



# FORUM

## ARTIFICIAL INTELLIGENCE: WHAT IT MAY MEAN FOR CUTANEOUS LYMPHOMA

Artificial intelligence, or AI, is not a new technology; however, its presence in our daily lives seems to have expanded significantly in the last few years. From digital voice assistants to personalized shopping recommendations to ChatGPT, many of us are already familiar with, and using, artificial intelligence. AI also has the potential to play an important role in healthcare.

AI and healthcare has been a topic at many of the medical and rare disease meetings the Foundation has attended in the last year. An entire session at the National Organization for Rare Disorders (NORD) Breakthrough Summit in 2023 was dedicated to how artificial intelligence may advance diagnosis and treatments for the rare disease community.

Chief Technology Officer Taha Kass-Hout (GE Healthcare), a panelist in the AI session, stated, “When we talk about AI today, it is a different type of AI...It can really churn through a lot of unstructured data that's being collected over time, which is really very relevant to healthcare data.” (NORD, 2023. 00:05:40)

Fellow panelist Kimberly Moran, PhD, Head of US Rare Diseases at UCB, added that the more different types and sources of data made available to AI platforms, like electronic health records (EHR), insurance claims data, lab data, and genetic information imaging, the more possible outcomes. Given the power of the algorithms, beneficial information can be found for even those rare diseases that impact only a very small group of people. (NORD, 2023. 00:17:05)

What might all of this mean for cutaneous lymphoma? We reached out to Dr. Jasmine Zain (City of Hope Medical Center) and Dr. Efrat Luttwak (Memorial Sloan Kettering) to share their perspectives on the use of artificial intelligence and cutaneous lymphoma.

### Currently, where and how do you see artificial intelligence playing a role in cutaneous lymphoma? What might its role be in the future?

**Dr. Zain:** Cutaneous lymphomas (CL) are a group of rare and heterogenous diseases that have a varied clinical presentation. They can pose a diagnostic challenge, especially in the early stages, since there is overlap with benign dermatosis like psoriasis. This can lead to considerable delay in diagnosis and treatment and may require the expertise of a specialist to confirm the diagnosis.

Artificial intelligence, machine learning and deep learning are tools that can be used to overcome some of these challenges. Using these tools, computers can process large amounts of data in a short period of time. The data is inputted based on algorithms inspired by the human brain and its neural networks. Each “network” is composed of units called nodes (processing units) that are connected to each other like neurons in the human brain and can transmit information to each other. There is an input node, hidden node, and an output node.

Deep learning models can use the data to recognize patterns in pictures, text, and sound. It can then give insights and predic-

*Artificial Intelligence...continued on page 10*

### 2024 Issue 1 - Research Edition

*Advance research and patient care focused on tackling the most important unmet needs of people with cutaneous lymphoma*

From the President and the Chief Executive Officer .....	3	Update on the GRIDD Initiative .....	7
My Cutaneous Lymphoma Journey .....	4	Lymphoma Coalition Abstract on Fatigue .....	7
Cutaneous Lymphoma Research Abstracts .....	5	IDEOM: Cutaneous Lymphoma Project .....	12
2-Day Conference & Anniversary Celebration.....	6	Frequently Asked Questions .....	14

## 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.*

### BOARD OF DIRECTORS

#### OFFICERS

Laurel Carlson	President
David Elefant	Vice President
Byron Vielehr	Treasurer
Marianne Tawa, RN, MSN, ANP	Secretary

#### DIRECTORS

Steven Horwitz, MD	Director
Youn Kim, MD	Director
Richard Tolsma	Director
Susan Thornton	Chief Executive Officer

#### RESEARCH ADVISORY COUNCIL

Christine Eischen, PhD (Co-Chair)	Thomas Jefferson University
Pierluigi Porcu, MD (Co-Chair)	Thomas Jefferson University
Jaehyuk Choi, MD, PhD	Northwestern University
Alejandro Gru, MD	University of Virginia
Bradley Haverkos, MD, MPH	University of Colorado
Michael Khodadoust, MD, PhD	Stanford University
Anjali Mishra, PhD	Sidney Kimmel Cancer Center
Alison Moskowitz, MD	Memorial Sloan Kettering Cancer Center

