CUTANEOUS
LYMPHOMA
FOUNDATION

FORUM

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FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

David Elefant, Board President; Susan Thornton, CEO

"Life isn't about waiting for the storm to pass…..it's about learning to dance in the rain." - Vivian Greene

David

David Elefant
Board President

Susan

Susan Thornton
CEO

Welcome the arrival of spring! With more sun, warmer temperatures, and blooming trees, we are reminded of the power of renewal and hope. As the season brings fresh starts, we continue to innovate our programs and services and strengthen community connections for everyone affected by all variations of cutaneous lymphoma. Watch for our new podcast coming this spring!

Keeping You Informed

Skin-directed therapies play an important role in many treatment paths for individuals with cutaneous lymphoma, including the use of light therapy. With the longer days that come along with the spring season, we decided to dive into light therapy in this issue of the Forum and kick-off a multi-part series. For those of you who have been treated with light, you will connect with this issue's patient story. For others, learning the basics about the various types of phototherapy in this first article will serve as a good baseline. With the ongoing clinical trials using new forms of light underway, there may be new options in the future.

Staying on top of initiatives in the field remains a focus for us. We are committed to informing you about treatment options, as well as what is happening in the cutaneous lymphoma space. Read about Rare Disease Week and the efforts made on behalf of our community in Washington, DC. Special thanks to the individuals who joined the efforts to educate legislators about the impact of living with a rare disease, and how policy and funding impact the ability to live well while living with cutaneous lymphoma.

We continue collaborating with cutaneous lymphoma experts, institutions, and industry partners to share updates on clinical trials, emerging therapies, and quality-of-life initiatives that bring us closer to new treatments and better outcomes. Make sure to subscribe to our eNews and follow us on the social media channels for the latest updates.

Support and Resources

Living with a rare cancer presents unique challenges. Our virtual networking groups continue growing, creating a safe and invit-

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Autumn Loffreda

We want to thank Autumn Loffreda for her four years of extraordinary service to the cutaneous lymphoma community as our Education Manager. Autumn will be leaving the Foundation to take a more active role in her cycling events business. We are excited for Autumn, but will miss her as a valued member of the CL Foundation team. Please join us in wishing Autumn much success in her next adventure.

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.

MY JOURNEY WITH CUTANEOUS LYMPHOMA

Shared by Dave O.

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

MY JOURNEY BEGINS

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

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

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

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

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

> **BE PROACTIVE!**
>
> My takeaway from this experience is that it is crucial to take proactive steps in advocating for oneself.

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

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

BE PROACTIVE

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

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

FOLLOW THE PROTOCOLS

There are numerous advantages to utilizing a personal light

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therapy unit, including cost savings and flexibility. However there are some precautions:

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

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

FINAL TAKEAWAYS

Some takeaways from my journey that I recommend are:

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

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IS HOME PHOTOTHERAPY FOR YOU?

Sue McCann, MSN, RN, DNC
Dermatology Nurse, University of Pittsburgh Medical Center

Phototherapy is a common treatment for cutaneous lymphoma; however, finding phototherapy services at a nearby medical facility can be challenging. This challenge has led many to ask about owning their own home phototherapy unit. Over the next three issues of the Forum, we will take a deep dive look at both the advantages and challenges in acquiring a personal unit.

In this first issue, Sue McCann provides a brief introduction to phototherapy itself, and then further explores the home lightbox option. In future issues, we'll address medical insurance related to home lightboxes and, lastly, current advocacy initiatives related to home lightbox coverage.

What is phototherapy?

