



FORUM

USE GENTLE CARE TO HELP SKIN

“I thought I just had dry skin. Then I got more and more patches. The itching is driving me mad. I’ve been using a back scratcher, taking hot showers, and scrubbing real good in the shower with Zest. The itching is so bad, but really worse at night. I can’t keep going on like this!”



Fifty-seven year old Jason was newly diagnosed with mycosis fungoides. What bothers him the most? The itching. The dryness. The cloud of dry skin that flies off whenever he takes off his clothes. His quality of life has taken a nosedive. The reality is that lack of sleep is taking a toll not only on his body, but on his skin too. His stress levels are increasing. He cannot help but scratch. The only time he feels relief is when he is taking a steaming, hot shower or scratching his skin. The problem? Afterwards, the itching gets worse!

So many patients share similar stories. The itching is so intense that it takes over everything. The dryness never ends, no matter how much lotion is used. The thin patches become thick, rough, and calloused, eventually cracking, bleeding and becoming infected. Waking up in the middle of the night because of scratching that results in bleeding into

the bedsheets. Covered in bandaids head to toe to take care of the skin cuts, the cuts can become infected, driving the MF to flare.

How do I get my life back?

Simple, consistent measures can drastically improve itch, the predominant symptom of cutaneous lymphomas (CL). The body’s natural pH is mildly acidic. The pH of water is more basic. The difference in pH means that just plain water on the outside of your body can be dehydrating to your skin. Add in hot water, and you are literally drying out your skin every time you wash your hands. Limiting showers to once a day, every other day, or even weekly can be helpful, depending on your clinical situation. A lot of people are quite fond of hot showers. Tip: If you can write your name on the mirror, your shower is too hot! Overall, adopting a “less is more” attitude focuses on a gentle skin care approach.

Try the following routine:

- Steam up the shower first while massaging a thin layer of organic coconut oil gently into the skin.
- Turn the temperature of the water down to lukewarm and step in.
- Using a gentle, non-soap cleanser such as Cetaphil or Dove soap/unscented body wash to clean the armpits, private area and feet, and then rinse off the rest of the skin using just your hands.
- Avoid traditional scented or harsh soaps which not only strip the body’s natural moisturizing oils, but also deposit irritating chemical fragrances onto the skin’s surface.

The reason for this approach is based on the fact that water is dehydrating. Water plus soap plus a washcloth can be utterly

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2024 Issue 2 - Education & Support Services Edition

Ensure that everyone with cutaneous lymphoma and their care partners are empowered to be involved in their care and live well with their condition.

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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. ❧

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

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FORUM

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Disclaimer

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

The Cutaneous Lymphoma Foundation's patient educational newsletter, Forum, has been made possible in part thanks to the following generous supporters:



FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

Laurel Carlson, Board President; Susan Thornton, CEO

Our 25th celebration in April recognized some of the important people who helped create and develop the CL Foundation into the amazing organization it is today. Founder Judy Jones is, of course, at the top of that list. I first met Judy in the mycosis fungoides listserv, a type of primitive email chat, that she created in 1996. When we first spoke, I think she was surprised to learn that I had been diagnosed with MF thirteen years prior. Her response, that I could be the mycosis fungoides poster child, amused and flattered me, but I think that her underlying message may have been that I could offer hope and encouragement to those who were newly diagnosed. Looking back, I may have provided her with just a little bit of that. I know that for the thirteen years before I found her, I was obsessed with trying to meet another person with my rare disease. I never forgot about that obsession, and in my time on the Board of Directors, promoting ways for patients and care partners to interact with each other has been one of my most important goals.

