Cutaneous Lymphoma Foundation

FORUM

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FROM THE CO-CHIEF EXECUTIVE OFFICERS

Holly Priebe, Co-CEO; Susan Thornton, Co-CEO

Holly Priebe
Co-CEO

Summer is a time to pause, reflect, and appreciate the strength of the cutaneous lymphoma community. As we look through the pages of this issue of the Forum, we are reminded that while every person's journey is unique, none of us travels it alone.

This issue showcases many of the voices, experiences, and ideas that make our community so special. You'll find highlights from our Annual Patient Conference in Mesa, where people living with cutaneous lymphoma and their care partners came together to learn, share experiences, and build meaningful connections. You'll read about promising developments discussed at the United States Cutaneous Lymphoma Consortium meeting and gain insight into the importance of advocacy through Kelly Paul's reflections on Rare Disease Week, reminding us that patient voices can help shape the future of rare disease care. You'll also find an overview of denileukin diftitox-cxdl (Lymphir™), a recently approved treatment option for certain patients with cutaneous T-cell lymphoma, offering important information about who may benefit, when it might be considered, and questions to discuss with your healthcare team.

Susan Thornton
Co-CEO

We are also pleased to share practical resources designed to help individuals navigate life with cutaneous lymphoma. Mark K's Health History Cheat Sheet provides a simple approach to organizing health information and becoming a stronger self-advocate, while our article on Donor-Advised Funds explores one way individuals and families can support the causes they care about while creating a lasting impact. Together, these stories reflect what makes this community extraordinary resilience in the face of challenges, generosity toward others, a commitment to education, and a willingness to share experiences that help fellow patients and care partners find information, support, and hope.

This spring also provided many opportunities to bring the patient perspective to important conversations, from Rare Disease Week and Hill Day to scientific meetings and global gatherings focused on advancing cutaneous lymphoma research and care. We are encouraged by the growing recognition that patients and care partners must remain at the center of progress.

Thank you to everyone who supported our Spring Appeal and helped make these programs and resources possible. Your generosity allows us to continue providing trusted education, advocacy, support, and connection for individuals and families around the world.

We are also excited to launch the 2026 CL Challenge this September. Whether you walk, run, cycle, hike, gather a team, or create a challenge that is uniquely your own, we look forward to celebrating the many ways our community comes together to raise awareness and support for people affected by cutaneous lymphoma.

Thank you for being part of this remarkable community and for all you do to strengthen it

With gratitude,

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.

USCLC 2026: PRECISION, PROGRESS, AND KEEPING PATIENTS AT THE CENTER

Shamir Geller, MD, Memorial Sloan Kettering Cancer Center

The recent United States Cutaneous Lymphoma Consortium meeting at the American Academy of Dermatology held in Denver in March 2026 brought together clinicians, pathologists, researchers, and patient-focused experts to discuss where the field of cutaneous T-cell lymphoma is heading. The meeting was dense, ambitious, and forward-looking, but one theme connected nearly every session: precision. Precision in diagnosis, precision in prognosis, precision in treatment selection, and, just as importantly, precision in understanding what patients actually experience.

Cutaneous T-cell lymphoma (CTCL), including mycosis fungoides and Sézary syndrome, is not one uniform disease. It is a spectrum. Patients can present with subtle patches, thicker plaques, tumors, blood involvement, lymph node changes, or symptoms such as severe itch that deeply affect daily life. Because of this complexity, the meeting emphasized that no single test, biopsy, blood result, or imaging study can tell the whole story. The best care comes from putting all of the pieces together.

A major focus was diagnosis. Pathology remains essential, but pathology alone is often not enough. Many skin conditions can look similar under the microscope, and many histologic patterns overlap. The meeting reinforced the importance of clinicopathologic correlation, meaning that the skin exam, biopsy findings, immune markers, molecular tests, and the patient's overall story must all be interpreted together.

One important pathology topic was large cell transformation. This occurs when larger, more aggressive-appearing lymphoma cells make up a significant portion of the skin infiltrate, often in tumor-stage disease. Its recognition matters because it can change prognosis, urgency, and treatment expectations. For patients and care partners, this is a reminder that repeat biopsies may sometimes be necessary when lesions change, grow, or behave differently.

