Cutaneous Lymphoma Foundation
25th Anniversary
FORUM

INTERNATIONAL COALITION FOR CUTANEOUS LYMPHOMA UPDATES

In our last International Community Edition of the Forum [www.clfoundation.org/forum], we introduced the International Coalition for Cutaneous Lymphoma (ICCL), an alliance of patient advocacy organizations seeking to improve access to care and treatment globally for people with cutaneous lymphoma.

The Coalition is actively working on its Charter and strategic plan in order to move their goals and objectives forward. Its member organizations want to develop a sense of community amongst themselves, sharing their resources and knowledge in order to put the needs of the people living with cutaneous lymphoma at the forefront of their goals. One goal is to identify, map, and compare the known expert centers across the globe so that it becomes clear where care currently exists and where it is lacking. Pulling information from collected patient stories and from medical professional organizations, like the International Society of Cutaneous Lymphoma (ISCL), are good starting points for collecting this data. Similarly, tracking what treatments are available and where is another goal for helping to identify areas of need.

RAISING AWARENESS

Also fundamental to improving access to care is raising the awareness of the disease in the medical community, both in dermatology and hematology. By leveraging existing relationships with professional societies, dermatology nurses, and pharmaceutical companies, the Coalition is developing strategies for raising awareness amongst clinicians.

The ICCL wants to help increase cutaneous lymphoma research by raising awareness about ongoing CL research and clinical trials, and by also establishing a cutaneous lymphoma Community Advisory Board (CAB) to ensure a strong CL patient voice in research.

The goals of the ICCL are ambitious, but its leaders are passionate about making them a reality. No single organization can meet all the needs of the people living with cutaneous lymphoma worldwide - but by working together to raise awareness, by sharing knowledge and resources, and promoting research, we can make a difference.

2024 Issue 3 - International Community 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.

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.

FORUM

The newsletter of the Cutaneous Lymphoma Foundation

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

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CUTANEOUS LYMPHOMA FOUNDATION

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FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

Laurel Carlson, Board President; Susan Thornton, CEO

Welcome to our annual issue focused on what is happening worldwide regarding cutaneous lymphoma.

As the world continues to get smaller, we learn more about our friends living with cutaneous lymphoma from all over the globe.

Seeing the growth and expansion of our translated materials and basics of cutaneous lymphoma videos is exciting. Reaching individuals with basic information in their language, tailored to their country and health system, is critical to ensuring each person impacted by this disease has what they need to navigate their journey. We are grateful for the generosity of the clinicians who have volunteered their time and talent to help with these translation projects. Connecting the patient community around the globe continues to be a focus. However, there is a lot of ground to cover - literally and figuratively.

To continue finding new ways of reaching patients and clinicians, we are collaborating with the cutaneous lymphoma nurses to bring together this vital group of clinicians to support the daily work nurses do caring for patients and their families. You can read more about the Cutaneous Lymphoma International Nurses Network (CLINN) on the following pages.

Through the CL Foundation's collaborative partnerships, we are able to bring the voice of our community to the table. Your participation in the Lymphoma Coalition's Global Patient Survey (GPS) has been instrumental in making this a reality. Updates about the GPS and the global awareness campaign hosted by the World Skin Health Coalition, #NotJustMySkin, are included in this issue. Your experiences and perspectives are crucial in these efforts, helping us to communicate the challenges you face to clinicians, regulators, and policymakers, and ultimately improve the

From the Board...continued on page 4

Laurel Carlson

Susan Thornton

BOARD OF DIRECTORS NEWS

Ricky Kitchen

The Cutaneous Lymphoma Foundation (CL Foundation) is pleased to introduce a new member to our Board of Directors, Ricky Kitchen.

Ricky has been an active member of the CL Foundation since 2008. He has spoken at a past 2-Day Patient Conference and participated in a webinar in 2022 for young patients and their families.

We are very excited to welcome Ricky to our Board of Directors.

