



**CUTANEOUS
LYMPHOMA
FOUNDATION**

FORUM

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www.clfoundation.org



FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

David Elefant, Board President; Susan Thornton, CEO

“Hope is the heartbeat of the soul. Let it guide you.”—Angela Martinez

As we approach the final weeks of the year, we pause to reflect on the year that is coming to a close and the inspiration that carries us forward into the year ahead.

The vibrant colors of fall may have faded. Still, the spirit of gratitude and resilience remains vivid in the stories we share.

This edition of the Forum highlights the ongoing challenges patients face in securing insurance coverage for home light therapy boxes—an essential tool for treatment that still lacks broad accessibility. While there are no permanent solutions yet, collaborating with your clinician to provide the necessary information for reimbursement can increase the likelihood of coverage. In addition, you will read powerful patient stories, including one about a steadfast oak tree that became a symbol of hope and gratitude during a difficult time, and another from "across the pond" describing a personal journey with diagnosis and treatments.

Each of us is part of the global community of individuals affected by cutaneous lymphoma, whether you are a patient, care partner, clinician, researcher, or a member of a company developing and providing therapies for this condition. The articles that follow highlight some of the incredible research being conducted around the world to continue uncovering the best approaches to treat all variations of this rare disease.

This year, the CL Foundation submitted a scientific abstract showcasing patient stories to the European cutaneous lymphoma meeting in Athens. This was a significant milestone in incorporating the patient's lived experience into the clinical research being conducted. All who participated

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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.

MEET THE NEW MEMBER OF OUR TEAM

The Cutaneous Lymphoma Foundation is pleased to welcome Laura Garman as our new Education Manager. With a strong background in health care and a passion for improving access, Laura has dedicated her career to helping to make positive health outcomes easier and more accessible for people. She brings that same commitment to supporting the Foundation's mission through impactful education and outreach. Please join us in welcoming Laura.



Laura Garman

IN MEMORIAM

We were saddened to hear of the passing of Prof. Dr. Willem Anton van Vloten (June 7, 1941 – September 25, 2025). Prof. Dr. van Vloten was a dermatology professor at the University of Utrecht (the Netherlands) and served as the president of the International Society of Cutaneous Lymphomas Board of Directors from 1992 to 2002. During his career in dermatology, Prof. Dr. van Vloten received the Vlissingen Prize, which is given to persons and institutions that contributed much to the research of the causes and treatment of malignant lymph node diseases and the improvement of the quality of life of the patients who suffer from such afflictions. We are grateful to Prof. Dr. Willem van Vloten for his work done on behalf of those affected by cutaneous lymphoma.



Prof. Dr. van Vloten

PATIENT CUTANEOUS LYMPHOMA JOURNEY

Shared by James P.

I'm James. I have never written about my condition before and hope my story is one that, whomever reads it, finds something helpful.

I am from the UK and was 45 years old when I was diagnosed with MF (Stage 1A) back in 2018. The path to diagnosis was unusual (having read others' stories) in that, while I had lived with these strange-looking patches on my torso for around 12 months, I put them down to eczema or psoriasis brought on by stress. It was only after trying a range of over-the-counter medicines—and seeing no change—that I went to the doctors to seek more information about the condition and treatment options. The first doctor I saw, what we call a General Practitioner (GP), was friendly but also thought it was just common old eczema. But after I went through the treatments I'd tried and the lack of results, the GP agreed it was worth me seeing a dermatologist.

“WELL, THIS IS INTERESTING”

A few weeks passed until my appointment came up, and I walked into the office of my dermatologist. After an explanatory chat, they asked to see the patches. What I then recall was what felt like a much longer inspection than I was expecting...and the words I can still recall: “Well, this is interesting.” I am sure most people don't really want to hear those words from their doctor! They explained that, while it was very unlikely—given how rare it is—to be a condition called mycosis fungoides, they still wanted to send me for a biopsy. The word “biopsy” was the point that I thought... Oh, this might be serious.

