

# My CTCL Story

Shared by Craig B.

I'm sharing my experience with cutaneous t-cell lymphoma (CTCL), so that others don't feel unique, isolated, or unaware of what their experience may be as they undergo treatment. CTCL specialists will diagnose the condition, prescribe treatment, and track progress, but the vast majority may have never experienced the full breadth of issues associated with having it, undergoing treatment, and dealing with lifestyle issues. Thus, I'm writing this story from the perspective of a patient, so that others can benefit from it.

## Pre-Diagnosis

For the record, I was born in 1960, so the adventure began just after my 60<sup>th</sup> birthday. In January 2021, I experienced a severe GI tract issue, followed by a rash developing on my torso a few days later. I made an appointment with an allergist, thinking it was a case of hives. She suspected a contact dermatitis (eczema), not an allergy. I was referred to a dermatologist who treated me over the next three years for eczema. The spots slowly spread, but the rate of appearance and distribution on my body increased over time. They appeared on my chest, abdomen, thighs, shins, and face. Despite trying various topical treatments, the spots continued to spread. The number and varied appearance impeded the ability of my dermatologist to identify potential basal cells, the more pressing need at the time as I had spent countless days in the sun during my younger days. One such spot was found and removed in 2023. In early 2024, I started treatment with Dupixent to treat the eczema, but the spots continued to spread. Interestingly, my spots were mostly not itchy.

## Diagnosis

Given that the treatments were failing to control the eczema, another biopsy was taken in July 2024. The diagnosis was a potential "cancer". Hearing the "C" word is a bit of a shock but was even more shocking as I wasn't familiar with lymphoma of the skin. The diagnosis rocked my image of invincibility.

The biopsy was forwarded to an organization that specializes in cancer diagnosis and treatment. I was placed in contact with a specialist in CTCL for further analysis. My initial appointment was during the first week of August 2024, only a few days after receiving the diagnosis; I was pleased that I was able to be seen so quickly. My CTCL specialist spent

time explaining the nature of CTCL and the usual treatment lifecycle. She was very relaxed, upbeat, and certain in her statements. She said that CTCL, if contained, shouldn't significantly reduce my lifespan. I like a positive attitude, so I "clicked" with my oncologist. CAT scans revealed that my lymph nodes seemed normal.

Was I surprised at having been officially diagnosed with cancer? Yes and no. A diagnosis of any condition that can be lethal should be a shock for anyone, whether it be heart disease, organ failure, or cancer. My brother died during childhood of leukemia and my mother passed away from lymphoma at 85. My paternal grandfather passed away from cancer and both my parents were treated in their 60s for cancer of reproductive organs. Thus, there has been cancer in my family.

## UVB Therapy

UVB treatment was prescribed and started in mid-August 2024. The lead dermatologist at the clinic administering the UVB therapy was rather direct: he told me that I had a form of cancer that was never curable, only treatable. Quite an interesting approach to working with a new patient and very different from my CTCL specialist! I trusted his judgment and opinions based on his experience and additionally holds both an MD and PhD credentials/certifications. I told him that I was committed to following the prescribed regime, so that I could lead a "normal" life.

Over the next 53 weeks, UVB exposure progressed from 20 seconds to 8 minutes three times per week. The treatment protocol involves increasing the intensity of the sessions slowly over time as the skin needs to adapt to the frequent exposures to UVB. Failure to receive treatment three times per week slows the progression to the level of UVB intensity (time) to be effective. My only breaks were due to a few holidays, any days when a doctor was not in the office, and two vacation days I took. I tried my best to be available and receive the treatment as prescribed.

I booked my sessions three or four months at a time, so that I could have the specific time slots that best suited my work schedule. The sessions were posted on my work calendar, so my co-workers didn't schedule calls during those times. I became a "regular" at the clinic, engaging the staff and some other patients in conversation. Connection, rather than denial or hiding the condition, was completely illogical at a clinic that delivers the therapy. I found joking about getting so tan to be a mental component of my overall treatment

Through conversation with both my CTCL specialist and the doctor at the clinic where I received the UVB therapy, I was aware that they were in regular communications, a good sign that my overall treatment was being coordinated!

There were two or three days during the course of that year when my face, if not other parts of my body, screamed that I couldn't handle a session that day; in those cases, I called to cancel my appointment, with the doctor agreeing that I should not have a session if in discomfort. After discussing the discomfort on my face from the amount of UVB, we moved to a plan in which my full body received the bulk of the session, with my face covered for the last minute or two to minimize overexposure. The discomfort on the skin on my face was a bit eased with this protocol.