## FORUM

The newsletter of the Cutaneous Lymphoma Foundation  
ALL RIGHTS RESERVED

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

Forum is published by the  
Cutaneous Lymphoma Foundation.  
Editor: Autumn Lintz Loffreda  
Layout & Design: Deb Van Zegeren

#### 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:

#### MEDICAL ADVISORY COUNCIL

Michi Shinohara, MD (Chair)	University of Washington
Wei Ai, MD	University of California San Francisco
Kim Bohjanan, MD	University of Minnesota
Francine Foss, MD	Yale University
Richard Hoppe, MD	Stanford Cancer Center
Erick Lansigan, MD	Dartmouth-Hitchcock Medical Center
Cecilia Larocca, MD	Dana-Farber/Brigham and Women's Cancer Center
Leora Lowenthal, LICSW, OSW-C, MPA	Beth Israel Deaconess Medical Center
Sue McCann, MSN, RN, DNC	University of Pittsburgh
Amy Musiek, MD	Washington University School of Medicine
Steve Rosen, MD, FACP	City of Hope
Debjani Sahni, MD	Boston University
Jasmine Zain, MD	City of Hope

#### MEDICAL ADVISORY COUNCIL EMERITUS ADVISORS

Madeleine Duvic, MD	University of Texas MD Anderson
Lars French, MD	University Hospital Zurich
Ellen Kim, MD	University of Pennsylvania
Robert Knobler, MD	Medical University of Vienna
Liliane LaRoche, MD	Hospital Avicenna
David Ramsay, MD	New York University School of Medicine
Alain Rook, MD	University of Pennsylvania
Martin Weinstock, MD, PhD	Brown University
Sean Whittaker, MRCP	Guy's and St. Thomas' Hospital

#### STAFF

Holly Priebe	Chief Operating and Financial Officer
Autumn Loffreda	Education Manager
Sue McCann, MSN, RN, DNC	Services Manager
Deb Van Zegeren	Special Projects Manager
Susette Arnot	Programs and Services Assistant
Bandna Virdi	Office Assistant



# FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

Laurel Carlson, Board President; Susan Thornton, CEO

## Navigating the Future: Insights from Our Research Edition

*"Hope is the heartbeat of research, promising a brighter future  
for everyone impacted by cutaneous lymphoma."*

*Susan Thornton*

I deeply believe those words, and am delighted to share our latest Forum highlighting cutaneous lymphoma research. This edition is particularly close to my heart as both the CEO of the Foundation and a patient living with mycosis fungoides for 30+ years. In the following pages, you will read more about the early stages of utilizing AI in cutaneous lymphoma, the significance of capturing patient experience data, and a beautiful, inspiring patient story.

### Artificial Intelligence (AI) in Cutaneous Lymphoma Research

AI promises to revolutionize how we approach diagnosis and personalized treatment plans. Drs. Jasmine Zane and Efrat Luttwak provide their insights into where this new technology is being used in cutaneous lymphoma and how it might impact diagnosis and treatment in the future. While still in very early stages, this is a critical step towards improving patient outcomes and ensuring that each person receives the proper treatment at the right time. A whole new world awaits!

### Patient Experience Data: A Vital Perspective

Understanding the patient journey is part of our mission to improve the lives of those affected by cutaneous lymphoma. That's why we collaborate with other patient organizations and their initiatives, such as the Lymphoma Coalition's Global Patient Survey and the International Alliance of Dermatology Patient Organizations' GRIDD study, and encourage all of you to share your experience. These efforts provide valuable insights into your challenges and offer guidance for developing patient-centered approaches to care. Your experiences matter. By contributing to these surveys, you are shaping the future of cutaneous lymphoma care. Make YOUR voice heard!

### Patient Story: A Journey with Sézary Syndrome

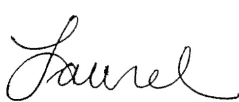
In this edition, we have the privilege of sharing a remarkable patient story by Lannie. I had the honor of meeting Lannie in person a few years ago. I was deeply inspired by her courage, resilience, and fortitude in the face of her journey with Sézary syndrome. You will be inspired too!