The next phase was a couple of biopsies (the first was inconclusive), but by the second, my dermatologist sat me down and said that, based on the results, it was cutaneous T-cell lymphoma. Now, at the word “lymphoma,” I had a reaction that was stronger than at the word “biopsy.” I knew lymphoma meant cancer, and as such, my mind raced. My doctor was very good—they explained the nature of blood cancers that manifest on the skin and the treatment options. I always remember coming away with the phrase in my head: “For the vast majority of people, this is a cancer you should die with rather than from.” That was, and is, a source of much reassurance.

NEXT PHASE...TREATMENT

The next phase was treatment, and I will briefly share what I undertook and the relative effects of each. For treatment options, I was referred to a cutaneous lymphoma specialist at a treatment center in London and was further comforted by what was clear: that in a world of rare cancers, I had the most common variant of a rare cancer. His calm, friendly demean-

nour, which gave off an air of “you are one of the easier ones I have to deal with,” did reassure me. He outlined the range of options, and we agreed to start with UVB therapy. After trudging to a clinic every few days to build up the dose, by the end of the course it made

very little difference, so we moved to PUVA. Getting access to the psoralen was lengthy and expensive, and the treatment—where I had to visit a clinic a long way from home for a session that often lasted just a few minutes—was a pain, especially as it involved travelling during the pandemic, which was challenging. By the end of the treatment however, it had some effect—not complete remission, but an improvement. He next suggested chlormethine (Ledaga in the UK), and after taking on board that it's a form of mustard gas (!) and highly toxic, I knew that I wanted something that I could use at home to treat the condition. I am very glad I did, as I have found it excellent—by far the best treatment for me. Over a period of weeks, it darkened and then cleared my plaques, and I use it to this day when a new plaque pops up.



SEVEN YEARS ON

So, I have now lived with this condition for 7 years. What are my main thoughts? I feel a bit of a fraud when it is described as a cancer, as it feels so much more manageable than many cancers. It has not prevented me from doing anything in life that I would have done anyway, and I feel very lucky to have had an early diagnosis and been under the care of great people with smart treatment options. I know not everyone's path to diagnosis and treatment has been as smooth, from listening to stories at the wonderful Patient Conference I attended in Philadelphia last year. Again, I am grateful that the community exists and to share stories of our respective journeys.

Seven years on, it is part of the fabric of my life, and I don't really give it much day-to-day thought...and frankly, long may that continue. I hope my doctor's initial words upon diagnosis remain true...I'll die with it rather than from it.

2025 EORTC-CLTG ANNUAL MEETING

The European Organisation for Research and Treatment of Cancer (EORTC) is an international non-profit organization whose mission is to “coordinate and conduct international translational and clinical research to improve the standard of cancer treatment for patients.”

In 2004, the EORTC created a cutaneous lymphoma task force, now formally called the Cutaneous Lymphoma Tumour Group (CLTG), to develop and publish an agreement on how to treat mycosis fungoides (MF) and Sézary Syndrome (SS). This agreement was published in 2006 and revised and updated in 2017.

The EORTC-CLTG continues to meet annually to bring together researchers and experts to share the latest developments in cutaneous lymphoma in the areas of diagnosis, research, and treatment.

The Cutaneous Lymphoma Foundation regularly attends this annual meeting to represent the patient community and learn more about new research developments. For the first time in our history with the EORTC-CLTG, we had a quality-of-life abstract accepted to be included in the meeting’s abstract hall. Our abstract provided an opportunity for the attending researchers and clinicians to learn more about the real-life experience of individuals living with the disease. Our thanks to the members of our community who provided the data shared in the abstract.

In the following articles, Dr. Shamir Geller highlights advances being made in treatment research presented at the annual meeting, and Dr. Thomas Paz Del Socorro shares the research he presented as an abstract that earned him our Young Investigator Award.