### **Self-Care with UVB Therapy**

There are effects of treatment that no one may tell you, but which may be due to one's specific skin characteristics or general make-up. First, as the tanning sessions became longer, I needed more rest to recover. While spending only 8 minutes three times per week doesn't sound like it should be impactful, for me, it was the equivalent of going to the beach almost every day for a few hours. Fortunately, I work full-time from home, so I was able to stretch out in bed for a few minutes during the middle of the day. In addition, I needed a full eight hours in bed at night, sometimes remaining fully asleep for the full time.

Second, my skin became a sponge for moisturizers. Three or four times per week, I covered every part of my body, except for my feet and hands, with a good coating of dermatologist-approved moisturizer. I chose Vanicream™. My face needed extra moisturizing; I was applying either Vanicream™ or argan oil as many as five times daily! Despite all these efforts, the skin on my face was stiff and hard. I started to develop "crepe-like" patches despite all my hydration efforts. Also, don't be surprised to see changes in the ability of your skin to absorb moisturizers, even from one day to another and one patch to another. I also noticed non-CTCL dry patches on my face that appeared for a day or two, then disappeared. By and large, my spots were not itchy other than the feeling that all my skin was dry.

### **From UVB to Medication**

While I was becoming VERY tan for a Caucasian, the spots were disappearing! The doctor at the UVB clinic wanted to reduce the intensity, as it was foolish for the treatment (UVB) to be worse than the underlying condition (CTCL). He was concerned that I could improve the

chances of developing a light-induced form of cancer, for which I had already been treated. Thus, starting in June 2025, the length of time for each session and frequency was gradually reduced as I was weaned off the UVB therapy in August.

Three or four stubborn spots defied the light therapy, so treatment pivoted to using a systemic medication. I started taking Bexarotene as prescribed by my CTCL specialist, also in conjunction with a statin to address potential side effects on cholesterol / blood chemistry characteristics and a thyroid hormone supplement to maintain my metabolism. Blood tests were performed every two weeks. Quickly, my cholesterol profile, usually exemplary, turned less favorable, and certain liver enzymes rose significantly. After stopping usage of the medications individually to identify the culprit for the changes in blood and liver profiles, it was determined that Bexarotene was the cause. Thus, this treatment was deemed not a good fit for me. At least I was able to obtain it inexpensively.

Working with my CTCL specialist, I was prescribed an interferon injection (PEGASYS by brand name) as an alternate therapy. Having used Dupixent in the past when the diagnosis was eczema, I had no problems self-injecting with a MUCH smaller diameter needle and administering much less medication. Starting in April 2025, I administered PEGASYS weekly.

I am fortunate to have virtually no side effects from interferon. I have no flu-like symptoms, and I'm not excessively tired from its use. The main side effect is bruising in the injection site, lasting for a few weeks. As I was injecting around my navel, the bruising enabled me to easily track the spot furthest in the past where I had injected the interferon.

While the number of spots had been reduced to only a few by the UVB treatment, interferon led to those spots becoming lighter and no new spots appearing. Thus, this treatment both agreed with my system and continued to treat my CTCL symptoms.

## Insurance

While I was very fortunate that both UVB and interferon were highly effective in containing CTCL, I had to work through the unmarked waters of health care insurance. In addition to the visits with doctors, I had co-payments for each UVB session. Unfortunately, I did not incur a sufficiently high-dollar value of these medical expenses to warrant itemizing them on my tax returns.

Another aspect of insurance is maintaining coverage – and assistance in the payment for expensive treatments, such as interferon – as one migrates from one coverage plan to another. I experienced being covered by four different plans over five months between

September 2025 and January 2026! As my out-of-pocket expenses were reset to zero dollars with every switch, the cost of treatment would have been unsustainable.

Once I realized the money blackhole I had entered, I contacted my CTCL specialist. We agreed that I could stop administration of interferon to determine whether the few months of treatment had re-enforced my immune system to control the CTCL for at least a few months. Almost no spots appeared during the first month of no treatment (October), but a few did appear during November. During a semi-annual checkup during the third month (December), my CTCL specialist and I agreed that due to the widespread reappearance of spots, I would resume treatment the following month (January) with the start of an annual insurance plan. In the meantime, I applied two different topical treatments to stave the appearance and/or growth of spots – with limited success. At this point, some spots, mostly those on my face and back of the neck, were itchy. As soon as possible during the annual coverage plan, I ordered, received, and began interferon treatment.