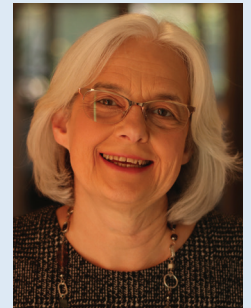
### Looking Ahead

As we celebrate the progress made in cutaneous lymphoma research, we remain committed to advancing understanding, treatment, and support for everyone affected by this condition. Together, we are shaping the future of cutaneous lymphoma care and creating a supportive community that uplifts and empowers each individual impacted.

Thank you for being a part of our journey. Your resilience and collaboration drive our commitment to making a meaningful difference in the lives of those affected by cutaneous lymphoma.

Wishing you health and hope,





Laurel Carlson



Susan Thornton

**P.S. Hope to see everyone at our upcoming 2-Day Patient Conference and 25th Anniversary Celebration in Pasadena, California April 13-14. Let's celebrate how far we have come and look ahead to where we are going in the next 25+ years!**

# MY CUTANEOUS LYMPHOMA JOURNEY

Shared by Lanni

In January 2013, I started the biggest fight of my life.

Nine years later, here I am—a wife to a wonderful husband, a mother of two, a grandmother, and still working as a practical nurse two days a week at a medical center, making every moment a special one.



It took a while to realize that it was up to the doctors to work on saving my life, but it was up to me to live it.

Before my cutaneous T-cell lymphoma (CTCL) diagnosis, my life was a busy one: I worked various full-time jobs for a hospital system, and more recently, with a clinic close to my hometown in Ohio. Aside from my work, I enjoyed spending time with my family and quality time with close neighborhood friends. To escape the cold Ohio winters, we became fond of going on cruises every year.

## Mystery Rash

It was in May 2011 when I noticed a red rash on my face as I got ready for work. My primary care doctor worked in the same building as I did, so I took advantage of the very convenient resource I had. She thought it was odd; maybe a sensitivity reaction to something I ate, new makeup I tried, or detergent. We went through a whole shopping list of potential suspects. Seemingly unbothered, she advised me to try over-the-counter medications and ointments, but nothing helped. The rash hung out on my face for a while, but over a two-month period, it gradually worsened and spread to my entire body. Nothing seemed to help, so my PCP became concerned and referred me to a dermatologist who also thought the growing rash was unusual. He ordered multiple biopsies that were inconclusive, and he prescribed steroids and light therapy to treat my then-unknown condition. Nothing seemed to help, and this had gone on for over a year.

In September 2012, I had my annual screening mammogram, and it showed enlarged lymph nodes in my armpits on both sides of my body. At that point, my dermatologist suspected cutaneous T-cell lymphoma—or CTCL—and immediately referred me to an oncologist. Following extensive and quite exhausting testing, my doctor entered the room, and his face told me everything.

He said, “This is a difficult conversation to have.” That was it. My CTCL diagnosis was confirmed, and I had an extremely rare form called Sézary syndrome.

I was first prescribed an oral chemo drug, interferon injections, and photopheresis treatments. Despite treatment, my LDH—a marker of cell and tissue damage in the body—was continuing to escalate, and my symptoms worsened. I had fissures on my feet. I had lost most of my hair and was extremely cold all the time. I couldn’t get away from those dang Ohio winters even if I tried! On top of that, my skin shed constantly, and I was embarrassed by my appearance.

## Promising Clinical Trial

By this time, I was referred to a doctor at a university hospital who was in the process of initiating a clinical trial of a new medicine for the treatment of mycosis fungoides and Sézary syndrome.

My doctor and I discussed the common side effects of treatment before I began the trial, including rash, tiredness, diarrhea, muscle and bone pain, and upper respiratory tract infection. I was told that I’d receive treatment once a week for the first 5 weeks and then every 2 weeks thereafter.

After I had my first treatment, later that evening I felt like I had been hit by a truck! I had numerous symptoms, all of which were discussed with my doctor. Due to this reaction, the pace of the next treatment was slowed to over two hours, and I was premedicated with over-the-counter medications to minimize any reaction. However, this is just my experience, others may be different.

It was around the time of my fourth treatment that I noticed my skin start to clear. My skin began to improve and eventually cleared completely.

The worst part of the trial was the monthly photo session to document the changes in my skin. I joked with my doctor that I had better not see ANY of these pictures on Facebook! But on a serious note, when I watched the video they prepared from the photos, it was amazing to see how my treatment had

## CATALYST RESEARCH GRANT UPDATE

improved my overall condition over time. My skin returned to normal on most of my body, and there was no longer any evidence of Sézary cells in my blood tests.

