

My Journey with Cutaneous T-Cell Lymphoma

As shared by Dave O.



In 2020, I noticed an approximately 4-inch circular rash on my left hip, initially mistaking it for dry skin due to its red and scaly appearance. Despite prolonged moisturizer application, the rash persisted. In the summer of 2022, a similar rash emerged on the inner surface of my right thigh.

MY JOURNEY BEGINS

My journey with mycosis fungoides (MF) truly began on November 7, 2023, during a routine appointment with my dermatologist. He noticed the rash on my left hip, which had grown slightly and exhibited thicker skin. A biopsy of the affected area was performed, and the results confirmed the diagnosis of “fairly conventional mycosis fungoides.”

I was prescribed clobetasol 0.5 daily, but unfortunately, after a few months of treatment it did not appear to alleviate my condition. I researched and discovered several promising studies suggesting that this disease is photosensitive. At my follow-up appointment, I mentioned to my dermatologist the studies I had read from the National Library of Medicine (NIH) reported phototherapy as a treatment of early-stage mycosis fungoides and provided predictive factors for disease recurrence.

Since this disease was photosensitive, I suggested going to a local tanning salon close to my workplace for treatments. He said that although phototherapy is a proven effective treatment for my condition, tanning beds are out of the question due to the risk factors: first, it's the wrong kind of radiation, and second, the light from tanning beds comes with a high risk of developing melanoma. He strongly recommended I begin light treatment immediately using the clinical phototherapy unit available at his practice.

In March 2024, I commenced my phototherapy treatments in a town approximately 30-minutes from my residence, followed by a 45-minute commute back to work after each session. Fortunately, my employer permitted me to adjust my work schedule, and my doctor only required me to pay a single copayment per week. My in-office treatments continued until the autumn of 2024. Over the course of several months of treatments and after accumulating a few thousand dollars in copays, my doctor observed a significant improvement in my condition since starting treatment. This ultimately led me to pursue an in-home lightbox unit.

In July 2024, I initiated researching potential in-home lightbox providers through the CL Foundation's website. After conversations with one company and my insurance provider, I was informed that their lightbox was not covered under my insurance policy. I then contacted a Canadian company, but promptly discovered that they were also not covered under my insurance.

I contacted my insurance company directly to inquire about their assistance in finding a lightbox provider. I was informed that even if the provider was covered, there was a possibility that my illness may not be. She suggested that the doctor submit a prescription to the insurance company to determine whether my disease would be covered for in-home treatments.

One key observation I gained from this process was that while a home unit may be covered by my insurance provider, the specific disease may not be covered for at-home light treatments even if covered for in-office treatments.

BE PROACTIVE!

I contacted a third company that had extensive experience collaborating with my insurance company over the years. Per their request, I completed and submitted an online patient inquiry form. I also took the initiative to complete the online form for the physician's written order to the best of my ability, printed it, and presented it to my dermatologist to review and update before submitting it to the provider.

After several weeks of waiting, the doctor informed me there had been errors in the original form, which had been rectified, and the form was resubmitted to the provider. I patiently waited for a response. When none was forthcoming, I completed another patient inquiry form online and was contacted by an agent the following day. My email and phone information on the original form were incorrect. They had been attempting to reach me to inform me that the insurance had approved my prescription 100% and just needed some follow-up information. My takeaway from this experience is that it is crucial to take proactive steps in advocating for oneself. Be actively engaged in the process by making repeated calls, completing necessary forms, and maintaining a persistent approach.

FOLLOW THE PROTOCOLS

There are numerous advantages to utilizing a personal light therapy unit, including cost savings and flexibility. However there are some precautions:

- You independently manage your dosage, so be sure you comprehend the treatment protocol that should be adhered to. It wasn't adequately communicated to me that it was crucial I understand and adhere to the protocol so I didn't burn my skin inadvertently. For instance, if I were to take a vacation or miss a dose or two, when resuming treatment I should have reduced the duration of exposure by a few seconds until I was able to reach my maximum exposure again.
- Please exercise caution when using the light box. While tempting to extend the exposure time, exceeding the allowable exposure time or disregarding the prescribed protocol can result in burns. During my initial experience using the light box at home, I suffered a severe burn.

Overall, despite the substantial effort I invested over the past twelve months, I have achieved satisfactory results. During my recent consultation with my oncologist, she confirmed what I had suspected - I currently have no active MF. Consequently, I am authorized to discontinue using topical steroids and commence the gradual reduction of light therapy.

TAKEAWAYS

Some takeaways from my journey that I recommend are:

1. Seek the expertise of an MF specialist if you have been diagnosed with MF.
2. Do not be alarmed by the term "cutaneous T-cell lymphoma" (CTCL). While it may not be curable, it is certainly manageable. Take care of yourself and follow your doctor's orders.
3. Never give up and never lose hope. You must be your own best advocate. Please do not be intimidated by the paperwork and phone calls that you will need to complete while working alongside your physician.
4. Avoid falling into the trap of constantly searching the internet or WebMD for information; it will only serve to make you more nervous and depressed. Instead, rely on the Cutaneous Lymphoma Foundation for the most up-to-date and reliable information available.
5. Don't change what you enjoy in life because of your diagnosis.