

My Journey with Cutaneous T-Cell Lymphoma

As shared by Mark E. V.

If sharing my story helps one person get diagnosed sooner, ask another question, seek another opinion, fight for access to care, or simply feel less alone, then my experience can serve a greater purpose.

For years, I knew something was wrong. I just didn't know what. Like many people living with cutaneous lymphoma, my journey did not begin with a diagnosis. It began with unanswered questions, failed treatments, and the frustration of knowing something was happening with my body but not knowing why.

When I was 41 years old, I started developing skin issues that would not go away. At first, I thought it would be something simple. Something that could be diagnosed, treated, and put behind me. But that was not my journey.

My first diagnosis was contact dermatitis. I was prescribed topical steroids and hoped that would finally solve the problem. It didn't. The symptoms continued.

The next diagnosis was psoriasis. Again, there was hope. A new diagnosis meant a new treatment. Maybe this time we had found the answer. I was prescribed Tacrolimus ointment and followed the treatment plan. Again, nothing changed.

Then came another diagnosis: eczema. This time, the treatment became more involved. I was prescribed Dupixent injections. Giving yourself injections is not something most people look forward to, but when you are desperate for answers and desperate for improvement, you do what you need to do.

I told myself that if this finally worked, it would all be worth it. But it didn't work. Treatment after treatment failed. Diagnosis after diagnosis turned out to be wrong.

One of the hardest parts about having an undiagnosed rare disease is the uncertainty.

Every appointment brings hope. Every new treatment makes you think, "Maybe this is finally it." Every failure takes some of that hope away. You start questioning everything. Why isn't anything working? What are we missing? In my case, what we were missing was cancer.

But getting to that answer was only part of the challenge. Because where you live matters. I live in a small town in Maine, and access to specialty health-care is not always easy. For many people, seeing a dermatologist may mean driving across town. For me, my first dermatologist was already a minimum 30-minute drive each way.

When that dermatologist was unable to determine what was happening, I needed another opinion. But there was no specialist right around the corner. There was no immediate appointment. I waited approximately eight months as a new patient to see another dermatologist located more than an hour away.

Eight more months of waiting.

Eight more months of symptoms.

Eight more months without answers.

Finally, four years after my symptoms first started, at age 45, I received the diagnosis that explained everything. Mycosis fungoides. A form of cutaneous T-cell lymphoma.

I had cancer.

That is a moment you do not forget. It is also a complicated moment. There is fear because you hear the word cancer. But there is also relief because after years of searching, you finally have an answer.

Unfortunately, with a rare disease, diagnosis is not the finish line. It is the beginning of a new journey.

After my diagnosis, I needed to see an oncologist who was located more than an hour from my home. Because CTCL is rare, I was then referred to specialists in Boston for further evaluation. Boston is more than four hours away. One way.

Living with a rare cancer in a rural community means healthcare is never just healthcare. Every appointment requires planning. Time away from work. Travel. Expenses. Sometimes overnight stays. The disease itself is already difficult. Accessing care should not have to be another battle.

Eventually, UVB phototherapy became part of my treatment plan. For approximately a year and a half, I drove 30 minutes each way, three times every week, for treatment. Three times a week. Every week. For a year and a half.

I also underwent three separate rounds of radiation therapy at a facility more than an hour and a half away from home. The treatments helped. But managing the treatment became its own challenge.

Then I learned about home phototherapy. For someone living in a rural area, this had the potential to be life-changing. It would not cure my CTCL. But it could give me back something incredibly valuable: time. Less driving. Less disruption. More ability to live my life while managing my disease.

I thought getting access to a treatment recommended by my doctor would be straightforward. I was wrong.

My insurance company told me the device was not covered. I asked how I could appeal that decision. I was told there was no appeal process because it was simply something they did not cover. That answer did not make sense to me. This was not about convenience. This was about accessing a medically necessary treatment for a rare cancer.

So I kept pushing. My doctor contacted the insurance company and was told the device would be approved. Finally, it seemed like we had an answer.

Then I called. I was told my doctor had been given incorrect information. There was no approval. So I searched for another option.

Eventually, I found an address where I could submit an appeal. I wrote my appeal. I explained my diagnosis. I explained my treatment. I explained the reality of traveling multiple times a week when the same treatment could be safely done at home. And I mailed it.

Meanwhile, my doctor called again.

Again, he was told everything was approved.

Again, I called.

Again, I was told there was no record of it.

My doctor was just as confused as I was. So he went further. He spent over an hour on the phone with the insurance company, reviewing every step of the process and making sure everything was documented. He even documented the conversation in my medical records. When I called again, I received the same answer. No record.

Eventually, I learned that the department patients spoke with and the department providers spoke with were completely separate and did not communicate with each other. For months, my doctor and I had been fighting through a disconnected system.

Then a letter arrived. It was from the appeals department—the appeal I had mailed months earlier. They reviewed everything. They acknowledged that both my doctor and I had been given incorrect information. And finally, after months of advocating for myself, my home phototherapy unit was approved.

That experience changed how I viewed advocacy.

Because I kept wondering:

What happens to the patient who does not know they can appeal?

What happens to the person who accepts the first no?

What happens to someone who does not have the time, confidence, or support to keep fighting?

Sometimes patients do not just need treatments. They need help accessing the treatments that already exist.

But CTCL continued to impact areas of my life I never expected. People often think cancer only affects doctor visits, medications, and treatments. It reaches much further. It affects your family. Your finances. Your career. I experienced that firsthand.

After years of managing my disease while continuing to work, lead teams, and build my career, my CTCL reached a point where I needed to take protected medical leave under FMLA to focus on my health. That was not an easy decision.

Like many people living with a chronic illness, I wanted to keep working. I wanted to continue contributing. I wanted to maintain the career I spent years building. But sometimes managing a disease means accepting that you need time to take care of yourself.

While I was out on approved FMLA leave related to my CTCL, I lost my job. After years of leadership, mentoring employees, and helping others succeed, I suddenly faced another unexpected challenge. Not a medical challenge. A life challenge.

That is something many people do not understand. Cancer does not stay inside the walls of a hospital. It comes home with you. It impacts decisions you never imagined having to make.

But my story is not only about the challenges. It is about what those challenges taught me.

Throughout my career, I spent years leading people, coaching teams, solving problems, and helping others navigate difficult situations. I never expected that one day I would need those same skills to navigate my own healthcare journey.

I learned the importance of asking questions.

Educating yourself.

Pushing for answers.

Advocating for yourself.

Because with a rare disease, advocacy matters.

The right doctor matters.

Access to treatment matters.

Community matters.

That is why organizations like the Cutaneous Lymphoma Foundation are so important.

When you receive a rare cancer diagnosis, one of the first feelings is isolation.

You wonder: “Who else understands what this is like?” The answer is that there are others. There is a community. There are people who understand.

Looking back, I wish I had found that community sooner. Today, my goal is not just to continue managing my own journey. It is to use what I have experienced to help others navigate theirs.

If sharing my story helps one person get diagnosed sooner, ask another question, seek another opinion, fight for access to care, or simply feel less alone, then my experience can serve a greater purpose.

I did not choose cutaneous lymphoma. But I can choose what I do with the experience. And I choose to help.