CUTANEOUS
LYMPHOMA
FOUNDATION

FORUM

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FROM THE CO-CHIEF EXECUTIVE OFFICERS

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We are excited to share this spring issue of the Forum, which brings together personal stories, research findings, and community insights to help us better understand the many sides of living with cutaneous lymphoma. Each article connects to the others, showing how patient experiences, and your voices, continue to guide every step we take at the CL Foundation.

In this edition, Charles shares his honest and powerful journey with advanced stage mycosis fungoides. His story shows the courage and resilience so many people in our community display every day. It also highlights the challenges - physical, emotional, and financial - that many individuals face. His experience helps remind us why strong support systems and ongoing research matter so much.

We also include Dr. Michi Shinohara's explanation of the "watch and wait" approach for some people with early-stage disease. She shares helpful insights about why this approach may make sense in certain situations and why treatment decisions can look different for each person. When you place her insights next to Charles's story, a fuller picture emerges - cutaneous lymphoma is not one single experience. People's needs can vary widely, and focusing on quality of life is important at every stage.

This theme of understanding the whole person experience continues in our feature on out-of-pocket costs, a research study supported by the CL Foundation. Many people have shared how difficult it can be to manage the financial side of this disease. This new research shows how costs increase with disease stage and how financial pressure can affect daily life. When we connect this research with the stories in this issue, we see how emotional stress, physical symptoms, and financial strain often overlap. These combined insights help us advocate more effectively for better support and resources.

Thank you to everyone who took part in the Global Patient Survey. Your responses give us clearer insight into quality of life, diagnosis experiences, symptoms, financial strain, treatment patterns, and other important issues. Later this year, we will begin developing scientific abstracts with data captured in the survey. We hope to share these at the major medical meetings so researchers, clinicians, and health leaders can learn directly from your experiences.

Up next, we will launch a new Needs Assessment to learn even more about what you and others across the community need most. Your voices will help us shape future programs, resources, and advocacy efforts.

Watch your mail for our Spring Appeal focused on advancing research. Thanks to a matching gift from our Board of Directors, the impact of your gift is doubled. Your support fuels important studies and helps us invest in young investigators, scholars, and researchers, as well as support important clinical trials, research projects and clinical conferences to bring hope for better care and better outcomes.

Thank you for being part of this community. Together, we are building a future where every person affected by cutaneous lymphoma feels supported, informed, and empowered.

Warmly,

Susan Holly

What Is Cutaneous Lymphoma?

Cutaneous lymphomas are cancers of lymphocytes (white blood cells) that primarily involve the skin. Classification is based on lymphocyte type: B-lymphocytes (B-cell) or T-lymphocytes (T-cell). Cutaneous T-cell lymphoma (CTCL) is the most common type of cutaneous lymphoma that typically presents with red, scaly patches or thickened plaques of skin that often mimic eczema or chronic dermatitis. Progression from limited skin involvement is variable and may be accompanied by tumor formation, ulceration and exfoliation, complicated by itching and infections. Advanced stages are defined by involvement of lymph nodes, peripheral blood, and internal organs.

LIVING WITH ADVANCED STAGE MYCOSIS FUNGOIDES

A Veterans Story Shared by Charles D. H., SGM, US Army (Ret)

We often read stories where experts say cutaneous T-cell lymphoma (CTCL)/mycosis fungoides (MF) is a disease that you die with rather than die of. That may be the case for those with an original early-stage diagnosis, but for the small percentage of us that are diagnosed at stage IIB or higher it can be a completely different story. The disease can be far more aggressive and rapidly progress to stage IV. However, that is no reason to give up hope. It is my desire that by sharing my story and approach to living with advanced stage disease, it may help others to cope with the peaks and valleys that we have to endure. After all, it's not a sprint, it's a marathon.

I was raised in an agricultural setting and was exposed to numerous additional hazardous substances while performing Explosive Ordnance Disposal duties for ten years during my 26-year Army career. While MF has not been definitively linked to any carcinogenic agents, it is believed to involve genetic mutations that may be influenced by environmental factors. My family has a history of basal cell carcinoma and melanoma, so I was always quick to run to the doctor whenever I noticed any changes to my skin.

SO HOW DID I GET HERE?