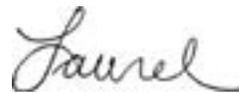
When you share your story with another person, you provide each other with so many different “feels.” For them, you may be offering hope and invaluable advice, and perhaps some answers to their many unanswered questions. And, for you, you might feel a sense of empowerment. When Judy referred to me being a poster child, I now realize that she was identifying my new superpower. My life with MF had been full of fear and insecurity, but she helped me realize that I had

the ability to share my experiences and offer support to others with the disease. Every month in our Patient Networking Groups, and daily in our Community Connection postings, patients and care partners with various experiences utilize their superpowers by sharing and supporting each other.

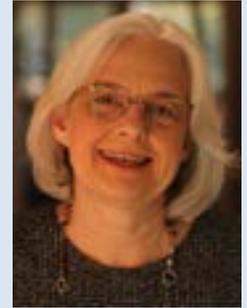
I cannot impress upon every one of you enough, if you feel comfortable sharing your story, doing so may be as beneficial for you as it is for your listeners.

Living with a rare disease is not usually seen as having a superpower, but using it to connect with others could be.

Power to the people, use your power wisely, and may you all live long and prosper!



“The things that make us different, those are our superpowers.”
Lena Waithe



Laurel Carlson



Susan Thornton

Wow - what a spring!

The highlight, of course, was our 25th Anniversary Celebration and annual 2-Day Patient Conference. I am humbled and honored to sit in the leadership chair of the Cutaneous Lymphoma Foundation. Twenty-five years is a very long time for a small, rare disease patient organization to operate sustainably. This is a testament to the power of our community, a small group of

people who have had an enormous impact. As I've said many times, I stand on the shoulders of those visionary individuals - Judy Jones, Judith Shay, Dr. Stuart Lessin, and Michael Young, to name a few. Many others have shaped the CL Foundation as we know it today, contributing their ideas, talents, and skills to our mission. And indeed, the small and mighty team of dedicated staff, who have been with us for many years,

make our work look effortless. It takes a lot of sweat and long hours behind the scenes to make everything work well. Thank you to everyone who could join us in person in Pasadena and made the Celebration so special. You will see some highlights of the weekend events on the following pages.

One of the new projects we launched at the 25th Celebration was the Patient Story Posters. They are not just posters, they are powerful narratives! During the cocktail reception, everyone could wander and read these stories. Each is unique and showcases not only an individual's journey with their cutaneous lymphoma diagnosis, but also the beautiful, real people who happen to be living with this disease. That is truly what the Foundation is all about. It's the people who drive the agenda and the mission, and these stories are a testament to their strength and resilience.

Now, back to making sure the Foundation can thrive and continue its innovative work for the next 25 years. While I will certainly not be at the helm in 25 years, I know the legacy left

From the CEO...continued on page 11

MY JOURNEY WITH CUTANEOUS LYMPHOMA

Shared by Randy Gaw (last name used with permission)

Randy Gaw is a 74-year-old resident of Kanata, Ontario, a western suburb of Canada's Capital city, Ottawa. He has been a friend of the Cutaneous Lymphoma Foundation for about four years, but let's let him tell his story.



It was February 11, 2020, a cold and snowy day in Ottawa, when Randy and his wife Nazira entered the office of his dermatologist to discuss the condition of his fingernails from the office visit a week before.

“Thank you Mr. and Mrs. Gaw for coming in on this miserable day. We have the results of your biopsy that we took of the pimple on your left temple. I wish I had better news, but you have cutaneous T-cell lymphoma.”

“Is that a special kind of pimple?” I asked.

“It's a lot more than that,” he replied. “It is a blood cancer that usually shows up in the skin. It is a very rare disease for which there is no cure. There are a number of subvariants that present differently on the skin. Often they can be benign for many years and only require monitoring and occasionally application of topical steroids or phototherapy. In other cases the variant may be more of a challenge requiring more aggressive intervention or treatments. But let's not get ahead of ourselves. We will assemble a team of experts, do a number of tests and get to know you better and determine the game plan. We will start you on a topical steroid and monitor you to see how you do. We may increase the dosage or change the medication. Patients can live many decades with the disease and die with it, but usually not from it. If you have any questions, I would be more than happy to answer them,” he said.