HIGHLIGHTS FROM THE EORTC-CLTG ANNUAL MEETING

Shamir Geller, MD, Memorial Sloan Kettering Cancer Center

The European Organisation for Research and Treatment of Cancer (EORTC)-Cutaneous Lymphoma Tumour Group (CLTG) meets annually to shed light on the latest developments in the cutaneous lymphoma field in the areas of diagnosis, research, and treatment. Each year, the annual meeting welcomes clinicians, scientists, and industry not only from Europe but also from the rest of the world.

This year, the EORTC-CLTG Annual Meeting was held in Athens, Greece, from October 16 to 18, 2025. With presentations and discussions focusing on the latest developments in the field, as well as those in the areas of diagnosis, research, and treatment of skin lymphomas, the meeting opened a wide window into the future and innovative solutions to existing problems.

Faithful in its tradition, the meeting included not only dermatologists focusing on skin cancer, but also pathologists, hematologists, and oncologists. Last but certainly not least, young scientists and researchers in the field are encouraged to participate, bringing into the field a fresh aura and paving new roads of diagnosis and treatment.

Promising Combination Therapies

This year’s keynote speaker was Dr. Steven Horwitz from Memorial Sloan Kettering Cancer Center in New York City.

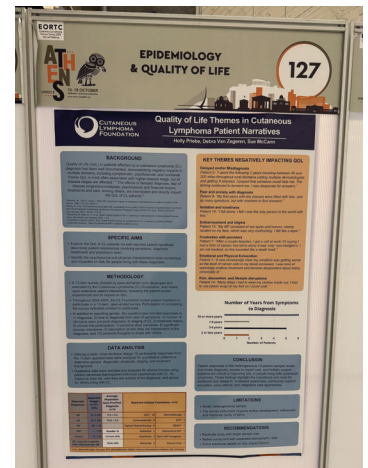
Dr Horwitz dedicated his talk to the current status of evidence-based medicine regarding treatment options in CTCL which target specific oncogenic, or tumor causing, pathways based on cellular activity such as JAK/STAT and PIK3. These treatment options are still under clinical trials with some regimens combining different therapies, such as oral ruxolitinib plus duvelisib, showing promising results.

Another support for the possible place of combination therapies was shown in a preclinical study performed on CTCL cells grown in the lab at the University of Athens. A combination of immunotherapies (mogamulizumab and pembrolizumab) with the JAK inhibitor ruxolitinib reduced cell growth and movement while increasing cell death, suggesting a promising new treatment approach worth further clinical testing.

Update on Lacutamab

KIR3DL2 is a protein found on cancer cells in about half of mycosis fungoides patients and in most people with Sézary syndrome. Lacutamab is a new antibody treatment designed to target and destroy cells that carry KIR3DL2, offering a potential new therapy for both mycosis fungoides (MF) and Sézary syndrome (SS).

Dr. Youn Kim (Stanford University, USA) and Dr. Martine Bagot (Hospital Saint-Louis, France) presented Phase 2 trial



results at the Athens meeting. Their results showed that lacutamab achieved strong responses in Sézary syndrome (42.9% response rate, 25.6-month duration) and mycosis fungoides (20.8% response rate, 13.8-month duration) with good safety. The FDA has just approved the Phase 3 TELLOMAK-3 trial, set to begin in early 2026, to further evaluate lacutamab in these conditions.

Update of PROCLIP

An international collaborative effort (PROCLIP) presented its findings of factors associated with MF and SS disease progression as published recently in the American Society of Hematology's Blood journal. PROCLIP is a prognostic index based on clinical data related to cutaneous lymphoma.

The findings were based on 280 patients with advanced-stage mycosis fungoides and Sézary syndrome who were stratified based on four baseline factors: age >60 years, nodal involvement by disease (N3), elevated LDH, and large-cell transformation of their cancer cells. Results showed that risk groups using the above parameters were linked to different disease progression patterns and treatment responses, suggesting that this prognostic score system could become an important tool for guiding treatment decisions and personalized care in advanced cutaneous lymphoma.