## **Restarted Interferon Therapy**

Within days of restarting interferon after a break of about 14 weeks, I noticed that the itchiness on my head was lessening as was the redness of some spots on my face. As I'm writing this in mid-January, it is too soon to expect to see changes in the spots. My fingers are crossed that I will notice changes within a few weeks.

## **Lessons**

This odyssey has identified seven key principles that have helped me over the last 18 months.

### **#1: Quality Knowledge is Your Best Friend**

You likely never heard of CTCL before your diagnosis. As it was unfamiliar, you may have jumped to dire conclusions about your future with this form of cancer. In addition to information from my CTCL specialist and facility where I received UVB treatment, I consulted reputable web resources for better information. These sources included government, academic, and medical journals. All provided similar information about the symptoms, treatments, and outcomes. Consensus across the sources of information enabled me to accept the diagnosis, understand the treatments, and reassure myself that I would still have a long life. I avoided researching any treatments options that were outliers,

as the small number of those with CTCL likely doesn't support the ability to identify unvalidated options.

## **#2: Commit to Following All Prescribed Therapy**

No matter the illness or condition, trust in the diagnosis and following prescribed therapies are the best approach. Specialists are not going to prescribe treatments for "routine" conditions that do not provide results. While initially shocked that UVB is widely prescribed for CTCL, as it seemed counter-intuitive, there was wide consensus among doctors I encountered as well as in the medical literature, that it was a primary and widely used option. Failure to follow the prescribed therapies may result in worsening of the condition.

Thrice weekly UVB sessions or weekly injections of interferon are trivial in comparison to chemotherapy, radiation, operations to remove infected tissue, etc. Plan and book the UVB sessions as you would daily workouts, meetings, or errands. Making therapy part of your daily ritual lessens the mental and emotional burden and increases the likelihood that you'll follow it.

## **#3: Be Patient**

I was administered UVB treatment for 53 weeks. While I wasn't able to see the spots lighten or disappear on a weekly or monthly basis, I was able to recognize progress over a span of months. After six months of treatment, I had a semi-annual appointment with my regular dermatologist. She was amazed at the reduction in spots. She noted even greater progress six months later as she was finally able to identify potential basal spots to zap with liquid nitrogen.

## **#4: RELAX!**

As with all illnesses and conditions, the ability to relax should result in more energy for your body to accept the therapy and heal. Relaxation takes many forms. You may need extra time for shuteye every evening or a nap during the day. I found that taking 10-15 minutes to stretch out to read or do a crossword puzzle was relaxing. Taking relaxing, warm baths or showers for 15-20 minutes can help to temporarily decrease outside stress (Have you read the news?!?!?). Or try a yoga class or get a massage. Take time to read a book or watch a movie. Focusing endlessly with no escape on your condition, and life in general, may negatively impact overall wellness and the effectiveness of the therapy.

## **#5: Don't Be "Crippled" by Having Cancer; Rather, Accept and Talk About It**

While you may have cancer, you're still a parent, spouse/other half, child, worker, volunteer, neighbor, and/or friend to others in your community. You performed those roles before being diagnosed; there is no reason for not continuing in those roles. Being a "victim" of

cancer deprives your community of all that you have to offer and experience and deprives you of your support networks.

The voices inside your head are not adequate to understand your condition. Talking openly with medical professionals is a first step. Your friends and family should be available to help you keep your perspective as well as provide an audience with whom you can discuss the medical and emotional aspects of having the dreaded “C” word. As spots may be easily visible, talk to even casual acquaintances about them. I was amazed at the number of cancer survivors I uncovered, with each regularly asking me about my health. My support network became larger.

### **#6: Have Perspective**

My experience with CTCL is a relatively benign condition relative to lots of other things that could impact my life, such as pancreatic cancer, a heart attack, Ebola, a car accident, etc. In other words, there are many other things, some of which are more likely than having CTCL, that could impact and shorten – potentially significantly – my life and or its quality. If I follow the prescribed therapies, there is a great likelihood that I’ll live a long life. The glass is half-full, not half-empty!

### **#7: Lead Your Life**

My experience with CTCL hasn’t been debilitating. As a condition that impacts mainly my skin, I have been able to work, spend time with friends and families, take up new hobbies, etc. I recommend you do the things you like doing and/or have always wanted to do. There may be limitations, such as restrictions on travel, so explore your immediate environment rather than jetting halfway around the globe. While on UVB treatment, you’ll need to avoid time in the sun, so identify indoor options or spend time outdoors in the shade. I found that the limitations were minimal, despite being a former sun worshipper and avid gardener. I expanded the areas with shade-loving plants in my yard, areas I had ignored in the past.