One of the primary skin-directed treatments for cutaneous lymphoma, prescribed by your dermatologist, is phototherapy. Phototherapy involves the use of ultraviolet radiation directed at the skin in incremental time intervals with an intent to decrease inflammation, itching, improve quality of life, and induce partial or complete remissions. Phototherapy is safe for most people and can be used for the elderly, immune-compromised, and during pregnancy. It is helpful in treating the patches and plaques of mycosis fungoides, some subtypes of cutaneous T-cell lymphoma, and in combination with other therapies for both mycosis fungoides and Sezary syndrome. Response rates are excellent, ranging between 60-90%, depending primarily on the extent/stage of disease. The ultraviolet light used in phototherapy is not visible and capitalizes on different wavelengths to induce treatment responses, depending on the type of lesions targeted by the therapy. The most widely used medical ultraviolet light (UVL) includes PUVA and nb-UVB:

- Ultraviolet light A (UVA) has a wavelength of 320-400 nm (nanometers) and is most beneficial for treating thicker plaques because of its deeper penetration into the skin. It requires the additional use of either an oral or topical photosensitizing psoralen compound. The acronym of PUVA came from the combination of terms: psoralen and UVA.
- Ultraviolet light B (UVB) has a wavelength between 290-320 nm and consists of two main types: broadband UVB (BB-UVB) and narrow band UVB (nb-UVB), so named because of its narrower spectrum of UVL between 311-312 nm. Broadband UVB is the older modality and is infrequently used. Currently, nb-UVB is most often prescribed to treat patches and thinner plaques.

Is home phototherapy for you?

The pathway to receiving phototherapy at home begins with a discussion with your dermatologist and takes into consideration several factors including diagnosis, history of melanoma and non-melanoma skin cancers, medications, lesion and skin type, and insurance coverage options for obtaining a home unit. It is a prescribed therapy and must be ordered and monitored by your dermatology health care providers.

- It's important to note that the vast majority of home phototherapy is nb-UVB.
- PUVA, while it is possible to deliver this UVL in the home, it is generally preferred to remain an in-office procedure due to safety and monitoring concerns, along with the need for required use of psoralen as a pre-medication.
- Several companies manufacture in-office and home phototherapy units. Your doctor's office works with one or two manufacturers to supply their patients with home units and will be able to facilitate the therapy for you.
- A set number of treatments will be added to your light box at the outset, and at regular intervals your dermatology office will need to provide you with a code to load additional treatments onto the machine. Your doctor will provide directions for the starting time in the booth and how to incrementally increase the time of treatments safely.
- UVL therapy is usually given 2-3 times per week to start until the desired response is achieved. Once a response is evident, your doctor will determine what your ongoing maintenance treatment plan with phototherapy will look like.

What are the benefits of home phototherapy?

- There is now no need to travel to the dermatologist's office for this purpose. This is especially important if you live a long distance from the treating office or if there are no offices offering phototherapy in your region, greatly reducing travel costs such as mileage, parking, and car use.

- No insurance co-pay or billing is required: Once your machine is privately purchased or paid for by your insurance company, it is yours to use at home.
- No time restrictions: This benefit allows you to fit your treatments into your schedule. There is no need to worry about an office's hours and other scheduling issues. No longer do you have to leave work early or worry about missing a visit. Any time of the day that works for you is the beauty of using home light. No appointments are required!
- Built-in safety precautions: Your unit will come with a safety electrical switch lock and a locking key to prevent use by others in the household and damage from electrical power surges when not in use. There is a set number of treatments loaded into the unit (generally 75 at a time) so that you cannot continue therapy for too long without being monitored by the providers at your dermatology office.

What is important to think about when choosing a home light unit?

Your dermatologist will discuss what type of home phototherapy unit you will need to treat your skin. There are multiple light boxes and devices to choose from, depending upon the extent of skin involvement.

- Hand-held and portable units: These can be very helpful for specific, hard to reach areas, such as the scalp or a localized body area where treatment is directed only at the affected area(s).
- Hand and foot units are available to specifically treat hand and foot involvement. These are compact units that can treat the hands and feet at the same time.
- Full body single panels or tri-fold panels are available for full body exposure that can hang over the back of a door (single panel) or triple panels that are foldable and freestanding.

Are there any downsides to doing phototherapy at home?