YOUNG INVESTIGATOR AWARD ABSTRACT PSGL-1: A NEW THERAPEUTIC TARGET TO TREAT CUTANEOUS T-CELL LYMPHOMAS

Dr. Thomas Paz Del Socorro, Dr. Martina Prochazkova-Carlotti, Dr. Sandrine Poglio and Pr Marie Beylot-Barry

Dr. Thomas Paz Del Socorro was the recipient of our Young Investigator Award for the EORTC-CLTG. The following is the research he presented as an abstract at the annual meeting.

OUR RESEARCH TEAM AND WHAT WE DO

Our team, led by Professor Marie Beylot-Barry and Dr. Laurence Bresson-Bepoldin, works at the BoRdeaux Institute of onCology (BRIC) at the University of Bordeaux in France. We study skin-related cancers, especially a rare type called cutaneous lymphoma. Our team includes doctors, scientists, teachers, and students from different fields, all working together to improve treatments for patients.

We focus on cutaneous lymphomas because they are hard to treat and not well understood. To help with our research, we use skin and blood samples from patients seen in the dermatology department, which is part of a national network specializing in these diseases. We also take part in early-stage clinical trials that test new treatments, including types of immunotherapy like mogamulizumab, lacutamab, and DT-7012.

HOW WE STUDY SKIN CANCER

We work closely with other teams at Bordeaux University Hospital on a large project about skin cancers. We use advanced lab models, including 3D models and animal studies, to learn more about how these cancers grow and behave. We also study the genes and traits of cancer cells,

how they survive and change, and how they interact with their surroundings. Our lab is one of the first to create special models that help us understand cutaneous lymphomas better and test new drugs.

UNDERSTANDING SÉZARY SYNDROME

The most common type of cutaneous lymphoma affects the immune system and mainly shows up on the skin. One serious form is called Sézary syndrome. It causes widespread redness, severe itching, and cancerous immune cells in the blood. This condition greatly affects patients' quality of life and is hard to treat. Even though new therapies have helped, the only treatment that might cure it is a stem cell transplant. But this option is only available to healthy patients who have a matching donor and respond well to treatment beforehand. So, finding a cure that works for more people is a major challenge.

OUR DISCOVERY: TARGETING PROTEINS ON CANCER CELLS

In earlier research, we found that a protein called CLA (Cutaneous Lymphocyte-associated Antigen) might be a good target for treatment. CLA helps cancer cells move into the skin. When we treated patient cells with an antibody against CLA, it killed the cancer cells and slowed their movement. But CLA levels vary a lot between patients, and there's no approved antibody for use in people yet.

So, we turned our attention to another protein called PSGL-1 (P-Selectin Glycoprotein Ligand-1), which also helps immune cells move from the blood into the skin. Unlike CLA,

PSGL-1...continued on page 10

**THANK YOU
FOR FUNDING
THE FIGHT AND
FUELING THE HOPE!**



You Showed Up. You Gave Generously. You Inspired Hope.

Thanks to 9 passionate fundraisers and 177 incredible supporters, we raised **\$27,878** through the CL Challenge fundraiser, and thanks to a generous match from our Board of Directors, the total impact is now **over \$50,000!**

These funds will directly support:

- **Research** that improves quality of life
- **Education** that empowers patients
- **Advocacy** that amplifies patient voices
- **Support programs** that connect and heal

You are the reason these programs exist.

Because of you, someone will find answers, feel less alone, and discover hope.

You acted, and made a difference.

We are deeply grateful.

FINDING GRATITUDE

Shared by Ellen V.