My story is not dissimilar to many others that endured years of misdiagnosis and multiple negative biopsies. Beginning in 2005, I started to notice discolored patches on my shins. My Army primary care doctor at the local military hospital told me I was tying my boots too tight. By 2009, patches began to appear on my upper back and shoulders, and on my separation physical it was diagnosed as eczema. At that point, the Army finally referred me to a dermatologist. Years went by as I underwent treatment with multiple topicals that failed to produce any tangible results. Finally, in 2014 my dermatologist decided to prescribe an immune system suppressant to more effectively treat what was perceived to be eczema. By doing so, it triggered lesions to appear on my scalp. At that point I was referred to the Walter Reed National Military Medical Center for a series of Grand Rounds.

"It is my desire that by sharing my story and approach to living with advanced stage disease, it may help others to cope with the peaks and valleys that we have to endure."

After much poking and prodding, the team consisting of military experts and leading personnel from the National Institute of Health (NIH), suspected MF, but subsequent biopsies failed to produce a positive diagnosis. I was continued on a course of corticosteroids and underwent several months of UVB sessions. In mid-2015 the lesions in my scalp began to abscess, but my primary Army dermatologist had transferred to another location and my care descended into confusion as I became a member of the "dermatologist of the week" club.

I then sought a second opinion from the dermatology team at the Washington DC VA Medical Center. They performed biopsies of the ulcerated lesions and confirmed stage IIB MF with a prognosis of 3-5 years. They immediately provided a community care referral to the Dermatology and Oncology Team at the local cancer center, where after some additional tests a diagnosis of large cell, transformed, CD30+, MF was confirmed. And they stated they could easily get me another three years added to my original prognosis.

First, once diagnosed we all go through a process like the five

A VETERANS STORY...continued on page 12

THE FINANCIAL BURDEN OF CUTANEOUS LYMPHOMA: WHAT AN INTERNATIONAL PATIENT SURVEY REVEALED

Gregg Murray, MD, BM BS, BSc, MSc, Tallaght University Hospital, Dublin, Ireland
Kevin Molloy, MB Bch BAO MRCPI PhD, Tallaght University Hospital, Dublin, Ireland

Cutaneous lymphoma is a chronic disease with well-recognised and often debilitating symptoms, including persistent itch, discomfort, and visible skin changes, and carries a substantial burden on patients' quality of life. What has been far less well understood is the personal financial cost of living with the disease. Although patients frequently describe significant out-of-pocket expenses related to their care, these costs have rarely been measured systematically or reported in the medical literature. This gap in knowledge limits our ability to fully understand the true burden of disease and to advocate effectively for patient support.

How the study was done

To address this gap, we conducted an international patient-reported survey designed to quantify the real-world financial burden of cutaneous lymphoma and to examine how costs vary according to disease stage and subtype. The study used validated patient-reported outcome measures to capture both financial impact and health-related quality of life in a standardised way. Over 270 adults with cutaneous lymphoma from multiple countries participated, providing detailed information on disease characteristics and personal costs incurred over a one-year period.

Financial burden was assessed using questions that captured direct medical costs, direct non-medical costs, and indirect costs such as lost income or reduced working capacity. Health-related quality of life was assessed using the Patient-Reported Impact of Dermatological Diseases (PRIDD) questionnaire. The PRIDD is a validated tool measuring physical, psychological, social, and day-to-day life impact of skin disease. This approach allowed us to examine not only how much patients spend, but how financial burden relates to overall wellbeing.

Out-of-pocket costs: the headline findings

Out-of-pocket costs were substantial among the respondents of the survey. The approximate average annual out-of-pocket cost per patient was approximately $2,700, with one quarter of patients reporting annual expenses exceeding $8,000. These costs extended well beyond medical treatments alone. Direct medical expenses, such as medications or therapies not fully reimbursed, had an annual cost of around $270. Direct non-medical expenses, including travel, parking, accommodations, and supportive care, contributed approximately $600 per year. Indirect costs, such as lost income, reduced working capacity, or reliance on informal caregiving, represented the largest component of financial burden, exceeding $700 annually. These findings highlight that the financial impact of cutaneous lymphoma is multifaceted and not confined to healthcare charges.