- Essentially, this boils down to not having the professional phototherapy staff at your fingertips on your treatment days to help with any treatment questions, determina-

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RARE DISEASE WEEK ON CAPITOL HILL

Members of the cutaneous lymphoma community gathered with over 600 rare disease advocates in Washington, DC, for Rare Disease Week in February. This annual event is hosted by the EveryLife Foundation's advocacy branch, the Rare Disease Legislative Advocates, and culminates in a day on Capitol Hill to meet with members of Congress. These meetings provide advocates with the opportunity to educate decision-makers about the challenges of living with a rare disease and to speak out on policies that currently affect, or may affect, them.

"What actually is considered a rare disease?" a member of our group asked during the legislative preparation day. You may also wonder why the CL Foundation acknowledges Rare Disease Day and attends a rare disease conference. According to the U.S. Genetic and Rare Diseases (GARD) Information Center, a rare disease is "a disease affecting fewer than 200,000 individuals in the United States (per the Rare Diseases Act of 2002)."[1] Within the U.S., there are an estimated 30,000 individuals with a cutaneous lymphoma diagnosis, which falls within GARD's rare disease definition. There are over 10,000 known rare diseases, with many affecting very small groups of people. By joining our voices together, we strengthen our message about the issues that impact everyone living with a rare disease.

Legislative Asks

Top of mind for many advocates at this year's event were the recent executive orders and staffing changes affecting the Department of Health and Human Services (HHS) agencies, including National Institutes of Health (NIH), Food and Drug Administration (FDA), and Centers for Disease Control and Prevention (CDC). These offices, to quote Everylife Foundation, "are essential to supporting timely diagnosis, conducting research, enabling therapy development, facilitating insurance coverage, and implementing public health programs."[2]

As we met with our members of Congress, we asked that they ensure steady and robust federal biomedical research funding and public health agency support. The advances we have seen in research and treatment development for rare diseases have been exciting and need to keep moving forward, which requires a level of expertise and funding. As one expert panelist said, "Rare disease can lead the way to advances that can help all diseases."

In addition to our request that our members support the HHS agencies, we asked that they join the Rare Disease Congressional Caucus or, if already a member, thank them for joining. The Caucus is bipartisan and is open for both Representatives and Senators to join. Its purpose is to raise awareness of rare diseases and the unique needs of the rare disease community. The Caucus also "creates opportunities to address barriers to the development of and access to life-altering treatments."[2]

One such barrier is the lack of access to off-label treatments for individuals with Medicare Part D coverage. Part D plans are prohibited from including off-label treatments if they are not listed in the Part D compendia; for example, off-label use of interferon or steroids for cutaneous lymphoma. Currently, there is no appeal or reconsideration method available for individuals who find themselves in this situation.

The **P**roviding **R**ealistic **O**pportunity to **E**qual and **C**omparable **T**reatment for Rare (PROTECT RARE) Act (H.R. 6094) would permit Medicare and Medicaid to use peer-reviewed literature and clinical guidelines to define off-label treatments as "medically accepted use" rather than adhering only to the FDA label and compendia. For the cutaneous lymphoma community, this could mean coverage for effective treatments that are currently inaccessible due to the price or lack of insurer coverage.[3]

The Cutaneous Lymphoma Foundation is very grateful to the members of our community who responded to our call for advocates. We realize it is a big ask, given that participants cover their own travel and lodging expenses, in addition to the giving of their time. We want to thank them for coming to DC to add their voice on behalf of all those affected by cutaneous lymphoma - we are stronger (and louder) together.