To learn more about Ricky, or our other Board members, visit our website at https://www.clfoundation.org/board-of-directors

MEET THE NEW MEMBER OF OUR TEAM

Liz Accad

Please join us in welcoming Liz Accad to the Cutaneous Lymphoma Foundation team. Liz is serving the Foundation as an Office & Community Assistant. She brings with her experience as a program coordinator at a cultural heritage-based nonprofit and as a legal intern and research analyst at an international law firm.

BUILDING A COMMUNITY IN IRELAND

Left to right: Shane M. - Patient, Michelle Greenwood - Irish Skin Foundation, Carmel Blake - Irish Skin Foundation, David McMahon - Irish Skin Foundation, Kevin Molloy, MD, Susan Thornton - CL Foundation, Martin S. - Patient

In May, we again had the privilege to co-host, with Dr. Kevin Molloy and the Irish Skin Foundation, our second patient program in Dublin, Ireland. This year, attendance more than doubled, and many who attended last year for our first program came back. Those who participated in the first program made sure the new people felt comfortable and part of the community, which was deeply gratifying. Of course, there is still a long way to go to bring the patient community together in Ireland, and ensure therapies and clinical trials are available, but it is great progress.

From the Board...*continued from pg 3*

quality of life for everyone. Your input provides the expert evidence that is required to make change happen. Thank you for your invaluable participation!

It's a big world out there, and with every connection, collaborative effort, and voice, we can make a difference no matter where you live. Progress may take time, and forward motion may seem small, but perseverance makes all the difference.

Thank you for being a part of our community of dedicated champions. Your participation is invaluable, and we want you to know that we recognize and appreciate your efforts. Together, we can achieve anything!

Enjoy the issue!

Laurel Susan

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

The Cutaneous Lymphoma International Nurses Network: An Update

It's been a year since we introduced the Cutaneous Lymphoma International Nurses Network (CLINN) in the 2023 Forum - Issue 3. If you didn't have a chance to read the article, you can access past Forums on the Foundation website https://www.clfoundation.org/forum. The CLINN was formally launched in 2022 with an international survey of interested nurses and allied health professionals to ascertain demographics and educational gaps and needs. These survey results afforded a framework for moving forward to help provide much needed support to nurses who work every day with patients and care partners living with cutaneous lymphoma. The CLINN's mission is to provide a source of education and collaboration for those working with this rare and orphan-designated disease. Through the CLINN, we have a vision of shared best practices among nurses that will result in improved outcomes for patients and care partners.

The CLINN's mission is to provide a source of education and collaboration for those working with this rare and orphan-designated disease.

Recent Happenings

To that end, the international CLINN Steering Committee, consisting of Marianne Tawa (Dana Farber, US), Sue McCann (formerly of University of Pittsburgh, US) , Odette Beulens (Peter MacCallum, Australia), Claire Lusted (Guys & St. Thomas, UK), and Susan Thornton (CL Foundation), has been making progress in several areas. The communication platform for connecting these professionals will be the Cutaneous Lymphoma Nurses Community where members can post messages on a 24/7 basis, ask questions, discuss challenging care issues, link to Foundation information, and find posted educational material in the information repository section. Resources pertinent to nurses and allied health professionals are stored in the Community. A special focus is geared toward providing resources on wound care principles, especially for difficult to treat wounds that can occur in advanced stages of cutaneous lymphoma.

Plans for the Future

For now, there will be two groups for nurses to access in the Community. One will be a general CLINN group, and one will be for extracorporeal photopheresis (ECP) professionals. Both groups are available to all CLINN members, and further development of the educational repository will continue. Other plans include a Nursing/Allied Professionals tab on the main CL Foundation website for medical professionals. Select essential information will be available through this tab, as well as a link to sign up for CLINN membership. Additionally, webinars for CLINN membership are planned for the latter half of 2024 and during 2025.

The CL Foundation is committed to providing continued guidance and essential infrastructure support to the CLINN. We want to support, connect, and empower nurses around the globe who will ultimately bring these shared best practices to the care of both patients and care partners. Please let us know of any cutaneous lymphoma nurses who may be interested in joining the CLINN. We would love to have them join the CLINN community.