Costs increased sharply with disease stage

Financial burden increased markedly with disease severity. Patients with early-stage disease reported annual out-of-pocket costs of approximately $2,400, whereas those with late-stage disease reported costs of around $7,000 per year, representing nearly a threefold increase. Among patients with more advanced disease, some reported annual out-of-pocket costs exceeding $12,000. This stage-dependent rise in costs reflects the cumulative impact of more intensive treatments, more frequent healthcare visits, and increased need for supportive care as disease progresses

Disease subtype mattered: especially Sézary syndrome

Clear differences were also observed between disease subtypes. Patients with mycosis fungoides reported annual out-of-pocket costs of approximately $2,800. In contrast, patients with Sézary syndrome experienced substantially higher financial burden, with costs exceeding $12,000 per year. Patients with primary cutaneous B-cell lymphoma reported considerably lower costs, with of approximately $1,000 annually. These differences likely reflect the complexity of care and treatment intensity associated with certain subtypes, particularly Sézary syndrome, which often requires systemic therapies, frequent monitoring, and additional supportive interventions.

Financial toxicity: cost relative to income

To better understand how out-of-pocket costs affect patients in real terms, financial toxicity was assessed by examining how much of a person's annual income was spent on cutaneous lymphoma-related expenses. While some patients reported relatively modest costs, a substantial proportion experienced significant financial strain.

> "These findings show that for a meaningful subset of patients, the financial impact of cutaneous lymphoma extends far beyond inconvenience and can represent a major economic burden."

Overall, more than one quarter of patients spent over 10% of their annual income on disease-related costs. Nearly one in ten patients spent more than 30% of their income, a level commonly regarded in cancer care as severe financial toxicity. These findings show that for a meaningful subset of patients, the financial impact of cutaneous lymphoma extends far beyond inconvenience and can represent a major economic burden.

Financial toxicity was notably greater in patients with more advanced disease. Patients with late-stage cutaneous lymphoma spent a much higher proportion of their income on out-of-pocket costs than those with early-stage disease, with nearly four in ten late-stage patients exceeding the 10% income threshold. Severe financial toxicity, defined as spending more than 30% of income, was also more common in late-stage disease.

The greatest financial strain was observed among patients with Sézary syndrome. In this group, over half of patients spent more than 10% of their annual income on disease-related expenses, and nearly one third spent more than 30% of their income. These figures highlight the disproportionate economic burden faced by certain patient groups within the cutaneous lymphoma community.

Why this matters

Importantly, financial burden was closely linked to quality of life. Patients who reported higher out-of-pocket costs also reported greater physical, emotional, and social impact from their disease. This reinforces that financial stress is not a separate issue, but an integral component of the lived experience of cutaneous lymphoma.

By systematically quantifying out-of-pocket costs, this study provides some of the first robust patient-reported evidence that financial toxicity is a core dimension of disease burden in cutaneous lymphoma. These findings can inform future advocacy efforts, encourage clinicians to address financial strain as part of routine care, and support the development of targeted financial and supportive interventions for those most at risk.

Most importantly, this work demonstrates the value of patient participation in research. By sharing their experiences, patients and care partners are helping to shape future care, improve awareness within the medical community, and ensure that the full impact of cutaneous lymphoma is recognised and addressed.

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Help Shape the Future of the Foundation: Your Voice Matters

The cutaneous lymphoma landscape is changing and so are the needs of the people and professionals who make up this community. As new treatments emerge, awareness grows, and expectations shift, the Cutaneous Lymphoma Foundation must evolve as well.

To ensure our programs, services, and resources continue to meet the needs of our community, we are conducting a **Community Needs Assessment**. This is a focused survey designed to help us understand how well we are serving you today — and where we must strengthen, expand, or adapt our work.

The results of this assessment will directly inform our next Strategic Plan and help determine where we focus our efforts over the next 3–5 years. Key areas under consideration include diagnosis and awareness, resources for the newly diagnosed, pediatric/teen/young adult support, mental health and quality of life, equity and inclusion, clinical trial navigation, public education, professional tools, and collaboration across the field.

Whether you are living with cutaneous lymphoma, supporting someone who is, practicing in dermatology or oncology, conducting research, developing therapies, or partnering with us as an advocate, **your insight is essential**.

It will take approximately **15 minutes** to fill out and help shape the next chapter of the Foundation.

Learn more and take the Needs Assessment at:
www.clfoundation.org/na2026 or scan the QR Code

Thank you for contributing to the strength and direction of our community.

THE WATCH AND WAIT APPROACH – PROS AND CONS

Michi Shinohara, MD, Fred Hutch Cancer Center
Seattle, Washington

When you are first diagnosed with mycosis fungoides or Sézary syndrome (MF/SS), there's often a firehose of information sent your way, including information about recommended treatments. Sometimes, we include the option of no treatment – also called "expectant" or "watch and wait" approach. In this approach, we might tell you not to treat your skin disease with any prescription medication.