The following story was shared at our 2025 Patient Conference during Sunday's Patient Panel session:

This is along the lines of gratitude. You know how when we all get the disease, we ask "Why me? Why me?" My sister lives in Detroit and I live in South Jersey and as I was trying to get over the diagnosis, she would talk to me weekly. In 2022, I developed breast cancer, and I was falling apart, and she would do anything for me...anything. So, she sent me these beautiful notebooks and these beautiful pens and said, "I want you to write down gratitude and whatever you're grateful for that day." I was like "Oh, you got to be kidding me. I'm not doing this." Anytime she suggests stuff, that is usually my response. She's the older sister. I'm the younger sister and my attitude is "You can't tell me what to do."

The notebooks are still in the plastic wrap they came in, and the pens are still where they were, but it did work. On my way to radiation which I had to do daily for four weeks, I would drive the same route to my treatment center. It was October and there was this beautiful oak tree that I passed every day. I called it my tree, and it was beautiful. I took in its beauty and that's what I was grateful for every day--that I got to see this beautiful tree; it was red and orange and I got to see it change every day. I took it in, and I told my sister, "I'm not writing it down, but I look."

I still go to my treatment center that way, and when I go, I look at the tree. It is now starting to bud, and it will be blooming soon. Because I have many dates at that office, I'm very grateful for my sister and grateful for that tree and grateful that I have all these things. Last night in the middle of the night the itch reared its head, and you know, I thought of everybody here (at the conference) and how it happens to all of us. I have my moisturizer tub next to my bed. I turned the lights really low and slathered myself up in the middle of the night and got through the night. I am grateful for everybody here and everything that's going on, that I have these opportunities, and that I'm alive and I'm going to live my full life. And now whenever something happens, I think of my tree.

ANNUAL PATIENT CONFERENCE

APRIL 24-26, 2026

Learn, Connect, Celebrate!



"This experience helped me have a more positive outlook. I feel less frightened, and isolated and feel more knowledgeable." - Conference Attendee

The annual Patient Conference is open to anyone affected by cutaneous lymphoma. Regardless of where you are in your journey, the conference is an opportunity to learn more about living with cutaneous lymphoma through:

**Clinical Presentations • Breakout Sessions
Networking Opportunities • And more...**



For more information and to register:
www.clfoundation.org/annualpatientconferencemesa
Or scan the QR code



"Do yourself a favor. Attend a conference, read the information on the website or attend a webinar. Talk about your condition to others who have it."
- Conference Attendee

ACCESS TO HOME PHOTOTHERAPY FOR CTCL PATIENTS

At the March 2025 American Academy of Dermatology Annual Meeting, we learned about the results of the LITE study, led by Dr. Joel Gelfand. The study showed that home phototherapy works just as well as in-office phototherapy for people with psoriasis. This finding is important because many patients struggle to attend regular office treatments. Taking time off work, finding childcare, traveling to appointments, and paying related costs can all be difficult. These challenges are even greater for people who live far from a dermatology office that offers phototherapy. In fact, about 90% of U.S. counties do not have a dermatology practice that provides it..

At the same time, newer targeted treatments for psoriasis and eczema have reduced the demand for in-office phototherapy. This shift affects patients with cutaneous T-cell lymphoma (CTCL), since phototherapy is one of the safest and most effective treatments for early-stage CTCL and may even help slow disease progression.

INSURANCE APPROVAL CHALLENGES

At the Hospital of the University of Pennsylvania, a major referral center for CTCL, we noticed that our CTCL patients had more trouble getting insurance approval for home phototherapy units compared to psoriasis patients. To confirm this, in spring 2024



we asked two major device companies, National Biological Corporation and Daavlin, for their insurance claims data from January 2022 to March 2024. The data showed that Medicare approved home phototherapy for 77% (1321 of 1719) of psoriasis patients, but only 35% (123 of 345) of CTCL patients and 43% (73 of 168) of those with mycosis fungoides.