The blur of the realization that I have cancer had not sunk in and I knew my wife, my daughters, and I all had many questions, but did not know where to start. He gave me a short brochure on types of lymphoma and asked us to come back in several weeks to answer our questions and meet the team of specialists. He also cautioned me not to seek advice from “Dr. Google.”

AND SO THE JOURNEY BEGINS

My wife and I returned home and assembled our daughters. We just sat and cried for a while. **Now what??** Our whole family was rocked with the news, but we knew we would fight this and come out on top. The brochure was very limited in the information on cutaneous lymphoma so, against our doctor's advice, we started a search on the internet. Very soon into our search we came across what appeared to be a very informative website with videos, information and links, beginning with the basics and progressing to more complicated or involved conditions. It was the Cutaneous Lymphoma Foundation website.

We each processed the new elephant in the room in our own way, but it usually involved a daily or more often return to the CL Foundation site to absorb as much as we could to prepare for our meeting with The Team.

We interrupt this article to remind you that my diagnosis was given just at the time when COVID-19 began to raise its ugly head and all the implications that went along with it. Surprise, no in-person Team Meeting with my specialists until further notice. Phone and video calls became the norm. We felt further beaten and isolated, as did most of the world as the pandemic began to set in.

BUT WAIT, THERE'S MORE

I said to myself that there must be some way to speak with others about my condition without in-person meetings. I knew I had seen something somewhere and checked the CL Foundation site first. Under one of the main headings entitled Patient Resources are a number of topics and links including Navigating My Diagnosis, Treatment Centers and Patient Support. There is also a title called Upcoming Events, which includes Answers From the Experts and Networking Groups - Online Meetings. When I read the purpose and requirements of the group meetings, I felt that this was something from which I might benefit.

“Meeting others who are affected by cutaneous lymphoma can be an important part of building a support network. The Online Networking Groups are open to all patients, and family and

friends of patients, regardless of location. Meetings are held on the Zoom platform and registration is required.”

When I began participating in the meetings, they were hosted on the first Tuesday of each month from 7:00 to 9:00 pm Eastern time, but the CL Foundation has since added meetings from 12:00 to 2:00 pm every second Thursday. I traditionally join the first Tuesday Networking Group and feel extremely welcome and comfortable in the Zoom group. The meeting is usually hosted by a CL Foundation Networking Group leader who cautions all participants that we are not doctors, and while we may present our experiences and possibly information, please do not start or stop any treatment before discussing it with your doctor or health care practitioner. The leader welcomes each participant and asks them, if they are comfortable in doing so, to give the other group participants a short outline of who they are, where they live, their diagnosis, and if there is anything in particular they would like to discuss that evening. Many of the participants have lengthy histories and experiences that may be useful to the others including newbies, or those recently diagnosed or new to the Networking Group.

Personally I have had a “long and winding road” in my “Journey” with a few bumps along the way. The regulars are always cordial and welcoming. If a regular has missed several meetings, there is always concern expressed for their well-being, but when they return safely, it is like old home week. While the Zoom meeting originates in the United States, there are regulars from Great Britain, Canada, Australia, with some from Tasmania and the Philippines.



SOME BENEFITS OF PATIENT NETWORKING GROUPS

Aside from providing a place to meet others with similar diagnoses, patient networking groups can provide a sense of community and emotional support for those who may feel lost, alone, or isolated when confronted with such a rare and complex disease. All of us are on our own journey, and everyone’s response to the disease is unique. There may be many similarities, but we are all special and may be able to learn some tips from others. An example could be topical steroids which may work for some but not others. Much discussion has centered on various types of phototherapy and possible side effects. They may also provide tips on skin care and the often present problem of itch.

Patient networking groups may provide a source of information or tips on navigating the many complex health care and insurance plans. While many patients may feel alone or isolated, patient networking groups can provide a collective voice for advocacy to assist in raising attention for this complex disease.