### Gaining Perspective

As I look back on when I first learned that I had cancer, I now realize how devastated I was at the time. I didn't want to accept that I would not see my children live their lives as adults, be together with my husband, or watch our grandchildren grow up. It took a while to realize that it was up to the doctors to work on saving my life, but it was up to me to live it. I vowed to exercise and keep healthy habits—and I've kept that promise.


We are so fortunate to live in a time when the medical field is researching and discovering new treatments and showing endless possibilities for the future of medicine. I learn something new about myself every day, and most of the time, it's through failure. But that's how we grow the most, right?

Funny enough, I failed at retirement. Yes, you heard me right...retirement! I retired in June 2021, and not even six weeks later, I called my boss at a local Ohio clinic to say, "I'm bored. Where do you need help?" So, now I work two days a week at the clinic to help with my boredom, and I've learned that I hate not learning more every day.

One last thought. Just a piece of advice that I give to my grandchildren that I think would benefit patients who are in a personal battle themselves:

You need to do three things every day:

- Laugh, even if it is at yourself
- Learn something new, and
- Live every moment like it's your last!

What more can you ask out of life? 

Would you like to share your story with others? Please consider writing and posting it in our online CL Community.

The Cutaneous Lymphoma Community is a place where you, as a person affected by cutaneous lymphoma, can interact online with others facing the same or similar experiences.

To learn more, visit  
[community.clfoundation.org](https://community.clfoundation.org)

Assia Angelova, PhD, 2021 Catalyst Research Grant recipient, has had a paper published in the MDPI scientific journal *Pathogens*, based on her CL Foundation supported research.


Below is a brief summary of the abstract content. The complete abstract is available in the Research section under the Learn tab in the CL Community as a pdf to read in full. See the call out box at the lower corner on the left to learn how you can join and access information like Dr. Angelova's abstract.

**Abstract Title:** The Complex Role of Infectious Agents in Human Cutaneous T-Cell Lymphoma Pathogenesis: From Candidate Etiological Factors to Potential Therapeutics

**Abstract Summary:** Cutaneous T-cell lymphoma (CTCL) is a devastating, potentially fatal T-lymphocyte malignancy affecting the skin. Despite all efforts, the etiology of this disease remains unknown. Infectious agents have long been suspected as factors or co-factors in CTCL pathogenesis. This review deals with the panel of bacterial and viral pathogens that have been investigated so far in an attempt to establish a potential link between infection/carriage and CTCL development. A special focus is given to a recently discovered human protoparvovirus, namely the cutavirus (CutaV), which has emerged as a plausible CTCL etiological agent. Available evidence in support of this hypothesis as well as alternative interpretations and uncertainties raised by some conflicting data are discussed. The complexity and multifacetedness of the Parvoviridae family of viruses are illustrated by presenting another protoparvovirus, the rat H-1 parvovirus (H-1PV). H-1PV belongs to the same genus as the CutaV but carries considerable potential for therapeutic applications in cutaneous lymphoma.

## QUALITY OF LIFE ABSTRACT POSTER PRESENTED AT ASH

The abstract poster "Health-Related Quality of Life (HRQL) in cutaneous T-cell lymphoma: A post hoc analysis examining disease burden and patient characteristics from the phase 3 MAVORIC trial in mycosis fungicides and Sézary syndrome" was accepted to be included in the 2023 American Society of Hematology (ASH) Annual Meeting's poster session.

As one of its authors representing the patient perspective, Susan Thornton was invited to present the abstract poster and share the high-level outcomes of the study with clinicians during the poster session. A summary of the abstract and a link to the full version, is available at [www.clfoundation.org/MAVORIC\\_Abtract](https://www.clfoundation.org/MAVORIC_Abtract) 

*Learn...Connect...*



*Celebrate!*

## 25th Anniversary Celebration

**Pasadena, California  
April 13, 2024**

Have you heard? The Cutaneous Lymphoma Foundation is celebrating 25 years of serving the cutaneous lymphoma community.

The celebratory event will include a reception, dinner, entertainment and time to honor those who have contributed to the Foundation's mission. We hope to see you there!