The meeting highlighted several biomarkers, measurable features on the lymphoma cell's membranes, that may help with diagnosis, prognosis, or treatment selection. CD30 was discussed extensively. CD30 is important because therapies targeting CD30 can produce meaningful responses in some patients with CTCL. However, the meeting made clear that CD30 is not a simple "positive or negative" marker.

Historically, clinical trials used cutoffs such as 10% CD30 expression, but newer data suggest that even patients with lower levels may benefit from CD30-directed therapy. At the same time, pathologists may differ in how they interpret CD30 staining. This makes clinical judgment essential.

CD70 was another marker that generated interest. CD70 is a favorable therapeutic target in CTCL because it is constitutively and highly expressed on malignant T cells, whereas its expression on normal immune cells is transient and limited to activated lymphocytes, providing a differential expression pattern (rather than absolute restriction) that creates a therapeutic window. Emerging treatments directed against CD70, including antibody-based and cellular approaches, are showing promise. Its diagnostic role is still being explored, but it may become an important tool in the future.

TOX was also discussed as a marker of interest. TOX is a transcription factor seen in many CD4-positive CTCL cases, and its expression appears to increase as disease progresses from patches to plaques to tumors. It may also help in assessment of disease outside of the skin. However, like all markers, TOX has limitations and does not apply to every CTCL subtype.

Another key area was clonality and sequencing. Tests such as TRBC1 flow cytometry and next-generation sequencing help determine whether T cells are part of the same malig-

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RARE DISEASE WEEK 2026: WHY OUR VOICES MATTER MORE THAN EVER

Shared by Kelly Paul, Board Member

I couldn't wait to go to Rare Disease Week in Washington, DC.

As someone with mycosis fungoides, and a board member of the Cutaneous Lymphoma Foundation, I was genuinely excited to advocate on Capitol Hill. I'm a planner, so I had read the agenda, I was aware of the policy topics we'd be discussing, and I had a general sense of how the week would unfold.

But I still had questions in the back of my mind.

- Would everyone else be polished and policy-fluent?
- Would my inexperience show?
- Would my voice actually matter?

Being a board member doesn't automatically make someone a policy expert. It doesn't eliminate the nerves that come with walking into a Senate meeting room for the first time. And it certainly doesn't guarantee you'll feel confident navigating conversations about FDA modernization or legislative appropriations.

What I discovered almost immediately, though, was this:

- No one was there because they were perfect.
- They were there because they cared.

The Power of the Collective

My first congressional briefing was held in a Senate meeting room that was simply too small for the number of people who showed up. Patients, parents, advocates, and industry leaders filled every seat and lined the walls.

This was my first insight:

- Individually our diseases are rare, but collectively we are not.
- This realization stayed with me all week.

Across panels and discussions, urgency was clear. Ninety-five percent of rare diseases still do not have an FDA-approved treatment. Many families face frightening timelines. Regulatory delays, lack of clinical trial access, diagnostic challenges, and affordability concerns are not abstract policy problems — they are daily realities.

While cutaneous lymphoma often presents differently than many rare diseases, especially those affecting children, the commonalities are undeniable.

- We all need faster research.
- We all need knowledgeable providers.
- We all need regulatory systems that can keep pace with scientific innovation while maintaining safety.
- We all need policymakers who understand that "rare" does not mean insignificant.

What Advocacy Actually Looks Like

If you are imagining dramatic speeches on the steps of the Capitol, Rare Disease Week may surprise you.

Much of the work happens in scheduled meetings with legislative staffers, the professionals who advise our Senators and Representatives and help shape policy decisions. It is normal not to meet directly with the elected official. This is simply how Capitol Hill functions.

And those meetings matter.

In our conversations, staffers asked thoughtful, practical questions.

- How would proposed policies be funded?
- How do we prevent misuse?
- What impact would changes have on patients right now?

These weren't dismissive questions, they were the kinds of questions that move ideas from passion to policy.

One of the most important lessons I learned is that **sharing your story is powerful, but connecting it to a specific, tangible ask is what drives progress.**

It's not just "this is hard." It's "this is hard, and here is the legislative solution that can help."

Real Talk for First-Time Attendees

Rare Disease Week is full. The schedule is packed. The topics are complex. As a first-time attendee, there were moments when it felt like a lot to absorb.