WITH GRATITUDE

Having provided a window onto the CL Foundation Patient Networking Group Zoom meetings and the great support I have personally found from participating in the Group, I must extend my greatest and undying love and thanks to my wife Nazira, and my daughters Jaime and Shannon. I certainly could not have done it without you. ●

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

The CL Foundation's Online Networking Groups are a great way to meet with others in realtime using Zoom.

Learn more at
clfoundation.org/patient-networking-groups

The Cutaneous Lymphoma Community is another place where you can interact via message boards with others facing the same or similar experiences as you.

To learn more, visit
community.clfoundation.org

2-Day Patient Conference Highlights Pasadena, California April 13 -14, 2024



It was wonderful to be together in Pasadena for this year's 2-Day Patient Conference. Being able to meet face-to-face and connect in person is invaluable to this community.

We were excited to be able to livestream most sessions for those who were not able to attend in person. Recordings are available on the Foundation's YouTube channel (<https://bit.ly/2Day2024>).

The Foundation works hard to raise awareness about cutaneous lymphoma and create a supportive environment for patients and their care partners to connect with others who understand what they're going through. We're pleased to report that the conference successfully accomplished this goal, as indicated by the positive feedback we received from participants.



The Foundation was fortunate to have the participation of numerous clinical specialists in the field of cutaneous lymphoma. They shared insights on various subjects, such as the most recent research and treatment options.

This year, we had the chance to showcase two patient panels where patients and their care partners shared their personal stories and strategies for dealing with their disease.



The two-day conference provided an opportunity for participants to obtain a mix of quality of life and clinical knowledge.



Learn...

Connect...

Stories of Help & Hope



"I wasn't able to attend in-person, but I so appreciate the opportunity we are given to attend online--I always learn so much. I especially get so much out of the patient stories--so GREAT! THANK YOU!"

"Really enjoyed connecting with the CL Foundation staff and community, hearing from and meeting some of the researchers and doctors. I plan to connect more with the CL Foundation community."



Expert Clinicians

"Each conference I have attended, I've grown with more knowledge and understanding towards my journey living with MF. Thank you!"

"My positive takeaway is the learnings, networking and the awesome support that comes from being involved."



Jina Chung MD



Michael Khodadoust MD, PhD

Emilia Hodak MD



Pierluigi Porcu MD



Niloufer Khan MD



Kevin Molloy MD



Jasmine Zain MD

Celebrate!

STRATEGIES FOR FINDING CARE FOR YOUR CUTANEOUS LYMPHOMA

A cutaneous lymphoma diagnosis can be challenging. It's not only the fact that you have a lymphoma diagnosis, but it's also the rarity of this condition that can cause significant anxiety. Many people have never even heard of cutaneous lymphoma, let alone have a grasp on its subtleties and complexities. Adding to these concerns is the very important task of trying to figure out which specialty practice physician or physicians to help you on this journey of living with, caring for, and treating your cutaneous lymphoma. It all can be very confusing and overwhelming.

You likely will undergo a thorough workup to determine the stage of your disease, which may include a physical exam, blood work, and possibly imaging tests like a CT scan. This will enable your physician to develop a suitable treatment plan for you. To guide this workup, it's advisable to see a cutaneous lymphoma specialist. The Cutaneous Lymphoma Foundation website provides a list of specialists' locations and contact information that can help you find a treatment team that meets your needs.

Dermatologist Or Hematologist/Oncologist

Dermatologists and hematologists/oncologists are two main types of specialists dedicated to managing and treating cutaneous lymphomas. If your disease is only affecting your skin, it's a good idea to see a dermatologist who specializes in this field to develop your treatment plan. They can provide or recommend skin-directed therapy using creams, gels, radiation and/or phototherapy. However, if your disease is in your blood or lymph nodes, you might want to consider also seeing a hematologist/oncologist in addition to a specializing dermatologist. Your treatment will likely involve both skin-directed therapy and systemic therapy, such as pills, injections, or infusions.