LYMPHOMA COALITION GLOBAL PATIENT SURVEY - AN UPDATE

The Cutaneous Lymphoma Foundation continues in our partnership with the Lymphoma Coalition (LC), and we are excited to provide an update on the Global Patient Survey. Briefly, the survey collects data from patients and care part

ners about their experience living with a lymphoma, including cutaneous lymphomas, and its treatment. In an effort to track and highlight the history, trends, and current issues people affected by lymphomas face, the survey must be completed every two years. Because of the number of people affected by cutaneous lymphoma (CL) participating in the survey, a report of the compiled data was created for the disease individually. We are in the early stages of getting the 2024 survey data back, and are already looking for opportunities to publish and/or present this very important information to the clinical, regulatory, and policy communities.

HOW THE DATA IS USED

Until the full analysis of the 2024 survey is completed, data from the 2022 survey* continues to be published abstracts and white papers, as well as presented to the medical community.

The most recent published white paper based on the 2022 survey focuses on gaining a better understanding of how treatment affects cancer-related fatigue in a variety of lymphoma subtypes, including cutaneous lymphoma. The white paper, *Cancer-Related Fatigue and the Additive Effect of Treatment in the Context of Lymphoma: An Analysis of the Lymphoma Coalition's 2022 Global Patient Survey,* was published in the American Association for Cancer Research's journal. [https://bit.ly/ACCRJournal]

According to the data reported in the white paper, 58% of the respondents with cutaneous lymphoma received treatment. Amongst all CL respondents, 34% reported fatigue as both a symptom of disease and a side effect of treatment. The authors estimated that 27% of reported cases of fatigue in CL patients are attributable to treatment. However, fatigue is not an unavoidable consequence of treatment. We encourage patients suffering from fatigue to have discussions with their treating physicians about interventions that can mitigate their symptoms.

AND SO THE JOURNEY BEGINS

These reports, based on patient and care partner reported data and published across multiple publications globally, offer a scientific approach that further validates the experiences of patients - thus translating to raised awareness and ultimately improved care. Thank you again for your participation. Stay tuned to learn more about where and when your experiences are impacting changes across cutaneous lymphomas.

*If you would like more details on the 2022 survey, please see the article titled *LC Global Patient Survey - Gathering Data for Cutaneous Lymphomas in Lymphomas (Hematology)* in the 2023 Forum - Issue 3 via the Foundation website https://www.clfoundation.org/forum.

Stay Up-To-Date With The Cutaneous Lymphoma Foundation

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

MY CUTANEOUS LYMPHOMA JOURNEY

Shared by Ronni B.

THE 'C' WORD THAT WASN'T THE END!

I think I was about 16 when I first noticed the round dark circle on the top of my left arm that didn't seem to go away whenever I had a bath or a wash. I thought that was strange, but I ignored it and just scrubbed a little harder whenever I had a wash, but it never went away.

Over the years, I tried different bath things to try and remove the marks and the increasing dandruff problem with my flaky scalp, as I got more of these spots and dark marks over my arms and legs. My mother noticed and told me to go to the doctor. Of course we went through the whole rigmarole of playing, 'Guess what I've got?' e.g., diagnosis of eczema, psoriasis, vitiligo, and any other skin pigmentation discoloration illness. I kept asking, "Are you sure it's not a skin cancer?" But the family doctor said he didn't think so. Let's try and treat it with this cream or ointment.

I finally started using baby shampoo for my hair and that sorted the dandruff issue out, but nothing seemed to stop my episodes of itching after a bath. I stopped using any bath bombs or scented bath creams and stuck with the old Avon Skin So Soft Bath Oil and Body Sprays. For my face, I started using unperfumed/unscented face washes, as I realized that anything too scented would have my eyes streaming and my face coming out in spots … it was years of trial and error finding things that didn't irritate my skin.

FINALLY, A DIAGNOSIS

"More than 25 years later, in 2005, I finally got a referral from my local doctor where I lived in Staffordshire, England, to one of the local hospitals for a second opinion. The dermatology consultant was baffled, but as it was a teacher training hospital, she asked if I would give permission for her to get a few doctors in to have a look at my skin. I thought she meant one or two other doctors would be in attendance, but there were 12 doctors and trainees in the room the day I was to be examined. They were very excited to see my skin and had me turn around so they could get a good look at the various patterns all over my body, and picked out a few areas of light and dark skin to have biopsies from.