References

1 Genetic and Rare Diseases (GARD) Information Center. About GARD. U.S. Department of Health and Human Services, National Institutes of Health, National Center for Advancing Translational Sciences. https://rarediseases.info.nih.gov/about

2 Rare Disease Legislative Advocates (2025). Hill Day Issue Information. Rare Disease Week on Capitol Hill - Program Booklet. Everylife Foundation. (pp. 15, 18)

3 Haystack Project. Protect Rare Act. https://haystackproject.org/protectrare

2024 YOUNG INVESTIGATOR AWARD - RESEARCH SUMMARY

Dr. Paola Ghione, a dermatologist and researcher at the Memorial Sloan Kettering Cancer Center, received the Cutaneous Lymphoma Foundation's Young Investigator Award for cutaneous lymphoma research which she presented at the American Society of Hematology's 2024 annual meeting. The following is a summary of Dr. Ghione's research.

Understanding the role of microbes inside the lymphoma patches/plaques/tumors in cutaneous T-cell lymphoma

People living with cutaneous T-cell lymphoma (CTCL) such as mycosis fungoides (MF) or Sezary syndrome (SS) are known to have some microbes on their skin that may be associated with how the CTCL behaves, for example Staph aureus which sometimes also infects the lesions.

In other skin tumors, for example melanoma, and other cancers, researchers found that even inside the tumor mass there are microbes. and these interact with the cancer cells directly, or through modifications of the support cells in the tumor, the so-called microenvironment. These intratumoral microbes can also influence response to certain treatments.

We have studied the skin tumor samples of 61 patients with CTCL, collected between 2015 and 2023, to detect these microbes inside the patch/plaque/tumor using a technique studied in other cancers. The patients were mostly men (57%) with an average age of 56 at diagnosis, and 68% were white. About two-thirds of them had received systemic treatments (like pills or infusions), while others used skin-directed treatments (like creams or light therapy).

We found 31 common types of microbes in the skin samples. Some of these were linked to better survival rates, meaning patients with these microbes found inside the samples tended to have a better disease course. Other microbes were more common in women, and one microbe was found only in white patients. The study also noted that certain microbes were more likely to show up in patients needing pills or infusions compared to those who only needed creams or light treatment.

This study suggests that microbes inside the CTCL might influence how the CTCL behaves, including how severe symptoms are. However, this is early research, and we are looking at more patients to confirm these findings.

Would you like to connect with others who share your cutaneous lymphoma experience?

Connecting online through one of the CL Foundation's networking groups is a great way to meet others affected by cutaneous lymphoma. Whether you have the disease or a loved one who does, these online groups offer an opportunity to share and learn from each other's stories and experiences.

To learn more about our Online Networking Group meetings held monthly on Zoom, visit: clfoundation.org/patient-networking-groups

To learn more about our Networking Group on Facebook, see Groups on: Facebook.com/clfoundation

Phototherapy...*continued from pg 5*

tions, changes to your regimen, or to document your treatment outcomes on a routine basis. If you are concerned that you may have burned or that you have skipped a few too many treatments, you should always communicate with the office and discuss your concerns, and/or send pictures of your skin if you are worried about what to do.

- Understand that there may be costs related to either purchasing a unit from a manufacturer or a private seller and for any maintenance costs not covered by a warranty.

What precautions should I take with home phototherapy?

Always discuss these with your doctor/phototherapy staff, but some of the considerations are:

- Treatments should not be done on back-to-back days. For 3 treatments/week, schedules such as Monday, Wednesday, and Friday OR Tuesday, Thursday, and Saturday are amenable to this restriction.
- It is essential to wear UVL shielding, protective eyewear during each treatment.
- Cover areas that don't require treatment such as your face, genitalia, or other uninvolved areas.
- Decrease exposure time if you have burned or have missed too many treatments due to any variety of reasons (vacations, work, travel, illness, etc.).
- It is generally recommended to avoid use of topical applications before doing your light treatments; however, discuss this specifically with your doctor, as your situation or prescribing practices differ.

What else should I consider?