## 2-Day Patient Conference (Hybrid)

**Pasadena, California  
April 13 -14, 2024**

Plan now to attend our annual 2-Day Patient Conference. The conference remains open and free to anyone affected by cutaneous lymphoma.

The Conference offers:

- Clinical presentations and Q&A's
- Research updates
- Connecting with others on a similar journey
- and more...

The conference is offered both in person and online, but registration is required.

We hope you will join us for this opportunity to learn... connect...and celebrate!



Learn more about both events at [clfoundation.org/pasadena2024](https://clfoundation.org/pasadena2024)



## UPDATE ON THE GRIDD INITIATIVE

An innovative approach to collecting data that could show the impact of the patient's experience was needed to drive change for patients living with dermatological diseases and conditions (including albinism and burns).


Where and how do you begin to do this? To help answer this question, the Global Research on the Impact of Dermatological Diseases (GRIDD) project was launched along with the launch of the International Alliance of Dermatology Patient Organizations (IADPO, commonly referred to as Global Skin).

The data collected focused on the impacts of living with skin conditions. With this data, the patient experience can be brought to the clinical community and beyond to help move patient care forward by stimulating research, optimizing healthcare spending, and influencing future policies for improved patient outcomes.

Responses from over 2,000 patients across 61 countries and over 90 dermatologic conditions were gathered.

This data will enhance the credibility of the dermatology community's advocacy efforts to promote patient-centric approaches in decision-making circles and eventually improve the lives of individuals living with the stigma, mental health impacts, and burdensome aspects of skin conditions worldwide.

Sharing patient experiences through the study will help to show clinicians, researchers, and policymakers the true impact of living with dermatological conditions. The accumulated data supports calls for access to care, improved treatment options, and increased affordability of medicines for dermatology patients on a global scale. Your input makes a difference in the lives of people with skin conditions worldwide.

The Cutaneous Lymphoma Foundation has the honor and privilege of being part of the initial inception of this project. We are excited about where the data will lead us in the future to serve our patient community across the globe. Learn more about the GRIDD project on the Global Skin website: <https://globalskin.org/research> 

## LYMPHOMA COALITION ABSTRACT ON FATIGUE

Cancer-related fatigue (CRF) is a widespread issue that has a great impact on patients. The severity of CRF varies by lymphoma subtype, stage, and treatment received. Little information is known about patients' experience with fatigue based on the rate of disease progression. The cancer-related fatigue study aims to offer a unique insight into the fatigue experience of patients with indolent lymphomas compared to patients with aggressive lymphomas, using the Lymphoma Coalition 2022 Global Patient Survey on Lymphomas and CLL.


The results show that fatigue is the leading physical issue affecting the well-being of patients with indolent and aggressive lymphomas. However, some differences exist in how patients may experience fatigue in terms of severity and duration. These differences may be because aggressive and indolent lymphomas often differ in symptom presentation, severity, treatment type or whether patients communicate their fatigue with their doctor.

This abstract and poster (see page 8-9) was presented at the American Society of Hematology (ASH) annual conference in 2022 .

### Volunteers needed

We need you to help advance research - earlier diagnosis, better treatment options, and access to anyone who needs it. The most powerful voice in advancing research is that of the patients and care partners.

The Lymphoma Coalition's Global Patient Survey helps achieve this by using the knowledge gained through the survey to represent the voices and values of patients and care partners.

Will you give 20 minutes of your time to help? Survey available at: <https://bit.ly/LCGPS2024> 



# Patient Reported Experience with Fatigue, a Cr... Examining Indolent and Aggressive Lymphoma

C.D. Bates<sup>1</sup>, O.A. Bamigbola<sup>1</sup>, L.E. Warwick<sup>2</sup>

<sup>1</sup> Department of Research & Information, Lymphoma Coalition, Mississauga, ON, Canada; <sup>2</sup> Management, Lymphoma

## Introduction

Cancer-related fatigue (CRF) is a persistent, subjective sense of physical, emotional, or cognitive tiredness related to cancer or cancer treatment which negatively impacts functioning and quality of life (NCCN, 2015). The severity of CRF varies by lymphoma subtype, stage, and treatment received. Little information is known about patients' experience with fatigue based on the rate of disease progression (indolent or aggressive lymphomas). This study aims to offer a unique insight into the fatigue experience of patients with indolent lymphomas compared to patients with aggressive lymphomas, using the Lymphoma Coalition (LC) 2022 Global Patient Survey (GPS) on Lymphomas and CLL.