About a week later, the consultant called me in to see her to inform me that they had finally gotten a diagnosis for me of mycosis fungoides from my DNA, which was a deficiency of the white blood cells which affects the skin … but they didn't know how to treat it. She gave me a piece of paper with a website address to get in touch with other sufferers who may be able to support and advise! So good luck and goodbye!

I was gobsmacked, shocked and scared, but joining that group was one of the best things I ever did and almost from the first week I was advised by someone who was supporting her mother to ask my doctor to refer me to another hospital in London.

I was referred to a consultant who examined me and arranged for me to start my first PUVA treatment in my local hospital in Staffordshire.

For the longest time when I was first diagnosed, I thought I was going to die straight away or in a few years, so I started to put my life in order and asked my girlfriend, now my wife, to marry me and made sure all my pensions, etc. were in order for her if anything happened to me.

NAVIGATING MY DISEASE

Nineteen years later, I'm turning 60 next year, I am still going to the dermatology department at the hospital in London annually, which has now moved into the local cancer centre nearby, for check ups and treatment plans which are sent over to my local hospital.

It hasn't been an easy journey learning to live with my skin flare ups over the years prior to treatment, and then managing the daily uses of creams and ointments, as well as the PUVA treatments which my skin usually responds well to.

Unfortunately, after the end of the first 3 months of PUVA, I started having trouble with my knees, and not long after this I was diagnosed with arthritis of the knees, which I have always said was a side effect, and alopecia, but all the hospital consultants say there is no evidence that these are linked.

I am currently having all body flare ups whilst waiting for another course of PUVA, so I'll contact my local hospital to hurry this along.

Patient Story...continued on page 10

#NOTJUSTMYSKIN: GLOBAL WORK TO IMPROVE ACCESS TO CARE, TREATMENT AND RECOGNITION OF SKIN HEALTH'S ACTUAL IMPACT

Skin diseases and conditions are the world's third most prevalent cause of illness and are in the top 10 causes of disability, and yet they are often misperceived as cosmetic or minor ailments.[1]

The quote above is from the World Skin Health Coalition (WSHC), the founders of the internationally focused movement #NotJustMySkin Campaign. The WSHC is a patient-led, multi-stakeholder organization with a shared mission and vision "to elevate the understanding and treatment of dermatological diseases and conditions. We are committed to raising awareness, improving policy prioritization, and advocating for enhanced access to diagnosis, care, and treatment for the over 2 billion people living with diverse dermatological conditions worldwide."[1] The Cutaneous Lymphoma Foundation is a member organization of the Coalition, along with 32 other partner organizations.

The Coalition was formally recognized and launched at the 75th World Health Assembly in 2022. It's important to note that the World Health Assembly functions as the decision-making body of the World Health Organization (WHO) and is responsible for moving health agendas forward. The Assembly is attended by delegations from 194 WHO Member States and focuses on a specific health agenda prepared by its Executive Board[2].

The World Skin Health Coalition seeks to put skin diseases front and center on the global stage. Data from 2019 shows that globally there were 4.86 billion new cases of skin and subcutaneous diseases reported. These statistics make it clear why skin conditions are amongst the most common reasons help is sought from a healthcare provider.[1] These issues drive the WSHC to raise awareness of the burden of skin disease and change the perception of what having a skin disease truly means. For those living with cutaneous lymphoma, the CL Foundation, as a member organization, is your voice. In alignment with its goal of global patient advocacy to improve the lives of those living with skin diseases, the WSHC launched its 2024 international campaign: **#NotJustMySkin**. Some of you may have participated in this campaign. If so, you are part of the impact report newly released by the campaign. Here are the highlights[1]:

- The campaign message reached 5,119,476 people located within 6 World Health Organization (WHO) regions.
- 2,778,199 people interacted with the campaign.
- Campaign materials that included data and patient stories were viewed 17,804,730 times.
- Over 6,800 people in 130 countries signed a letter requesting action amongst health policy leaders.
- Major findings confirmed the following:
  - The right care and treatment of skin conditions requires a timely diagnosis.
  - Many can't afford recommended treatments, or they can't access them.
  - Poor mental health outcomes are associated with people dealing with skin conditions.