It's worth noting that some hematologists specialize in non-malignant blood conditions (such as anemia), while some oncologists only treat solid tumors and may not regularly treat blood-based malignancies. So, before your visit, it's helpful to ask the physician about the conditions they treat. Similarly, there are dermatologists who may not feel comfortable treating cutaneous lymphoma. In such cases, it's beneficial to contact the clinic beforehand to ensure they can provide appropriate care for you.

Dermatologists and hematologists/oncologists frequently team up to provide care for cutaneous lymphoma patients. You can find multidisciplinary treatment centers on the CL Foundation's website. If you attend a multidisciplinary treatment center, you may see multiple specialists in one visit, such as the dermatologist, oncologist, radiation oncologist, and dermatopathologist. Together, they will develop a treatment plan for you.

If you can't find a specialist in cutaneous lymphoma, it's still a good idea to see a dermatologist or hematologist/oncologist in your area. Talk to them about your specific diagnosis and see if they feel comfortable and have experience treating it. If you can't travel to see a specialist, your local doctor may be able to communicate with a specialist to provide better guidance for your care.

Managing Collaborative Care Relationships

Here are some suggestions that could assist you in receiving optimal care, even from a distance:

- Establish a collaborative relationship with your local healthcare provider who is willing to work with the cutaneous lymphoma specialist identified to assist in your care. In certain remote areas, access to physician providers may be limited. In such instances, mid-level providers like Physician Assistants or Nurse Practitioners can be valuable in collaborating with the cutaneous lymphoma specialist.
- Arrange an initial consultation with the cutaneous lymphoma specialist to establish the diagnosis (if necessary), treatment goals, and management plan. In this approach, the cutaneous lymphoma expert devises the care plan and assesses its outcomes, while the local provider aids in implementing and delivering the plan of care.
- Cultivate a relationship with the personnel at your local provider's office and the cutaneous lymphoma specialist's office so that you have a designated individual at each location who can act as your point of contact for inquiries and serve as a direct liaison to your physicians. Having a known contact person makes it easier and less daunting to ask questions or voice concerns about your situation.
- It may be possible to have interim video visits with the

The Cutaneous Lymphoma Foundation Needs Your Continued Support

We are filled with gratitude and enthusiasm for the amazing community that stands with us. We are truly humbled by donors who have played a crucial role in funding the Cutaneous Lymphoma Foundation.

We've discussed in previous articles some of the different techniques that can be used to make a donation to the CL Foundation. Approximately 30% of our budget comes from gifts from individuals like you, memorial and honorary gifts, donations from retirement accounts, and also gifts that take place at one's passing, such as gifts through wills, trusts, and life insurance.

Honor and memorial gifts are wonderful tributes. Friends and family often want to make a donation to acknowledge someone who has played an important role in their life. By donating to the CL Foundation to help those affected by cutaneous lymphoma, you can provide a lasting impact in someone's honor or memory.

You can leave a future gift to the CL Foundation in your Will or Trust by including either a fixed dollar amount or a percentage of your estate. The CL Foundation can be named as the beneficiary (either in whole or in part) of a life insurance policy.

Qualified Charitable Distributions (QCD) from IRAs are getting a lot of press these days. While there are a number of technical rules, a QCD may provide both you and the CL Foundation with immediate benefits. The potential benefits to you include reducing your taxable income, avoiding being forced into higher tax brackets, preventing phaseouts of other potential tax deductions, and satisfying some or all of your required minimum distribution. Some of the rules governing QCD's include: you must be at least 70 ½ years old at the time of distribution, total gifts cannot exceed \$105,000 per donor per year, and the IRA custodian must distribute the gift directly to the CL Foundation.