There are training sessions, policy briefings, and logistics to learn. There are appointment schedules to navigate and team roles to coordinate. You quickly realize that advocacy is not a one-time event, it's the beginning of an ongoing relationship with lawmakers and their staff.

You also see that everyone is learning. Some people are seasoned advocates, others are sharing their story publicly for the very first time. There is no single mold.
What matters most is preparation, authenticity, and follow-up.

And I cannot overstate how meaningful it was to have the support of the Cutaneous Lymphoma Foundation team throughout the week. They checked in, helped interpret policy language, provided guidance before meetings, and made sure I felt confident representing our community. Advocacy feels much less intimidating when you are supported.

Why Cutaneous Lymphoma Patients Should Be There

Cutaneous lymphoma may not look like many of the rare diseases most commonly highlighted during Rare Disease Week.

But we face real barriers:

- Delayed diagnosis
- Limited standardized treatment pathways
- Insurance hurdles
- Evolving standards of care

Our experiences belong in these conversations. **When lawmakers hear from someone living with cutaneous lymphoma, policy stops being theoretical.** It becomes personal. And that is when momentum builds.

What I Left With

I left Washington with a deeper understanding of how policy is shaped, and how much persistence it requires. Progress takes follow-up. It takes building consensus. It takes answering hard questions thoughtfully.

But I also left energized.

There is bipartisan recognition that rare disease patients need better solutions. There is acknowledgement that speed and safety in drug development are not mutually exclusive. There

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A NEW TREATMENT OPTION FOR PEOPLE LIVING WITH CTCL

Brad Haverkos, MD, MPH, MS, UC Cancer Center - Anschutz

For people living with cutaneous T-cell lymphoma (CTCL), treatment is often a journey. Many patients receive several different therapies over time as their disease changes or becomes less responsive to treatment. Having additional options is important, especially when CTCL returns after previous therapy or becomes more difficult to control.

Denileukin diftitox-cxdl (LYMPHIR™) is one of the newest FDA-approved systemic treatments for adults with relapsed or refractory stage I–III CTCL who have received at least one prior systemic therapy. Approved by the U.S. Food and Drug Administration (FDA) in 2024, denileukin diftitox-cxdl represented the first new FDA-approved systemic treatment for CTCL in more than seven years, offering an additional option for patients and their healthcare teams.

Unlike traditional chemotherapy, denileukin diftitox-cxdl is a targeted biologic therapy. It is designed to recognize the interleukin-2 (IL-2) receptor, which is found on many CTCL cells. After attaching to these cells, the medication delivers a toxin inside the cell, leading to lymphoma cell death. Researchers also believe it may help change the immune environment around the lymphoma in ways that make it less supportive of cancer growth. Together, these actions make denileukin diftitox-cxdl different from other currently available CTCL treatments.

Some members of the CTCL community may remember Ontak®, an earlier version of denileukin diftitox that was available years ago. Ontak was voluntarily withdrawn from the market in 2014 because of manufacturing issues, not because the treatment approach itself was found to be ineffective. Denileukin diftitox-cxdl is a reformulated, newly manufactured version with improved purity that underwent new clinical testing before receiving FDA approval. For patients familiar with Ontak, this history helps explain why denileukin diftitox-cxdl may sound familiar while representing a newly approved treatment.

Denileukin diftitox-cxdl is given by intravenous (IV) infusion. Treatment is administered once daily for five consecutive days (Days 1 through 5) of a 21-day treatment cycle. Each infusion takes about one hour, although additional time is usually needed for premedications, preparation, and observation before patients leave the infusion center. In the pivotal clinical trial, patients could receive up to eight treatment cycles, with additional treatment allowed for those who

continued to benefit. Because treatment requires five consecutive infusion visits every three weeks, patients may want to consider how the schedule fits with work, family responsibilities, travel, and other commitments.

The treatment was studied in a clinical trial known as Study 302. About one in three patients (36%) experienced an objective response, meaning their CTCL improved with treatment. Some patients achieved complete responses, while others experienced partial improvement. Responses often occurred relatively quickly, with a median time to response of about six weeks. Among patients who responded, more than half maintained their response for at least six months. For many people living with CTCL, improvement is measured not only by changes in skin lesions but also by relief from symptoms that affect daily life. In the study, about one-third of patients who had itching before treatment experienced a clinically meaningful reduction in pruritus that lasted at least four weeks.