- Insurance coverage: Obtaining insurance coverage for home units often takes time for approvals and requires working closely with insurance companies. Your dermatology office will initiate the order and a letter of medical necessity with the home light company and, along with you, will work with both the insurance and home light company to obtain approval for coverage. However, it's important to remember that out-of-pocket costs can vary, even with insurance agreeing to pay for the home unit. One final option is to purchase the phototherapy unit outright, if insurance coverage is not forthcoming.
- Specifics on home light units:
    - Home light units require a typical 3-prong, grounded outlet for use in North America. In other countries, different units may be required that meet the electrical requirements in that specific country. Options for use should be explored with the selected light unit manufacturer.
    - The bulbs in home units can become hot, mostly at each end of the lightbulb. It's important to use caution and avoid touching bulbs during/after use.
- The fluorescent lights used in home units contain mercury and must be handled cautiously if they are broken. If this occurs, contact the manufacturer for specific safety instructions on disposal or recycling.

If you are interested in exploring the possibility of a home phototherapy unit, please discuss the option with your doctor prior to making any decisions. The following is a list of companies we are currently aware of that offer home equipment. It is provided for informational purposes only and does not represent a recommendation or endorsement by the Cutaneous Lymphoma Foundation.

Phothera (Daavlin and NatBio Merger)
https://www.phothera.com/

SolRx Systems (United States/Canada)
https://solarcsystems.com/

Ultralite
https://ultralitesystems.com/

UVBioTek
https://uvbiotek.com/

What are the risks and benefits of purchasing a used unit from a private person?

Although home light manufacturers, the Cutaneous Lymphoma Foundation, and your dermatology office cannot promote the purchase of a used machine, this does not preclude you from considering this option if a unit becomes available in a private sale. The unit manufacturer can sometimes help with arrangements to recycle a unit as well. Buying a used phototherapy unit is generally a safe option, but it's important to remember a few things if this is the option you pursue.

- Determine what kind of unit it is (UVA or nb-UVB), how old it is, how old the bulbs are, how much it has been used, and the size/portability of the unit.
- Check with your physician to see if the specifications of this used unit will meet your treatment needs and ensure that your physician will order and monitor the phototherapy treatments in the same way they would if you obtained the unit directly from the manufacturer.
- Your dermatology office will still need to load a set of treatments on the unit at periodic intervals and instruct you on initial time settings and interval increases in time.
- Recognize that there is no longer a valid manufacturer's

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Phototherapy...*continued from pg 8*

guarantee should the unit stop working or otherwise malfunction. You may have more difficulty getting the unit repaired or serviced/calibrated.

- You will have to make your own arrangements for delivery and set-up of the unit.

I hope this information is helpful when considering whether home phototherapy is right for you.

References

Cutaneous Lymphoma Foundation https://www.clfoundation.org/phototherapy-2

Marka, A. & Carter, J. Phototherapy for Cutaneous T-Cell Lymphoma. Dermatologic Clinics, 2020 Jan: (38), 1, pp127-135.

Olsen EA, Hodak E, Anderson T, Carter JB, Henderson M, Cooper K, Lim HW. Guidelines for phototherapy of mycosis fungoides and Sézary syndrome: A consensus statement of the United States Cutaneous Lymphoma Consortium. J Am Acad Dermatol. 2016 Jan;74(1):27-58. doi: 10.1016/j.jaad.2015.09.033. Epub 2015 Nov 4. PMID: 26547257.

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Subscribe to the Foundation's YouTube channel: CutaneousLymphomaFnd

From the Board...*continued from pg 2*

ing space for individuals to share their experiences. Check out our monthly groups and share your wisdom. You never know the impact your story may have on someone!

Strength of Community

Spring is also a time of gathering and enjoying the nicer weather - at least in many parts of the world. We invite you to attend our upcoming programs, created to empower you with the knowledge you need to make the best, informed decisions for you. Whether you are newly diagnosed, a long-term patient pro, care partner, or a volunteer, your participation is essential to ensure the Foundation is serving your needs, continuing to be of service, and contributing to the community. Let us know what you are interested in learning about - we love feedback and suggestions!

As the world dances with the colors of spring, let's support each other and remember our collective resilience and incredible strength to navigate any storms that may come our way. Thank you for being a part of the journey with us—we are stronger together.

