

# It's Up to Me to Live My Life

As shared by Lannie



In January 2013, I started the biggest fight of my life.

Nine years later, here I am—a wife to a wonderful husband, a mother of two, a grandmother, and still working as a practical nurse two days a week at a medical center, making every moment a special one.

Before my cutaneous T-cell lymphoma (CTCL) diagnosis, my life was a busy one: I worked various full-time jobs for a hospital system, and more recently, with a clinic close to my hometown in Ohio. Aside from my work, I enjoyed spending time with my family and quality time with close neighborhood friends. To escape the cold Ohio winters, we became fond of going on cruises every year.

## Mystery Rash

It was in May 2011 when I noticed a red rash on my face as I got ready for work. My primary care doctor worked in the same building as I did, so I took advantage of the very convenient resource I had. She thought it was odd; maybe a sensitivity reaction to something I ate, new makeup I tried, or detergent. We went through a whole shopping list of potential suspects. Seemingly unbothered, she advised me to try over-the-counter medications and ointments, but nothing helped. The rash hung out on my face for a while, but over a two-month period, it gradually worsened and spread to my entire body. Nothing seemed to help, so my PCP became concerned and referred me to a dermatologist who also thought the growing rash was unusual. He ordered multiple biopsies that were inconclusive, and he prescribed steroids and light therapy to treat my then-unknown condition. Nothing seemed to help, and this had gone on for over a year.

In September 2012, I had my annual screening mammogram, and it showed enlarged lymph nodes in my armpits on both sides of my body. At that point, my dermatologist suspected cutaneous T-cell lymphoma—or CTCL—and immediately referred me to an oncologist. Following extensive and quite exhausting testing, my doctor entered the room, and his face told me everything.

He said, “This is a difficult conversation to have.” That was it. My CTCL diagnosis was confirmed, and I had an extremely rare form called Sézary syndrome.

I was first prescribed an oral chemo drug, interferon injections, and photopheresis treatments. Despite treatment, my LDH—a marker of cell and tissue damage in the body—was continuing to escalate, and my symptoms worsened. I had fissures on my feet. I had lost most of my hair and was extremely cold all the time. I couldn’t get away from those dang Ohio winters even if I tried! On top of that, my skin shed constantly, and I was embarrassed by my appearance.

## Promising Clinical Trial

By this time, I was referred to a doctor at a university hospital who was in the process of initiating a clinical trial of a new medicine for the treatment of mycosis fungoides and Sézary syndrome.

My doctor and I discussed the common side effects of mogamulizumab before I began the trial, including rash, tiredness, diarrhea, muscle and bone pain, and upper respiratory tract infection. I was told that I’d receive infusions once a week for the first 5 weeks and then every 2 weeks thereafter.

After I had my first infusion, later that evening I felt like I had been hit by a truck! I had numerous symptoms, all of which were discussed with my doctor. Due to this reaction, the pace of the next infusion was slowed to over two

hours, and I was premedicated with over-the-counter medications to minimize any reaction. However, this is just my experience, others may be different.

It was around the time of my fourth infusion that I noticed my skin start to clear. My skin began to improve and eventually cleared completely.

The worst part of the trial was the monthly photo session to document the changes in my skin. I joked with my doctor that I had better not see ANY of these pictures on Facebook! But on a serious note, when I watched the video they prepared from the photos, it was amazing to see how mogamulizumab had improved my overall condition over time. My skin returned to normal on most of my body, and there was no longer any evidence of Sézary cells in my blood tests.

## Gaining Perspective

As I look back on when I first learned that I had cancer, I now realize how devastated I was at the time. I didn't want to accept that I would not see my children live their lives as adults, be together with my husband, or watch our grandchildren grow up. It took a while to realize that it was up to the doctors to work on saving my life, but it was up to me to live it. I vowed to exercise and keep healthy habits—and I've kept that promise.

We are so fortunate to live in a time when the medical field is researching and discovering new treatments and showing endless possibilities for the future of medicine. I learn something new about myself every day, and most of the time, it's through failure. But that's how we grow the most, right?

Funny enough, I failed at retirement. Yes, you heard me right...retirement! I retired in June 2021, and not even six weeks later, I called my boss at a local Ohio clinic to say, "I'm bored. Where do you need help?" So, now I work two days a week at the clinic to help with my boredom, and I've learned that I hate not learning more every day.

One last thought. Just a piece of advice that I give to my grandchildren that I think would benefit patients who are in a personal battle themselves—

You need to do three things every day:

- Laugh, even if it is at yourself
- Learn something new, and
- Live every moment like it's your last!

What more can you ask out of life?