Like all cancer treatments, denileukin diftitox-cxdl has potential risks and side effects. The medication carries the FDA's strongest safety warning (a Boxed Warning) for capillary leak syndrome (CLS), a potentially serious condition in which fluid leaks from blood vessels into surrounding tissues. Symptoms may include swelling, rapid weight gain, dizziness, low blood pressure, or shortness of breath. Most cases of CLS in

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2026 ANNUAL PATIENT CONFERENCE

The Cutaneous Lymphoma Foundation's 2026 Annual Patient Conference held April 24–26 in Mesa, Arizona, brought together patients, care partners, healthcare professionals, and industry partners for a weekend of education, support, and connection. The hybrid conference gave attendees the opportunity to learn about the latest advances in cutaneous lymphoma research, treatment options, symptom management, and quality of life considerations while connecting with others affected by the disease.

A highlight of the conference was the lineup of expert presenters, including Dr. Lauren Pinter-Brown, Dr. Pamela Allen, Dr. Henry Wong, and Dr. Christiane Querfeld, who shared clinical updates and answered questions from attendees. Their presentations covered current treatment approaches, emerging therapies, and ongoing research, helping patients and caregivers better understand their disease and available treatment options.

Some of the most meaningful moments of the conference came from patients and care partners sharing their personal journeys. Those living with and caring for patients with cutaneous lymphoma shared their experiences, offering hope, encouragement, and practical advice to others facing similar challenges. Cutaneous Lymphoma Foundation's own Sue McCann also presented tips for living well with cutaneous lymphoma, focusing on skin care, self-care, and everyday strategies for managing the disease.

In addition to the educational sessions, networking events and social gatherings gave attendees the chance to meet others who understand what they are going through. Patients, care partners, and families formed new connections, shared experiences, and built friendships that will continue to provide support beyond the conference.

SAVE THE DATE!

HEALTH HISTORY CHEAT SHEET

Shared by Mark K.

As a member of the patient panel at the Mesa Patient Conference, Mark shared his process for keeping track of his health history. We asked Mark to provide a description his spreadsheet in hopes that it may help others.

Was that appointment last month or two months ago? When did I start this medication? Who was the doctor that I saw last August and was that for PT, dermatology or other? All legitimate questions that could have you going through lots of records and take a good bit of time before maybe finding an answer. To break through the confusion, I have created for myself a top-level timeline Cheat Sheet that is easy to use and provides quick answers to most of those types of questions.

The first rule of this timeline aid is that there are no rules. Each person is different in what information they want to track, the format they use to track the information, as well as the technology used that best fits the need. An overall guideline I will state is that this aid should have easy access for timely updating and be very minimalist in nature. All those photos, downloaded reports, and note taking should be referenced as existing but not included.

I will present an example of how I have approached this timeline. Feel free to use as is or modify it to fit your needs. I use an Excel spreadsheet with no formatting or templates.

The majority of entries are 'EVENTS' that consist of two lines:

	a	*b*	*c*	*d*	*e*
15	05/07/26	Med	VA - Telederm	Mail Receipt of Pills	Dr Smith
16		*f*	MedicationXX 150 mg	rx: 311250XXXX	5/21/26 last pill

First Line:

a Date of Event

b Key label for type of event, in this case a medication.

- Others: Derm, PT, Opth (ophthalmology), Physical
- I use the key label 'Mark' for personal notes such as feeling a racing heart

c Where the event occurred

d Title of event

e Doctor seen (if relevant)

Second Line:

f Summary line of event (one line only)

- Include 'File name' if other data regarding this event present

A second type of entry is a documentation event (DOC). The number of lines used is variable depending on what you are capturing:

	g	*h*	*i*			
21	04/15/26	DOC	Medications Apr 2026			
22		*j*	Rx#	Meloxicam	15 MG	Joint Pain
23			Rx#	Amlodipine Besylate	5 MG	Blood Pressure
24			Rx#	Triamcinolone Acetonide 0.1%		Cream
25			Rx#	Clobetasol Propionate 0.05%		Cream

First Line:

g Date Information Captured

h Key label of DOC for documentation

i Title of Documentation Content

Following Line(s):

j Information you want captured for easy retrieval

This type of entry is used to capture specific information that you wish to track. For example, I find it helpful every six months to record all the medications that I am currently taking (especially just before my yearly physical). Perhaps there is a specific blood test you are following (A1C, for example). Just put that specific result under this DOC category.