To understand why, we reviewed Medicare's National Coverage Determination (NCD) for durable medical equipment. It currently lists home phototherapy units as covered only for certain patients with severe psoriasis. Because CTCL was not included, in late 2024, we and our colleagues from several universities including Columbia, Northwestern, Duke, and the University of Washington, asked Medicare to expand the policy to include CTCL.

After review, Medicare denied the request. In follow-up discussions, they explained that there is not enough published evidence showing home phototherapy is effective for CTCL

patients who are Medicare-aged. They also stated that cost was not part of their decision-making process. Interestingly, although home phototherapy units cost around \$3,000–\$5,000, they are far less expensive than many other CTCL treatments, such as bexarotene or interferons. Medicare officials suggested that a large observational study or randomized controlled trial in older CTCL patients could provide the evidence needed. However, such a study would require major funding and time, and recruiting patients would be difficult since many currently cannot get coverage for home units

DOCUMENT...DOCUMENT...DOCUMENT

In the meantime, Medicare reviews each request for home phototherapy on a case-by-case basis. They look for clear documentation showing that the treatment is “reasonable and necessary.” Clinicians can help by noting all prior treatments a patient has tried, their experience with in-office phototherapy, and any personal challenges such as transportation or mobility issues that make in-office treatments difficult. This detailed documentation can improve the chance for approval for CTCL patients under any insurance plan.



To help educate our colleagues, we have written an article accepted for publication in the Journal of the American Academy of Dermatology (JAAD).

In summary, as dermatology continues to evolve and more patients use targeted therapies, access to in-office phototherapy may keep decreasing. We expect this to especially affect those with CTCL. We will continue advocating for better access to phototherapy—one of the safest and most cost-effective treatments available. The LITE study gives us strong evidence that home phototherapy can be just as effective as in-office care. By understanding Medicare's criteria and documenting medical need carefully, dermatologists and patients can work together to improve approval rates for home phototherapy units.

Leah S. Cohen, MD

University Park Dermatology
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Oluwaseyi Adeuyan, MD

Dermatology Resident Physician
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TOP FIVE THINGS YOU CAN DO TO CREATE A LEGACY

- **Basic Estate Planning:** With a will or trust, you can designate your beneficiaries and what you want them to receive. You can name the Cutaneous Lymphoma (CL) Foundation as a beneficiary of a specific dollar amount or a percentage of your estate.
- **Retirement accounts:** You can name the CL Foundation as a beneficiary of part or all of your retirement account. By having it passed to a charity, such as the CL Foundation, no income taxes are paid as would be the case if an individual were the beneficiary. And donors over age 70½ can donate up to \$108,000 directly from their IRA to the CL Foundation, effectively excluding the distribution from their taxable income and helping satisfy their required minimum distribution.
- **Life Insurance:** If you own a life insurance policy, you can name the CL Foundation as a partial or full beneficiary to receive the insurance payout on your death.
- **Donations:** Donations of cash are the easiest and most common gift to the CL Foundation. However, other types of assets, such as stock and real estate, can also be gifted. Gifting assets that have appreciated in value gives you an income tax deduction for the full fair market value of the gift at the time of the gift, and capital gains tax is completely avoided. This results in a gift that is greater in value than its cost to you.
- **Memorial Gifts/Tributes:** A donation to the CL Foundation is a wonderful and meaningful way to honor a loved one or friend affected by cutaneous lymphoma. It helps raise awareness of the disease and also helps to ensure that the next person diagnosed with cutaneous lymphoma has access to the Foundation's programs and services.

As with any estate or financial planning, be sure to consult your financial advisor or estate planning attorney to consider all the relevant factors that apply to your personal situation. For more information about making a gift to the CL Foundation, please contact info@clfoundation.org or call 248.644.9014.

From the Board...continued from pg 2

in sharing their experience helped to bring the person behind the disease to light for the clinicians and researchers. Thank you for participating!

We look forward to more opportunities like this where you can share your experience and help support changes in care and quality of life for everyone.

