. One of the bumps had grown quite large by this time. Thus, I went to my dermatology appointment with trepidation. When the dermatologist was done with his inspection, he sat down at his computer and announced I had an infection. He was going to give me antibiotics, and I should schedule a follow-up appointment sometime after. Goodbye! Next patient. My response was, "What? How can this be an infection?" The dermatologist, however, didn't appreciate being questioned.

About a month later as I continued taking the antibiotics, the large bump turned red and began oozing blood. Seeing a large, blood-red, oozing bump on my head inspired an email to the doctor letting him know I needed a biopsy done pronto. Surprise, surprise! The tests showed I had a form of T-cell lymphoma. OMG! Even though I was expecting bad news, the diagnosis virtually knocked the wind out of me.

What Do I Have?

I was at work at the time. Somehow, I managed to get an oncology appointment that very same day. Appointment secured, I rocketed from work, leaving my colleagues wondering, to the oncologist's office to find out what the heck I had and what could be done.

The oncologist told me I had a very rare T-cell lymphoma, primary cutaneous anaplastic lymphoma, and people with this unusual form of cancer tend to die with the disease not from the disease. Whew! That was welcome news! I underwent a PET scan which confirmed the lymphoma was only on my head, so I was sent for radiation treatment.

The radiation oncology practice was great! They zapped the disease on my head into oblivion and left me with a shiny, glowing red pate. They also reviewed my PET scan – everything, not just my head. One of the nurses sat me down and told me when I was done with my treatments, I should go see a urologist.

What?! But it was true. Like many patients whose battles become complicated due to other opportunistic cancers, I found myself diagnosed with prostate cancer within two months of eradicating the CTCL on my head. I won't belabor the experience except to say my surgery was a complete success. I remain blessedly free of that bugger to this day.

An Odd Development

So! Two cancers extinguished, I was ready to get back to normal life. Or was I? Within six weeks of my prostate surgery, I suddenly developed sciatica. I thought it an odd development, but I know things do wear out over time. So I started seeing medical professionals to find a cause and hopefully a solution for the pain. Turns out, though, I was talking to the wrong doctors. You see, the lymphoma had gone systemic! There was a tumor pressing on my sciatic nerve causing me all that trouble.

Since discovering my cutaneous, indolent lymphoma was having a party all throughout my body, I've become acquainted with many of the drugs and procedures used to treat indolent and aggressive lymphomas (primarily T-cell). Some by reputa-

tion and others personally. The ones I've had personal experience with have included chemotherapy, immunotherapy, a drug conjugate (immunotherapy and chemotherapy), and a bone marrow transplant.

Get Educated

What I mean by saying I know some drugs/procedures by reputation is that I've made it my business to get educated about the disease. The Cutaneous Lymphoma Foundation has been a lynch pin in that effort through their online resources, their many great programs for patients to hear from experts, and the networking meetings. I've picked up some very important info and insightful wisdom from fellow patients in those meetings.

Why did I push to educate myself? Well, we do have a rare disease. Not all my doctors have been well versed in this kind of cancer. Actually, none of my regular doctors have been. One of my oncologists even told me she didn't think anything would work for me. Admittedly, things weren't looking good at the time. But that was four years ago. Four years! Clearly, something did work.

Expressing Gratitude

Thank goodness I found my way to the experts. In my experience, getting specialty consultation has been key to receiving the kind of care I need. I don't visit the specialists often, but they've been critical in helping my oncologist see her way toward successful treatment strategies.

Before I wrap it up, I absolutely must mention my stalwart partner, Patrick, who has been through all this with me. He's been an amazing caregiver, cheerleader, and understanding ear. Longsuffering, he even spent two months hunkered down with me in a tiny apartment across the street from Johns Hopkins during my transplant. What a super guy! We were social distancing and wearing masks before it was cool (or a requirement).

Unfortunately, my disease is still active. Although I've been through the transplant and have been a candidate for clinical trials, I haven't found a cure or an enduring remission. We have, however, found a treatment which is currently keeping the lymphoma controlled. Basically, I'm on a maintenance Bexarotene regimen. Hey, I'll gladly take it!