Putting it all together a Health History Cheat Sheet example could be:

2	04/22/26	Physical	VA	9:00	Dr DeXXXX		
3			Labs in folder		Directed to attend PT for knee pain		
4	04/22/26	DOC	Blood Test Result		FILE: PhysApr26Blood		
5			A1C: 5.5				
6	04/24/26	DOC	CLF Conference - Phoenix				
7			24 - 26 Delta Hotels Phoenix Mesa				
8	05/01/26	Derm	VA - Telederm		1330		
9			Pictures of left calf, neck and between toes				
10	05/06/26	Mark	Derm		Finger Note		
11			2 Fingers split open and very sore - 5 days				
12	05/07/26	Med	VA - Telederm		Mail Receipt of Pills	Dr Smith	
13			MedicationXX 150 mg		rx: 311250XXXX	5/21/26 last pill	

For those wanting the more 'advanced' options in Excel, I also keep a 'futures' tab for all upcoming/booked appointments. They then can be moved to the timeline once they have occurred. I also have found helpful at the start of each year to create a new tab labeled as such. This provides an easy year by year lookup.

The key is keeping the timeline updated and (most importantly) minimalist in content. If just starting this cheat sheet, do you need to recreate your medical history from scratch? Absolutely not. Just start from the current date and go forward. If you have the data and want to backfill, that would be great but is not necessary. If you fail to update for a few months – don't worry, just start capturing again from the current date.

When working across several doctors, disciplines, and locations, anything that can unwind confusion can make a big difference in lowering stress and getting timely answers quickly. You are your own best health advocate, hopefully this Health History Cheat Sheet can help you as it has me.

nant clone. This matters because CTCL can involve skin, blood, and lymph nodes, and understanding whether the same clone is present in different sites can help with staging, prognosis, and treatment monitoring. These tools may also help distinguish active lymphoma from treatment-related rashes or other inflammatory conditions.

Imaging was another important topic. Traditional lymph node size criteria were not developed specifically for CTCL. Newer approaches, including volumetric assessment and kinetic modeling, may better predict how lymph nodes behave over time. Rather than looking only at whether a node is "big" or "small," these methods evaluate growth and regression patterns, which may provide earlier insight into a patient's disease trajectory.

Artificial intelligence was woven throughout the meeting, not as a replacement for physicians or researchers, but as a tool to help identify patterns. Sessions addressed AI in dermatopathology, radiology, clinical practice, and quality of life. One particularly meaningful discussion focused on using AI to analyze patient interviews. AI may help researchers better understand patient experiences, including identity, fear, self-advocacy, body image, and unmet needs that may not be captured by standard surveys.

The program also addressed new therapies, including CAR-T approaches, T-cell receptor targeting, and other agents in development. Clinical controversies were discussed as well, including the overlap between atopic dermatitis and CTCL, the role of JAK inhibitors and immunotherapies for eczema. These discussions are important because patients with CTCL often live with diagnostic uncertainty and may receive various treatments that affect their immune system before the diagnosis of CTCL becomes clear.

Finally, the meeting ended with a look toward collaboration, registries, and future directions. Progress in rare diseases depends on shared data, multicenter efforts, and continued partnership among clinicians, researchers, patients, and advocacy organizations.

"The future of CTCL care will not be defined by one biomarker or one technology, but by integration and bringing science, clinical expertise, and patient voices together."

For patients and care partners, the message from USCLC was hopeful but realistic. The field is moving toward more precise diagnosis, better risk assessment, more individualized treatments, and a deeper appreciation of the lived experience of patients. The future of CTCL care will not be defined by one biomarker or one technology, but by integration and bringing science, clinical expertise, and patient voices together.

SHOW YOUR SUPPORT THROUGH A DONOR ADVISED FUND

A Donor Advised Fund (DAF) is becoming a popular way to accomplish tax efficient charitable giving. Essentially, a DAF is a charitable giving account administered by a sponsoring organization (Sponsor), usually a brokerage firm or community foundation. Generally, you as the Donor, contribute stock, cash or other assets to the DAF, receive an immediate tax deduction and later recommend grants to IRS qualified charities, such as the Cutaneous Lymphoma Foundation (CLFoundation), over time.