I often hear from patients: "Wait. You just told me I had a type of lymphoma. Why wouldn't I want to treat this?" My answer is that for many patients with early-stage MF, their disease is either not progressing at all or very slowly progressing. In early disease, the abnormal T-cells that cause MF behave very similarly to normal healthy T-cells. Patients with early MF are expected to live essentially normal life spans. Because these conditions are not curable, the treatment of MF/SS are almost always palliative, meaning geared towards either reducing disease burden or symptoms or both.

How do we know that it's safe to watch and wait?

Although there isn't a lot of formal data, there is evidence that it's likely safe to use a "watch and wait" approach for some patients, especially those with early MF. The first comes anecdotally, or from physician experience. Many patients don't get an accurate diagnosis of MF until they have had their disease for many years, and many have not had appropriate therapy for MF in that time, particularly if their disease isn't very noticeable or isn't symptomatic. Despite that, most patients with early MF don't have significant progression of their disease. Based on this, the European Organisation for Research and Treatment of Cancer (EORTC) includes expectant or watchful waiting as an option for patients with MF, though they note that this approach should really only be used for patients with stage IA disease (<10% body surface area) with thinner patches.

It's important to note that "watch and wait" doesn't mean do nothing, and that it may not be the right approach forever. Patients who are getting a watch and wait approach should be monitored with regular visits with their doctor, as the patient or the doctor might later decide to start treatment. The PROCLIPI (Prospective Cutaneous Lymphoma International Prognostic Index) study is a large ongoing study of newly diagnosed patients with MF/SS. In this study, a watch and wait approach was chosen for a proportion of patients with early-stage MF. About half of these patients with a watch and wait approach eventually received some type of therapy.

When is watch and wait not appropriate?

Patients with active, advanced MF/SS are usually not good candidates for a watch and wait approach. In addition, anyone with significant symptoms like itching or burning skin might prefer to treat to reduce symptoms.

In the end, the decision about whether to treat or watch and wait has to be made after a discussion between the patient and provider. The primary goal of treating an incurable condition like MF is reducing disease burden and improving quality of life. For patients with a disease that isn't expected to impact their life expectancy, the focus on quality of life becomes even more paramount, and I often tell patients (especially those with early-stage MF) that if the treatment is more bothersome than the disease then it might not be worth treating.

YOUNG INVESTIGATOR SUMMARIZES CUTANEOUS LYMPHOMA RESEARCH

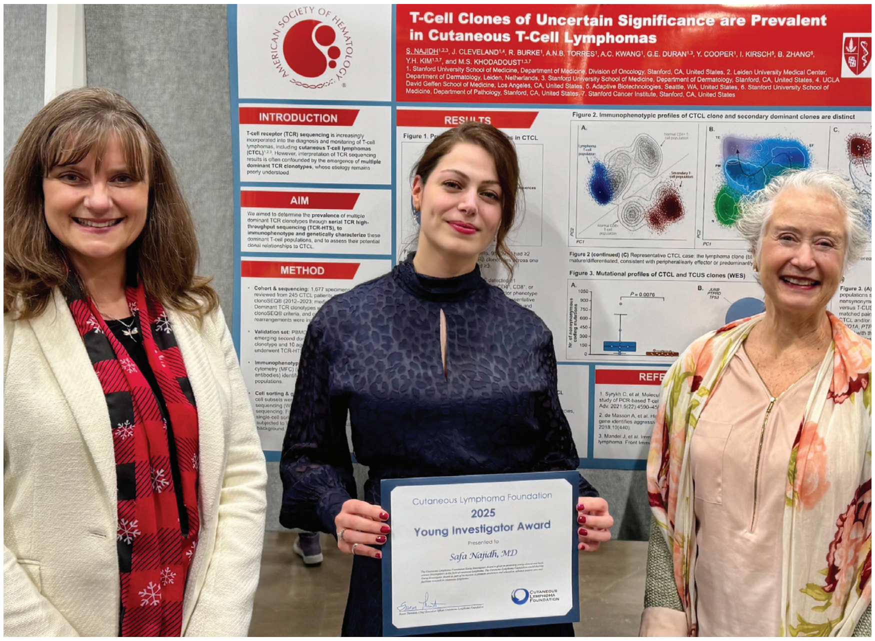
Safa Najidh MD, Stanford University School of Medicine, Stanford, California
Leiden University Medical Center, Leiden, Netherlands

The Cutaneous Lymphoma Foundation offers Young Investigator Travel Awards to early career physicians and scientists presenting cutaneous lymphoma research at major medical conferences. These awards help increase visibility for both the research and the researcher, while creating opportunities to connect with leaders in the field. By providing recognition, credibility, and meaningful professional connections, we hope to encourage these investigators to remain engaged in cutaneous lymphoma research for the long term.