You are an integral part of the CL Foundation, and your gift will provide meaningful assistance to help us achieve our mission of eliminating the burden of cutaneous lymphoma by promoting awareness, providing education, advancing patient care, and fostering research. This work is realized thanks in large part to the generosity of our donors, like you!

If you have any questions or would like to discuss this further, you can contact your personal estate planning attorney, contact us by phone at 248-644-9014 or email info@clfoundation.org.

Thank you again for your support – we can't do it without you! ●

specialist. This is one option to continue your care from afar while decreasing the need for more frequent, in-person visits.

- Consider exploring the possibility of participating in clinical trials, as they may assist with expenses related to transportation and accommodations for the trial. You can find information on current clinical trials on the Foundation's website <https://www.clfoundation.org/directory>
- Schedule regular follow-up visits with the cutaneous lymphoma specialist, as agreed upon between you and your physician, to ensure that your management plans and response to treatment are thoroughly assessed.

We hope the information above will help you get the care that best meets your needs on your journey with cutaneous lymphoma. ●



Gentle Skin Care...continued from pg 1

devastating. Think of a steel wool pad scrubbing a pot. That is what is happening to your skin. Microscopic trauma occurs, cracking the skin's barrier, allowing bacteria to enter, and changing the chemical environment to create CL flare ups. Scary situation? Yes!

Try the following tips for lukewarm showers:

- The temperature of the steam will prevent you from feeling uncomfortable.
- Play your favorite song to set a time limit in the shower.
- Gently pat dry with a soft towel. Do not rub!
- Apply medicine first, then a fragrance free moisturizer such as Aquaphor, Vaseline petroleum jelly, CeraVe, Cetaphil or Aveeno cream.
- Avoid lotions which have water as their primary ingredient. They will simply evaporate, resulting in all that work for very little benefit.
- Medicine first, then moisturizer.

Your skin is sensitive and special. Treat it like you would a newborn baby, gently and with care. Avoid fabric softeners, smell remover sprays, fragranced products, and any exfoliating or abrasive agents such as washcloths, loofas or sponges. Limit time in the shower, followed by gently patting dry. Fragrances and perfumes are not recommended. Afterwards, wearing natural, cooling fibers such as cotton can be helpful in minimizing skin irritation.

Why is my itch worse at night while lying in bed?

At night, the rest of the world melts away. The only signal that reaches the brain is the one that is screaming scratch me! It can be so jolting, disturbing a good night's rest, and in turn activating the itch scratch cycle. Swapping the mattress cover to a breathable and cooling version and upgrading bed sheets to cool, cotton ones will increase night time comfort by decreasing sweating. Sweating itself can be a reason to cause increased itching.

Keeping a cool mist humidifier on in the bedroom helps maintain a certain level of moisture, in addition to keeping the ambient temperature at a comfortably cool level, and helps to prevent attacks of itching. Cracking open a window in winter can be helpful. Cool wet compresses can be applied to itchy areas of skin to prevent the itch signal from reaching the brain. Pressing ice packs or frozen bags of peas to a flaring area is helpful in an itch attack. Avoid scratching. It feels good at the moment, but it makes things infinitely worse, like adding fuel to a fire. Antihistamines can be helpful in mitigating itch, and multiple H1 and H2 blockers, such as famotidine, can be used together to effectively calm down and downregulate the itch signal.

What else can I do to decrease itch and turn the dial down on the itch scratch cycle?

Stress management is critical to reducing the body's response to itch and the potential progression of cutaneous lymphoma. Here are some effective methods of stress management with proven benefits to the skin.

- Practicing Yoga (mindful movement)
- Meditation (allowing the mind to be gently focused), deep belly breathing (inhale for 4, hold for 4, release for 8 seconds)
- Forest bathing (being in the presence of nature without distraction)

Is there anything non-medicinal I that I can apply to my skin to decrease the itch?