DAFs are relatively inexpensive and easy to establish. The Sponsor handles administration, tax reporting, investment management, and grant processing. Instead of keeping records for all your charitable gifts each year, you receive one tax receipt from the Sponsor.

You can contribute appreciated securities or other appreciated assets and often avoid capital gains taxes while receiving an immediate charitable deduction for the full fair market value of the asset, even if the grants to the qualified charities are distributed years later. Tax deductions are tied to the date the contribution is completed, not when grants are distributed.

DAFs are flexible. You may contribute assets to a DAF during a high-income year to secure a tax deduction, then decide gradually which charities to support. Funds remain invested and potentially grow income tax free while awaiting distribution.

However, DAFs have some disadvantages. Once the asset is contributed, the donation is irrevocable, and you no longer legally own the money. Although you can recommend grants, the Sponsor has final legal control over distributions. In practice, Sponsors almost always follow Donor recommendations if the recipient is an IRS qualified charity, and the request complies with law. To help ensure funds ultimately go where intended, you should carefully review the Sponsor's guidelines and any restrictions. Naming successor advisors is also important so family members or trusted individuals can continue recommending grants after your death. Lastly, fees must be considered as most Sponsors charge administrative and/or investment fees.

Setting up a DAF is straightforward. You choose a Sponsor, complete an application, contribute assets, and choose how the funds will be invested. Many DAF accounts can be established online within days. Timing is important, and you generally must set up the account and contribute the funds by December 31 to claim a deduction for that year. There is currently no universal requirement that DAFs distribute assets to charities within a specific timeframe; as a result, funds can usually remain in a DAF for years before grants are made.

> **"DAFs allow individuals and families to organize long-term charitable giving in an efficient and tax-effective way."**

DAFs allow individuals and families to organize long-term charitable giving in an efficient and tax-effective way. Families sometimes create written mission statements to guide future generations. The CLFoundation has an account set up to receive distributions from DAFs. If you have any questions or wish to discuss how to use a DAF to benefit the CLFoundation, please contact us at info@clfoundation.org.

The above summary is provided for informational purposes only and is not intended to be legal, tax or investment advice. Please contact your attorney or financial advisor regarding your personal circumstances.

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Frequently Asked Questions

I'm undiagnosed, but doctors are suspicious due to my itching patches, etc. Are there any new state-of-the-art avenues to early detection?

Dr. Chung: Mycosis fungoides is a condition that can sometimes take years to be diagnosed because it can look so subtle under the microscope. I know that very well because I'm also a dermatopathologist who specializes in the diagnosis of MF and I know how hard it can be.

There is a tool that we do sometimes use, T-cell receptor gene rearrangement studies, which is basically a test to look for T-cell clonality. Sometimes when the biopsy itself does not look very diagnostic, if you have the presence of a persistent identical T-cell clone that is identified in multiple skin biopsies over different periods in time and you consistently see that same clone demonstrated in the biopsies, that can be a helpful clue that is fairly specific for mycosis fungoides. That is a test that can be helpful. But of course, clonality does not always equal neoplasia (abnormal or uncontrolled cell growth), and you always have to take it under consideration with the histology (the microscopic structure of tissues). So, I think that if you have a strong suspicion for CTCL, I think that the good thing is to request you have your slide reviewed by an expert dermatopathologist with a specialty in cutaneous T-cells and you can also get the T- cell clonality test done off of the biopsy that you already had.

Dr. Moskowitz: Something to add is that it often takes multiple biopsies and so maybe just being open to getting a repeat biopsy, which unfortunately sometimes is needed.

Is there any way to manage skin shedding?

Dr. Chung: Skin shedding is typically a result of cutaneous T-cell lymphoma. In a way, almost like the itch, it's a symptom of the disease. So, the best treatment is to treat the underlying disease. But, of course, I know that is something that takes time. In the meantime, I think that there are things that can help with the skin shedding. Keeping the skin well moisturized can definitely be helpful. Sometimes when a patient's skin is really flaring, I can also prescribe topical steroid wet wraps where you soak in a tub and then you come out and you cover your body with a topical triamcinolone and then you try to occlude it with clothing to try to really make that medication soak in.