Dr. Safa Najidh was a recent recipient for her research presented at the American Society of Hematology Annual Meeting. Dr. Najidh provides an explanation of her research, it's importance, and what receiving the award means to her.

Dr. Najidh's research: T-cell clones of uncertain significance are prevalent in cutaneous T-cell lymphomas

Receiving the Young Investigator Award means a great deal to me. Professionally, it is an important recognition, and it gives me confidence that this work is making a meaningful contribution. Personally, it is special because this project is rooted in a question that matters to patients. That makes the award feel like more than an academic milestone. It feels like recognition of work that may help bring more clarity to a difficult disease.



My research focuses on cutaneous T-cell lymphoma, or CTCL, a rare type of lymphoma that affects T cells, which are part of the immune system. In CTCL, these cells become abnormal and can build up in the skin, and sometimes in the blood and/or lymph nodes. In recent years, new molecular techniques have made it possible to study these cells in much greater detail. One of the most useful tools is T-cell receptor sequencing. This allows us to identify and track different T-cell populations very precisely.

That has improved our ability to study CTCL, but it has also raised new questions. In some patients, testing shows not just one dominant T-cell clone, but several. A clone is a group of cells that all come from the same original cell. When multiple clones appear, it can be difficult to know what that means. Does it show that the lymphoma is changing? Could it point to a second cancer? These are important questions because they affect how doctors interpret results and what patients are told.

That uncertainty was the starting point for our work. We wanted to understand what these additional T-cell clones actually are and whether they truly form part of the lymphoma.

To answer that, we studied a large number of samples from patients with CTCL collected over many years. One of the first clear findings was that more than one dominant clone is actually quite common. That matters because it shows that seeing an extra clone should not automatically be taken as a sign that the lymphoma is progressing.

We then looked more closely at what those extra clones represented. Were they part of the CTCL itself, or were they separate cell populations? To answer that, we compared them with the known lymphoma cells using immune profiling and genetic analysis. In simple terms, we looked at the features of the cells and at the mutations they carried.

What we found was that the additional dominant clones did not look like the CTCL cells. They had different characteristics and appeared more like mature T cells that had expanded for other reasons. In other words, they seemed to be separate from the lymphoma rather than part of it. We describe these as T-cell clones of uncertain significance, or T-CUS. The term may sound technical, but the message is simple: these are real clonal T-cell populations, but they do not appear to be the cancer itself. We also found no evidence that these clones were progressing into a second T-cell cancer.

The main message of this work is that new molecular tests are powerful, but they need careful interpretation. The more detail we can detect, the more important it becomes to understand what that detail actually means. In CTCL, seeing a new dominant T-cell clone may look alarming at first, but our findings suggest that it often reflects a separate and less worrying cell population rather than worsening lymphoma.

I think this matters because uncertainty around test results can be stressful for patients. CTCL is already a complex disease, and unclear results can make that harder. If research can help us interpret these findings more accurately, it can support better decisions and more informed conversations.

"That is the kind of research I want to do: work that helps answer practical questions and improves understanding for both doctors and patients."

That is why receiving this award means so much to me. It recognizes work that is not only scientifically interesting, but also clinically relevant. That is the kind of research I want to do: work that helps answer practical questions and improves understanding for both doctors and patients. Although I am the one receiving it, this work depends on many people: the patients who contributed samples, the mentors who guided me, and the colleagues and collaborators who helped shape the project. I am very grateful to all of them. Receiving the Young Investigator Award is an honor.

Frequently Asked Questions

What happens when the tumors form?

Dr. Zain: I think one of the first things to do when a tumor forms is a biopsy and see what's going on. There are certain markers that we can look for on the tumor. The biopsy can tell us if there is transformation, what's called large cell transformation. That's an important thing to know because that may indicate a more aggressive course and require more aggressive therapy.

We can also look for things like CD30 expression or PD-1 expression to see if one of the treatments that we have for this disease may be more effective. For example, if there's CD30 positivity, we could consider brentuximab vedotin as one of the treatments.