Natural remedies such as oat paste and Neem powder are natural, potent, topical anti-itch therapies. Grinding oats into a powder, mixing with water and applying directly to the skin or mixing with water and pouring over the body while in the shower are two effective ways of introducing oats' natural anti-itch properties to the skin. Similarly, organic Neem powder can be mixed into a poultice and applied to specific areas as a mask or added to a rinse while in the shower using a mug and bucket.

Turmeric is a natural antioxidant and has antimicrobial properties. It can be eaten in food, drank as a tea or applied to the skin (it will leave a yellow tinge). Coconut oil is a topical antiviral, antibacterial and boosts skin moisture content due to its key component, lauric acid. Traditionally used in bathing and skin care routines in South Asia, it is lauded as most closely mimicking the skin's natural oils.

Will calamine lotion help my itchy spots?

Avoid calamine containing products. It is drying and will dry your skin out further.

I have one persistent dry skin patch that won't heal. How can I keep my medicine and moisturizer from wiping off?

Using Tegaderm clear bandages is an effective method of occlusion, thereby keeping medicine and moisturizer in place.

I have deep fissures and cracks in my feet and my palms. Is there anything I can apply?

Using super glue to seal fissures and cracks can be helpful in holding the skin together while it has a chance to heal from the inside.

Adopting a gentle skin care regimen can have many advan-

tages for maintaining the health of your skin, even while dealing with your diagnosis. Using gentle skin care strategies can help to improve the overall health of your skin and may help prevent disease flares. It can also minimize the symptoms of CL that adversely affect your quality of life. As with any change in your medical or skin care regimen, speak to your health care provider before initiating anything that is a new tool in your toolbox for living well while living with cutaneous lymphoma.

Joya Sahu, MD
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The Cutaneous Lymphoma Foundation**

Subscribe to the Foundation's YouTube channel (CutaneousLymphomaFnd) and follow us on Facebook and LinkedIn.

From the CEO...continued from pg 3

by our beloved founders and early volunteers will continue for as long as the Foundation needs to be of service to this special, unique community of individuals navigating their cutaneous lymphoma journey.

Here's to another fantastic, innovative, and transformational 25 years ahead!

We are deeply grateful for your trust and support. We look forward to having you join us in our quest to serve and support all who are impacted by this rare group of lymphomas. Your presence and contributions are invaluable to us. Thank you for being a part of our family.

Onward we go!

Frequently Asked Questions

What are your thoughts about clinical trials?

In general, we are such strong advocates for considering clinical trials, and I think one of the challenges is across the different types of cancers and disorders we treat in medicine, patients with cutaneous lymphoma are often left behind because there are fewer trials for patients with rarer conditions. I think that really is one area we really need to improve on as a community.

If you are able to seek out opportunities to participate in clinical trials or understand where they might be offered, I think it's really important to consider whether that would be logistically feasible for you to at least get more information about. We know that we have a large toolbox of therapies, whether skin-directed or systemic oral pills or IV, but we know that there's such an unmet need, even despite the presence of existing treatments for us to improve everyone's long-term success rates who live with this condition.

Any advice for newly diagnosed mycosis fungoides?

I would recommend you find your community, and that may be here through the CL Foundation. Just caring for patients in my practice with cutaneous lymphomas, I've come to recognize sometimes how it can feel a little bit isolating because it's an uncommon condition with uncommon treatments, and it's chronic. It's a lifelong process for many people, so finding support in your community and finding good reliable information is really crucial, because if you are newly diagnosed and you jump onto Google, there's a lot of information and, as we all know, especially for conditions that are uncommon and where expertise is less prominent, you can find a lot of misinformation out there. So really connect yourself with trusted sources. You can ask for leads from your dermatologist or hematologist, but I think the Cutaneous Lymphoma Foundation is obviously a wonderful place and a hub to center around as you move forward.

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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>



CUTANEOUS LYMPHOMA FOUNDATION
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TIME SENSITIVE MATERIALS ENCLOSED



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EMPOWERING individuals through education and support.

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