For wet wraps, typically I just recommend (using) kind of old cotton pajamas, ones that you don't mind getting very greasy because a triamcinolone ointment is very greasy. So, typically I tell patients to use something that you don't mind ruining. The important thing is just to have something that creates an occlusion barrier for the moisture and the triamcinolone to soak into the skin. Wet wraps can be a helpful thing.

And then topical creams such as those containing lactic acid can be helpful. Those are available in over-the-counter moisturizers and because lactic acid is a weak keratolytic, it helps get rid of some of this excessive scale as well. So, these are treatments that can be helpful for skin shedding.

When should patients consider full body radiation?

Dr. Moskowitz: So, this has changed over time. I think because in the past when we gave full body radiation, we were giving a higher dose, and we're always worried about giving it because then we couldn't give it again. I often liked to reserve full body radiation as something like a trick in my back pocket that I could use when I really needed to get somebody out of trouble if they had a lot of disease. Or, we often also consider using it for someone who is undergoing an allogeneic stem cell transplant to get their disease really well under control right before the transplant. So, we didn't want to use it up early if that was a possibility.

Now the radiation oncologists are using lower dose total skin, we call it total skin electron beam. They're using lower doses of radiation which means that we actually can give repeat courses sometimes. That being said, I still will reserve it for someone who needs it. I think generally it's someone who has widespread disease, is really symptomatic, needs something to work fast, potentially is at risk for infection because they have multiple open sores, and we're worried about using systemic therapy which may put them at higher risk for infection, particularly if it's going to weaken their immune system.

Total skin radiation can be really helpful in that setting. One major downside of total skin radiation is that it doesn't last forever. I often need to be ready for what I am going to use next or to really aim to maintain the response. And so, I often will try to use something mild, like bexarotene or interferon or maybe low dose methotrexate, something like one of these milder treatments that maybe wouldn't have worked when the disease is at a higher burden state but hopefully could work

to help maintain the response someone achieves with total skin electron beam.

Dr. Chung: Yes, I totally agree with Dr. Moskowitz. I think that it is something that I try to reserve for when I really need it because you can't do it infinitely even if it's low dose. I do think that it's very effective and works quicker than other treatments. I think that one scenario I might use it in the beginning might be someone that I think is high risk for progression. Someone who has extensive plaque disease and maybe a few tumors that I think is high risk. Then we could treat with total skin in the beginning and while starting systemic therapy such as bexarotene or interferon or methotrexate as you said, because those medications take a longer time to work. I think that is also a potential scenario.

My specialist has never really told me what stage I'm in. I'm on my third year of light therapy and various ointments. What is the importance of knowing my stage?

Dr. Chung: So, it's a good question. I think that based on what you're describing, if you are only on topical skin-directed therapy, it is most likely that you are in early-stage disease. And I will say that it is important to know your stage. The stage that you're in can change over time. You can go to a lower or higher disease stage based on how you're doing. I think that if you are curious, you can always ask your doctor, "What stage would you say I'm in?" Because your staging is something that has an impact on your overall prognosis.

Jina Chung, MD
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Alison Moskowitz, MD
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Questions and responses taken from the recording of our "Answers From the Experts: Q&A - June 2026." For the full-length recording, please visit: https://youtu.be/2RyLKUBfAn8

I have MF and was diagnosed when I was 22. I am 29 now. I was misdiagnosed for years before that. I'm just curious about your thoughts on our immune system. It is down because of the T-cell lymphoma. Does this make us more prone to other lymphomas or other diagnoses?

Dr. Pinter-Brown: Well, so it's a chicken and egg phenomenon. I don't know whether somebody gets lymphoma because their immune system isn't totally normal or the lymphoma makes the immune system misbehave. It might be both. But in general, people with lymphoma have a higher incidence of other lymphomas. The most common one that would be associated with mycosis fungoides would be Hodgkin's lymphoma which is curable but does require treatment that's systemic. Another one is anaplastic large cell and other skin lymphomas or skin conditions like lymphomatoid papulosis. So that would be one end of it. On the other end, there's been a lot of different epidemiologic studies looking to see if people with lymphomas and people with mycosis fungoides have other cancers. Probably the most common thread in mycosis fungoides would be colon cancer. So, you don't need a colonoscopy now (at 29) but be aware that they do now start screening at 45 years old. So, it is important to follow through with the general recommendations made for screening cancers.