The other thing to do if tumors are starting to develop is restage the patient as well. Because if it's more than one tumor it may indicate that the disease is becoming more aggressive and so we need to restage with an imaging like a PET scan or CT scan--certainly repeat blood work and flow cytometry to see if there is blood involvement.

So, restaging the patient, doing a biopsy, and then at that point if the patient has not already seen a hematologist/oncologist, you may want to get them involved because the patient will probably require something more than just topical therapies.

One or two tumors, I think, can still be radiated and may not require systemic therapy, but certainly extensive tumors you would need to go to more systemic treatments.

Dr. Villasenor-Park: I agree. I think it depends on how many tumors the patient has. Patients can have limited tumors and with limited tumors you can certainly treat with radiation.

You also have to think about the tempo of the disease. If a patient is developing tumors at a fast rate, then certainly changing therapy and seeing radiation oncology is important to do.

When a treatment modality fails and a patient continues to show progression, how long before you would move on to another perhaps more aggressive therapy?

Dr. Zain: If the patient's progressing, then obviously it really depends on what's going on: Are they rapidly progressing? Is there an organ that's being affected? Do they have systemic problems happening as a result of their treatment? We don't want to wait and make things worse. Once the toxicity of the previous treatment, if there is any, has been resolved, we can certainly move on to the next line of therapy. I think this becomes more important only in clinical trials where there is sometimes a washout period required from previous therapy just to make sure that the studies are done in a more sort of clean manner. But again, patient safety comes first. So, if somebody needs to be treated urgently and a clinical trial is going to delay things, we would definitely go with the standard therapy to make sure that we don't make things worse.

So, I think there is really no specific time that you have to wait before going to the next line of therapy other than just recovering from treatment-related toxicities from the previous therapy. For example, if somebody had chemotherapy and their blood counts are low from that particular treatment, you may have to wait till the blood counts recover before you go to the next line of treatment. Other than that, I don't see why you would need to wait if you're progressing.

Jennifer Villasenor-Park, MD
Perelman School of Medicine, University of Pennsylvania
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Jasmine Zain, MD
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Questions and responses taken from the recording of our "Answers From the Experts: Q&A - February 2026." For the full-length recording, please visit: https://youtu.be/3Zw4-sJTWM4

As a patient, how does one intelligently differentiate from CTCL on the skin and any other thing that appears on the skin such as skin cancer, bug bite reaction, or other benign lesion when applying topicals to the skin and before seeking medical expertise?

Dr. Larocca: This is a tough one because I think this is something that, you know, we struggle with too: How do we best counsel you to know when to reach out for help?

I would say in general, CTCL tends to present in a certain way in a particular individual. So, if you're someone who tends to get lots of patches or lots of flat spots, chances are a new flat spot is probably the same thing. If you have a new really itchy bump and it’s summertime and you know you were around mosquitoes, and there's other people around you that are also itchy, it’s probably okay to wait a couple of weeks to see if that improves or even if a little steroid cream helps.

The challenge is that there's sometimes folks who even though have had really wimpy looking disease might present with a new bump that we would want to treat more seriously or really get that evaluated. So, it does come with experience.

I really encourage my patients to send photographs. It's easy for us to look at a photograph and say, "Yeah, I'm not really sure what this is. I need to see you” or “Oh, this is nothing. Give it a couple of weeks or try one of your steroid creams." So, I think when in doubt, reach for help. If your dermatologist feels comfortable, send photographs. I do think patients do get better differentiating over time once they get a sense of what their level of disease activity is and what it typically presents like in the skin. So, it's an ongoing conversation.

I am new to CTCL and have been through six months of light treatment and chemo and was clear for 10 months and then erupted again followed by treatment with an emollient. This eruption was different than the first and now I am not sure what to expect. How might hot flashes before or during the eruption change or increase the eruption and overall severe fatigue? Now being 6 months out, I am relatively clear with no new breakouts and hot flashes are much reduced. What might I expect?

Dr. Larocca: I think the challenge with CTCL is if this rash in the skin is because the disease is coming back or is it related to some other medical reason. So, I think that that would be the first step.

It's not unusual for the disease to come back at some point in time, especially if they've been off therapy, which is very normal practice. Once we achieve remission, it's not unusual to stop phototherapy or stop whatever therapy that they were on.

So, if it were to come back, and depending on how much came back, would then dictate whether or not we start with a topical or go back to the phototherapy or some other option.