How will the #NotJustMySkin Campaign impact you?

The answer to that question lies in the call to action for policy makers with the following asks excerpted from the World Health Skin Coalition's open impact letter signed by 6,800 people:

1. **Public Recognition:** We urge a public declaration by policy makers through a World Health Assembly reso-

#NOTJUSTMYSKIN...continued on page 10

Help the Cutaneous Lymphoma Foundation Support You

The Cutaneous Lymphoma Foundation provides valuable resources, support, and education for patients, care partners, and healthcare professionals. It serves as a valuable source of information for those navigating a complex and often challenging disease.

The Foundation relies heavily on the generosity of donors and volunteers to continue its important work. Your continued support is essential in ensuring that the Foundation can fulfill its mission.

We are the voice of the cutaneous lymphoma patient community that:

- strives to empower people with cutaneous lymphomas and their care partners through impactful education and support services.
- influences decisions that can transform lives.
- promotes research focused on addressing the most critical unmet needs.

You can help improve the lives of individuals with cutaneous lymphoma through financial contributions or volunteering your time and expertise. Every bit makes a difference in helping those affected by this rare form of cancer.

A few options on how you can financially support the Foundation:

- Retirement Accounts - You can designate the Cutaneous Lymphoma Foundation as a partial or full beneficiary of your retirement account, such as an IRA or 401(k), allowing the Foundation, as a charity, to receive all of the funds income tax-free upon your passing.*
- Life Insurance Beneficiary - The Foundation can be named as a beneficiary of a life insurance policy, either alone or alongside family members, and can also be named as a contingent beneficiary.*
- Account Beneficiary - Many states allow people to set up beneficiary designations for bank or brokerage accounts by creating a “POD” (payable on death) or “TOD” (transfer on death) account.

**The beneficiary designation on both retirement accounts and life insurance policies can be updated/changed at any time by completing a simple form with the retirement or insurance company.*

If you have any questions or would like to discuss this further, please contact Holly Priebe at the Cutaneous Lymphoma Foundation (holly@clfoundation.org) and your personal estate planning attorney.

#NotJustMySkin...*continued from pg 8*

lution acknowledging the significant impact and burden of skin conditions on individuals' lives, thereby placing it as a priority on the global and national health agendas.

2. **Strategic Action Plan:** We seek a comprehensive, transparent strategy to address the burden of skin diseases within healthcare systems. Informed by the dermatology community (including doctors, patients, and researchers), this plan would detail tangible steps toward increasing funding for research on prevention, which is also critical to reducing costs, improving diagnosis and treatment of skin diseases and strengthening the health workforce worldwide by providing more training to front line healtcare workers ensuring universal health coverage.

3. **Collaboration with Experts:** We recommend meeting and involving specialized groups, like the World Skin-Health Coalition and/or national societies that represent skin patients and dermatologists in your country, in discussions to ensure that policies and healthcare solutions are informed by a wealth of expertise and the lived experiences of patients.

The World Skin Health Coalition seeks to put skin diseases front and center on the global stage

Next steps to keep the project moving forward

In order to present the resolution as outlined above, the WSHC will make an application to be placed on the agenda at the next World Health Assembly gathering, slated for the spring of 2025 in Geneva, Switzerland. If the application is accepted to add to the 2025 agenda, we hope to have good news to report about it this time next year! We will keep you posted.

References

1 Impact Report. (2024) https://skinhealthcoalition.org/wp-content/uploads/2024/05/NotJustMySkin-_ImpactReport.pdf

2 World Health Assembly. (2024) https://www.who.int/about governance/world-health-assembly

Patient Story...*continued from pg 7*

Finally, as I'm a night owl, jumping on the laptop at midnight during lockdown, I found the monthly Online Networking

Group which meets the 1st Tuesday of the month. It has been a great source of comfort and support for my mental health well-being. I can't tell you how great it is to speak to people who know what I'm going through, even though we're miles apart, and I've found out so much information on treatments, food, etc., and being able to share my experiences and knowledge with any newbies too.