Lauren Pinter-Brown, MD
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Questions and responses taken from the recording of our "2026 Annual Patient Conference" For the full-length recording, please visit: https://youtu.be/6jE36jfRi7o

A New Treatment Option...*continued from pg 6*

the clinical trial occurred during the first two treatment cycles, making careful monitoring especially important early in treatment. The risk is higher in patients with low blood albumin levels, so patients must have an albumin level greater than 3 g/dL before starting therapy, and albumin is monitored throughout treatment. Other possible side effects include infusion reactions, changes in liver tests, vision changes, fatigue, rash, nausea, swelling, chills, fever, constipation, muscle or joint pain, and changes in blood counts or other laboratory tests. Patients should promptly report new or worsening symptoms to their healthcare team.

A conversation about denileukin diftitox-cxdl may be appropriate when CTCL remains active despite one or more previous systemic treatments, particularly if skin tumors, plaques, or persistent itching continue to affect quality of life. It may be especially relevant for some patients with tumor-stage disease (i.e., Stage IIB), although treatment decisions are always individualized. A CTCL specialist can help determine whether it fits into a patient's overall treatment plan based on prior therapies, disease characteristics, other medical conditions, and personal goals.

For many people with CTCL, a successful treatment does not necessarily mean that every sign of disease disappears. Success may instead mean fewer or flatter skin lesions, less itching, fewer tumors or plaques, better sleep, improved comfort, less need for additional therapies, or simply feeling better day to day. Some patients may achieve a partial response that makes their disease easier to manage, while others may experience a deeper or more durable remission. The goals of treatment are different for every person, and those goals should guide conversations about whether denileukin diftitox-cxdl is an appropriate option.

As with any CTCL treatment, choosing denileukin diftitox-cxdl is a shared decision between patients and their healthcare team. Understanding how the treatment works, what benefits it may offer, the possible risks, and the commitment required for treatment and monitoring can help patients make informed decisions about where denileukin diftitox-cxdl fits into their CTCL journey.

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Rare Disease Week...*continued from pg 5*

is growing awareness that patient experience data and real-world evidence must be part of regulatory decision-making.

Change is possible. Especially when patients show up.

Join Us Next Year

If you have ever wondered whether you are "qualified" to advocate, let me reassure you: **lived experience is qualification.**

You do not need to be a policy expert. You do not need to have the perfect words. You simply need to be willing to share your story and connect it to meaningful action.

Rare Disease Week reminded me that there is real power in numbers. When we stand together across diseases, across backgrounds, across levels of experience, we are impossible to ignore.

I hope more members of the Cutaneous Lymphoma Foundation community will join us next year.

Your voice matters. And there is a seat in that room for you.

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What to Expect at Rare Disease Week

- **Educational briefings on rare disease policy priorities**
- **Advocacy training sessions for new and experienced advocates**
- **Scheduled meetings with congressional staff**
- **Clear policy "asks" to guide conversations**
- **A supportive community of patients, caregivers, and advocates**
- **A fast-paced schedule, comfortable shoes recommended**
- **Follow-up work after the event. Advocacy is the beginning of an ongoing relationship, not a one-time conversation.**

No prior advocacy experience required. Just bring your story.

CUTANEOUS LYMPHOMA FOUNDATION

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

FORUM

The newsletter of the Cutaneous Lymphoma Foundation

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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

CL CHALLENGE • FUND THE FIGHT • FUEL THE HOPE •

Fund the Fight. Fuel the Hope.

This September, awareness becomes impact.

September is packed with powerful moments of awareness: Blood Cancer Awareness Month, World Lymphoma Awareness Day on September 15, and Rare Cancer Day on September 30. This year, we're turning awareness into action through the CL Challenge, a global movement dedicated to raising funds and visibility for people living with cutaneous lymphoma.

Every dollar you raise will be matched 1:1 - up to $30,000!

Every dollar raised helps fuel:

- **Research that improves quality of life**
- **Education that empowers patients and healthcare providers**
- **Advocacy that elevates patient voices**
- **Support programs that foster connection and community**

Together, we can raise awareness, inspire action, and create hope.

Start planning your fundraiser today visit: clfoundation.org/CLChallenge or scan the QR Code