I think hot flashes are tough because it certainly can make you more itchy and more uncomfortable, especially if you have a lot of spots on the skin. That is something your dermatologist or a medical oncologist might not be the best person to manage. Your primary care or OB/GYN, in conjunction with your dermatologist or medical oncologist, can help manage some of the endocrine peri-menopausal-related side effects assuming that's what is driving the hot flashes.

So, it's a complicated question to answer without seeing the rash, but it certainly can complicate things when we're going through other side effects.

Cecilia Larocca, MD
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Questions and responses taken from the recording of our "Answers From the Experts: Q&A - December 2025." For the full-length recording, please visit: https://youtu.be/6WV0BwloiNo stages of grief, but we are mourning for ourselves. It doesn't follow the same predictable progression, but each emotion can be triggered by a particular circumstance or change in circumstances. Personally, early on I had brief stints with anger and depression but moved rapidly to acceptance within a couple weeks. I asked myself how I can try to make this better for myself and not make my loved ones, friends, and coworkers overly sympathetic and downright miserable. It was easier said than done.

CHAOS IS NOT ALWAYS BAD

Being a retired Army veteran with a service-connected disability brings a host of additional administrative complications with insurance confusion by service providers. My care is 100% covered under the Veterans Administration Community Care Program. It is not that simple though. It's not like they refer you to the local cancer center and everything is done. Each specialty requires its own referral, and each specialty is managed by a different care team.

Until recently, referrals were only good for three months and took two months to process. So, I was caught up in this never ending administrative "do loop" with oncologists, dermatologists, cardiologists, infectious disease specialists, wound care specialist, etc. However, as a retired service member I am also covered under TRICARE. They are two distinct programs with each having distinct benefits. Outside service providers prefer TRICARE due to its different payment schedule and ease of processing, but Service members incur additional cost for co-pays and point of service charges.

It may not seem like it is something you should worry about with all the other problems, but I did not want my family to have to learn how to navigate all these bureaucratic processes and decipher a mountain of erroneous medical bills after the fact in order to properly settle my affairs. As I am about to turn 65, I can't wait to see how Medicare changes it all. With that being said, the chaos does keep me engaged. It may be for all the wrong reasons, but staying engaged keeps you focused on problem solving and gives you purpose. It does not allow you to slip into a period of remorse.

SHORT TERM GOALS

Shortly after my original diagnosis, I went into rapid decline requiring multiple surgeries and an extended recovery period that actually delayed disease treatment. However, this valley was followed by a two-year period with little disease progression. I realized that it was best for me and my loved ones to try and lead a normal life, not sit around and wait to die.

My oncologists once asked me why I would consider quitting something I enjoyed just because I had cancer. He had a point. We both laugh about it now; I am not sure either one of us expected me to live this long. I accomplished this by making very few lifestyle changes and setting short term goals. These goals were not extravagant "bucket list" items, but rather simple pleasures such as a family outing, a weekend gathering or short trips out west to visit my son. Getting fancy or planning too far out often leads to disappointment when the disease flares up unexpectedly. During that initial period of depression, I wondered if I would see my son graduate from college, get a good job, get married, or even buy a house? As it turns out, I witnessed them all.

> "You'll be surprised at how much sharing your story with others in a similar circumstance can make you feel like you are not going it alone."

TALKING ABOUT YOUR CANCER CAN BE THERAPEUTIC

How many times have we been to the doctor's office or infusion clinic and watch others huddle in the corner, refuse to make eye contact, or utter a word to anyone. It actually feels like the facility prefers us to remain segregated and doesn't want us sharing prognosis or treatment regimens.

Keeping things pent up and experiencing emotional suppression is not conducive to good mental health. At least not for me. Get involved in networking or support groups. You'll be surprised at how much sharing your story with others in a similar circumstance can make you feel like you are not going it alone. These groups also provide forums with experts that allow you to stay up to date on the latest developments in treatment rather than being overly reliant on outdated information on the internet. You will also learn that no matter how bad you think your situation is, there is probably someone that faces far more challenges than you.

DON'T BE OVERLY RELIANT ON OTHERS

You learn pretty quickly that this disease will have an immediate impact on not only you, but also those around you. It is a shared experience. We certainly can't do everything on our own like we once could, but I try and do everything that I am capable of when I can. It is only a matter of time before you may experience a period of extreme reliance on others just to accomplish the basic necessities of living. Staying active keeps you in a balanced mental and physical state and provides your loved ones with space to maintain some semblance of normalcy that is not dominated by your needs.

THE CHOICES ARE YOURS; IT'S REALLY ABOUT QUALITY OF LIFE.