David Susan

ANNUAL PATIENT CONFERENCE

Thank you!

It was a pleasure to come together in Philadelphia for this year's annual Patient Conference. The ability to meet face-to-face and connect in person is truly invaluable to our community.

As the highlight of our year, the conference is an opportunity to connect our community with cutaneous lymphoma specialists who share valuable insights on diagnosis, treatment options, and the latest research. This year, we also enjoyed a variety of breakouts on creative ways to add more enjoyment to life, despite the impact of the disease.

We realize that many members of the cutaneous lymphoma community are unable to attend the conference in person. To ensure more people could benefit from this year's conference in real time, all of the clinical presentations were live streamed, including the clinical Q&A and Dr. Steve Daveluy's breakout session on laugh yoga. Curious about what you may have missed? Recordings can be found on the Foundation's YouTube channel:
https://bit.ly/CutaneousLymphomaFnd

If you joined us either in person or via Zoom, thank you for helping to make this year's conference another memorable event.

Frequently Asked Questions

Does successful topical treatment for patches/plaques mean that they clear/go away? If treatment for six months hasn't cleared or reduced patches in size, is a new treatment plan warranted?

Dr. Amrita Goyal-O'Leary: This can be a tricky question because when you have patches and plaques, even if they're treated successfully, you can actually end up with post-inflammatory hyperpigmentation which leaves (something) like a shadow of pigmentation in the area that the patch or plaque was. You may still have areas that look different (compared) to your normal skin, but they may not have active disease. I would want you to show those areas to your dermatologist and ask if they think that there's been clearance, or if there's just residual hyperpigmentation. If the areas are not bothersome to you, then you may be able to just continue as you are. If they continue to be itchy and bothersome, then I would have you discuss that with the dermatologist and see if a different topical treatment might get you better symptomatic relief.

Amrita Goyal-O'Leary, MD
University of Minnesota Medical School
Minneapolis, Minnesota

Questions and responses taken from the recording of our "Answers From the Experts: Q&A - January 2024." For the full-length recording, please visit: https://youtu.be/FD1dx3mdaRs

How does moisturizer help people with MF and how often should we moisturize?

Dr. Ellen Kim: That is a common question. When the skin barrier is affected by dryness, that can cause and trigger more inflammation and result in flares of a variety of inflammatory skin conditions. Eczema gets worse with dry skin, so does psoriasis. Many patients, during the wintertime, can have flares of eczema or psoriasis, and that also applies to mycosis fungoides CTCL. Moisturizing is really, really important.

We recommend definitely doing it at least once a day after a shower while you're still a little damp. Use a cream or an ointment. You may need to do it a second time in a day if you live in a cold, kind of dry environment. I know this is hard. There are some people, and I don't want to generalize, but for some men it's not part of their routine to put topicals on their skin, but once you have the diagnosis of mycosis fungoides, it is very helpful to pay attention to it and moisturize regularly.

Does brentuximab carry long-term side effects?

Dr. Lauren Pinter-Brown: The biggest side effect from brentuximab vedotin is called peripheral neuropathy. It usually manifests as numbness or pain in fingertips and tips of toes, that then, as it goes on, progresses up the hand or foot. That can be reduced by reducing the dose of the drug and sometimes even lengthening the time in between doses. I would say that is the biggest long-term toxicity of that drug.

Ellen Kim, MD
Perelman Center for Advanced Medicine
Philadelphia, Pennsylvania

Lauren Pinter-Brown, MD
Chao Family Comprehensive Cancer Center
Orange, California

Questions and responses taken from the recording of our "Answers From the Experts: Q&A - March 2024." For the full-length recording, please visit: https://youtu.be/TD1s2GQz7NE

For more information visit www.clfoundation.org.

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FORUM

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Cutaneous Lymphoma Foundation
PO Box 969
Warren, MI 48090
Telephone: (248) 644-9014
Email: info@clfoundation.org
www.clfoundation.org

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