Thank you for giving me the opportunity to share this with you all.

Ronni B.

Frequently Asked Questions

How should the skin be cared for after each phototherapy treatment within the African American population? What products are best?

Dr. Goyal-O'Leary: This is a great question and it's an answer that's applicable to pretty much everybody, especially anybody with ongoing dermatologic conditions. We want you to focus on gentle skin care after your phototherapy sessions and in between them. As part of phototherapy, there is always a risk of burning. You always can have some skin irritation, so you should focus on taking lukewarm showers. You do not have to shower every day. Use gentle soaps like Dove, sensitive skin type things. Moisturize when you get out of the shower. I do recommend a cream formulation; it is a little more moisturizing than just a lotion. Ointments are also great. That is kind of the basics of gentle skin care. If you do sustain a burn during a phototherapy session, I would encourage you to talk to the dermatologist that's guiding your treatment and see if a low-potency or mid-potency topical steroid might be helpful, in their opinion. Other than that, just over-the-counter products like CeraVe, Vanicream, Aquaphor, anything you can get at a general drugstore, is what I would recommend.

What is the doctor looking for when doing a PET scan?

Dr. Mou: We often think about cutaneous lymphomas as being skin-related diseases, and that's true, that's the focal point of how we evaluate people. We also know that though uncommon, depending on the extent or the characteristics of the cutaneous lymphoma, the lymphoma can sometimes involve areas outside the skin. The main compartments we think about are internally, so commonly lymph nodes of the body or internal organs. The other compartment we think about is the blood, and for the blood we can obviously look into this via blood work and blood tests.

A scan, whether a CT scan or a PET CT scan, is an effective way to understand whether there are any concerning appearing lymph nodes or areas of organs that we can see that might raise concern for additional testing or even biopsies that could be performed and considered, if it's thought that the lymphoma is involving those areas. The decision to do a scan is also individualized because we understand that for people with lesser amounts of disease or thin plaques or patches, sometimes the chances of finding something internally are so low that we may be able to defer that study. The decision is ultimately a shared one between you as the patient and your doctor team.

Should we consider getting second opinions?

Dr. Goyal-O'Leary: I'm a strong believer that second opinions are very useful and informative. I think it goes along with the theme that in diseases like cutaneous lymphomas, which are uncommon, advocating for oneself is so key. This is something that often goes unrecognized for a long time, and even when recognized because they are rare diseases, they can be very hard to understand what the perfect or correct treatment is in any given situation

If you meet your healthcare providers and believe that their plan of care makes sense and you agree with it, then that's the most important thing, and you could comfortably proceed with that plan of care; but, if there's any part of you that says either I want to hear another thought process or I would just like to get more information, I think you should advocate for yourself and not be shy about requesting that second opinion.

I would hope that any provider that you meet and you raise this question would be willing to entertain that and actually encourage it. It's not about following the directions of a specific person, it's about understanding what's best for the patient, no matter who they get that information from and how many opinions it takes.

Amrita Goyal-O'Leary, MD
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University of Iowa Hospitals and Clinics
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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

JOIN THE 2024 CL CHALLENGE

Sunday, September 15, 2024
World Lymphoma Awareness Day

WHAT Challenge yourself and others to #StepOutOfYourComfortSpot.

WHY To spread awareness about cutaneous lymphoma and help people outside the CL Community understand and experience uncomfortableness with their appearance, which is only a small part of what someone with cutaneous lymphoma has to experience daily.

HOW Wear an #OOTD (outfit of the day) that you do not feel comfortable in – something physically uncomfortable, the opposite of your style, something silly. Then take a picture or video, use #CLChallenge, tag us on Instagram @CL.Foundation, and challenge 3 friends or family to do the same! Finally, donate to support the mission to eliminate the burdens of people affected by cutaneous lymphomas.

- **Donate Online:** https://givebutter.com/CLChallenge
- **By Phone:** (248) 644-9014, Ext 100
- **By Mail:** PO Box 969, Warren, MI 48090
  (a remittance envelope has been enclosed for your convenience)