It's a tough subject to discuss, but very few of us have not had to experience watching a loved one wither away while they battle some sort of cancer. For CTCL/MF the last ten years have brought forth many exciting breakthroughs that may not be curative but definitely improve quality of life. With that being said, there have been times when I have responded well to a particular treatment regimen while the secondary infections or toxicity has made me downright miserable. On at least one occasion I had to go to my doctors and say that if this is the best we can do maybe we should just let the disease run its course. It's a delicate balancing act and it requires us all to do some pretty intense soul searching, but for me it all comes down to quality of life. I rely heavily on my doctors' guidance, but the final decisions are ultimately mine.

As always, there is much more to the story. It is now 2026, I am still with the excellent team at the cancer center and am thankful to the support I receive from the military and veterans' medical community, and Cutaneous Lymphoma Foundation. I have just begun my 11th line of systemic therapy, have had several rounds of whole-body electron beam radiation, as well as several rounds of regular radiation therapy to stem bone metastasis. I have now developed large ulcerated lesions on my hip and waistline that can be so painful that morphine and oxycontin can't suppress it. Additionally, I have developed a resistance to many oral antibiotics making treatment of secondary infections problematic, often requiring hospitalization. I am told that I have few options left going forward, but am hopefully optimistic about my latest treatment as things seem to be trending in the right direction.

By calling on the resiliency learned from a lifetime of military service, the support of friends and loved ones, and constantly reminding myself of the few simple rules that I set for myself, I can now look forward to celebrating my nation's 250th birthday later this summer.

●

PLAN NOW TO HELP ENSURE THE CUTANEOUS LYMPHOMA FOUNDATION'S FUTURE

There are many ways you can support the future of the programs and services the Cutaneous Lymphoma Foundation provides. Here are just a few:

- **Estate planning:** Make a gift to the Cutaneous Lymphoma Foundation through your Will or Revocable Trust, or by designating the Cutaneous Lymphoma Foundation as a beneficiary of a life insurance policy or retirement account. The Cutaneous Lymphoma Foundation can be named to receive all or a portion of the gift. For those over 70½, a Qualified Charitable Distribution (QCD), where you can make a charitable donation from your IRA to a charity and the QCD can be counted towards satisfying your required minimum distribution, may be an excellent option.

- **Employer Matching Gifts:** Many employers will match charitable contributions made by their employees. Check with your HR department to see if your company sponsors such a program…you may be surprised to learn that your company has such opportunities.

- **Gifts of Appreciated Assets:** An example is stock, where you will receive a charitable deduction for the full fair market value of the donated stock and avoid payment of any capital gains tax if you have owned it for at least one year.

Learn more about how you can help ensure the programs and services provided by the Cutaneous LymphomFoundation continue at www.clfoundation.org/why-give

We're deeply grateful to everyone who took part in the Lymphoma Coalition's Global Patient Survey. Thanks to your strong participation our community qualified for a dedicated cutaneous lymphoma report. Your collective data will...

Lymphoma Coalition 2026
Global Patient Survey on Lymphomas & CLL

- be featured at the November 2026 Quality of Life Workshop.
- provide the evidence we need to shape programs and initiatives that truly reflect patient needs over the next two years.
- allow us to continue submitting, publishing, and presenting objective data at major medical meetings, in peer-reviewed journals, and across stakeholder platforms ensuring your voice drives research, education, and advocacy worldwide.

CUTANEOUS LYMPHOMA FOUNDATION

Cutaneous Lymphoma Foundation is a 501(c)(3) non-profit organization. Donations are tax deductible to the extent allowed by law.

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FORUM

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Disclaimer

The Cutaneous Lymphoma Foundation does not endorse any drugs, treatments or products reported in this newsletter. Information is provided for informational purposes only. Because the symptoms and severity of cutaneous lymphoma vary among individuals, the Cutaneous Lymphoma Foundation recommends that all drugs and treatments be discussed with the reader's physician(s) for proper evaluation, treatment and medical care.

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TIME SENSITIVE MATERIALS ENCLOSED

Spring into Action for Research

Your impact is doubled this spring, advancing research that brings real relief, better options, and renewed hope for people living with cutaneous lymphoma.

The Board of Directors will match:

- **Every one-time gift dollar for dollar**
- **The first three months of every new monthly donor's gift, dollar for dollar**

(Up to a combined $25,000 match pool)

Double your impact • Double the research • Double the progress

Give today: www.clfoundation.org/donate