These stories remind us that healing is more than medicine; it is rooted in perseverance, community, and hope. Whether through advocacy, raising awareness, education, or simple acts of connection, the Foundation remains committed to supporting every person's path, no matter how much it may twist and turn.

Thank you for being part of our community. As we enter the season of giving thanks, we are deeply grateful for your ongoing support and engagement. Remember, no one needs to walk alone.

Together, we can change the quality of life for everyone living with cutaneous lymphoma.

Enjoy the articles!



A handwritten signature in black ink that reads "David".

David Elefant
Board President



A handwritten signature in black ink that reads "Susan".

Susan Thornton
CEO

Frequently Asked Questions



Do you support the use of alternative medicines such as the use of herbs and acupuncture treatments? Are they effective? Are there some alternative medicine treatments that you would advise against using?

Dr. Mehta-Shah: There's not any known alternative medicines that are approved or have been studied widely in cutaneous lymphomas, so I don't know of one working better than the other, specifically for this disease. I think we're not opposed to people using supplements or using acupuncture or other holistic approaches to cancer treatment. But, I would say that if you're on treatment through the body, like pills or IV chemotherapy or other IV anti-cancer treatments, then you want to be really open and upfront with your doctors about what you're taking because there are some medicines that do interact with other alternative supplements. You want to be aware of whether you could be doing yourself undue harm or making the other treatment not work as well as a result of taking some alternative treatment, strategies, or supplements. I often refer patients to a site on the Memorial Sloan Kettering website called "About Herbs" which collates information about alternative treatments and has sections specifically for doctors and for patients about what the risks are and known benefits of some of these alternative supplements. I think that's a very well-vetted resource that is really useful for patients and for doctors.

Dr. Musiek: I think if patients are wondering, "What else can I do?", one of the most important things they could do is take care of their overall health, like being up to date on health maintenance and being as close as possible to their ideal body weight, so that if complications or the need for more intense therapy arises, they're in their best health when they're entering those sorts of treatments

Neha Mehta-Shah, MD

Washington University School of Medicine
Pullman, Washington

Amy Musiek, MD

Washington University School of Medicine
Pullman, Washington

Questions and responses taken from the recording of our "Answers From the Experts: Q&A - October 2025." For the full-length recording, please visit: <https://youtu.be/YVfF7BO-xxM>

Will my CTCL ever go into remission although there is no cure?

Dr. Chung: This is a really good question and one that a lot of patients ask. It depends on the stage. It can go into remission. Sometimes when you have early-stage disease, we don't always shoot for 100% remission because a lot of early-stage patients have a really good prognosis even if they have a little bit of leftover disease. We try to manage the risk against the benefits and try to find the treatment that preserves the patient's quality of life in the best way.

Dr. Sethi: I agree. CTCL is one of the diseases where quality of life is of utmost importance because it is ultimately a chronic disease, especially in early stages.

Jina Chung, MD

Perelman Center for Advanced Medicine
Philadelphia, Pennsylvania

Tarsheen Sethi, MD

Smilow Cancer Hospital
New Haven, Connecticut

Questions and responses taken from the recording of our "Answers From the Experts: Q&A - August 2025." For the full-length recording, please visit: <https://youtu.be/DFiV8KHV-eM>

PSGL-1...continued from pg 5

PSGL-1 is found at similar levels in all patients, making it easier to target. We tested an antibody against PSGL-1 on cancer cells from patients and healthy donors. It killed only the cancer cells, not the healthy ones, showing that PSGL-1 plays a special role in Sézary syndrome.

We're also testing whether this treatment can stop cancer cells from moving into the skin. If it works, it could reduce skin symptoms like plaques and itching, helping patients feel better.

NEXT STEPS AND COLLABORATION

We need to do more research to understand exactly how PSGL-1 causes cancer cells to die. Attending the EORTC-CLTG conference gave us a chance to meet other scientists, learn about new treatments, and share our findings. We hope to build partnerships and get advice to make our project even stronger.

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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