## Methods

Globally, 8637 respondents comprised of 7,113 patients and 1,524 caregivers from 84 countries completed the 2022 LC GPS. This analysis compared patients' experience with fatigue in a subset of patients with aggressive lymphomas (n=2921) ('AL group') and indolent lymphomas (including CLL) (n=4573) ('IL group'). Demographics of both patient groups were used to analyze questions relating to patients' experience of fatigue. Chi-square and p-values were calculated as needed, and the statistical analyses were performed with IBM SPSS v27.

## Fatigue as a symptom of lymphoma and treatment

Of the 6287 respondents, 4085 were classified as being indolent (IL) with the remainder being classified as aggressive (AL) (N = 2202)\*. Sixty-six and sixty-seven per cent of respondents reported some degree of fatigue in the IL and AL groups respectively (p = 0.3).

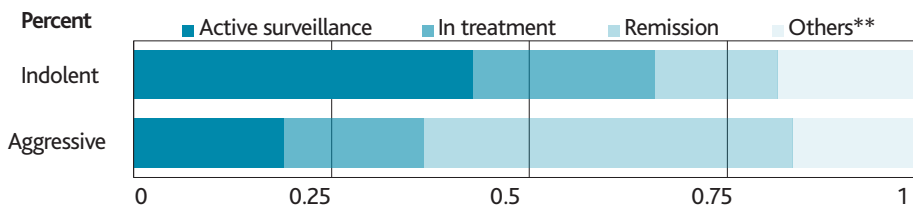


Figure 1. Representation of current treatment status for those with indolent and advanced lymphomas. Those with IL are over twice as likely to be undergoing active surveillance while those with AL are over twice as likely to be classified as being in remission (p<0.001).

Alleviation of fatigue was significantly associated with treatment in AL relative to IL\*\*\*

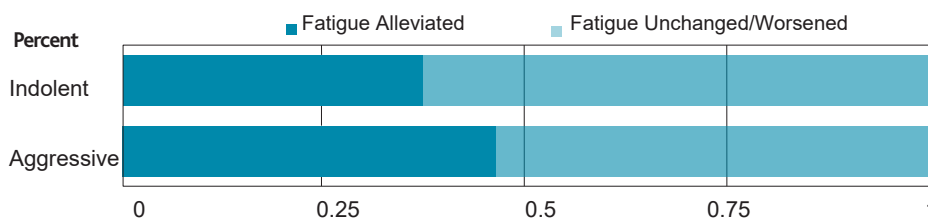


Figure 2. Reduction in fatigue was significantly reduced in those with AL relative to IL (p < 0.001).

Fatigue was a high prevalence side effect a... slightly enriched in those with AL relative t...

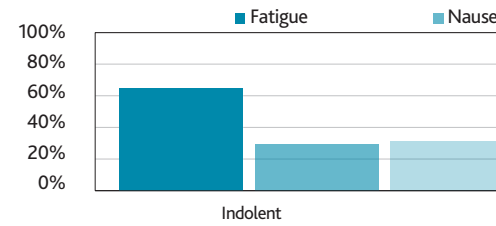


Figure 3. Fatigue attributable to therapy was cited by 65 and 69 per cent of respondents with AL and IL respectively. Both nausea/vomiting and hair loss were significantly more prevalent in those with AL relative to IL (p<0.001).

## Fatigue and health-related quality of life

Fatigue was perceived to be more severe in...

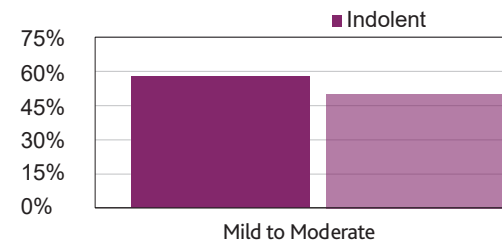


Figure 4. Respondents with IL classify their fatigue as mild to moderate (60%) compared to those with AL (45%) (p<0.001).

The duration of fatigue was enriched in those with AL...

	<1 Year	1<2 Years
Indolent	22%	19%
Aggressive	39%	24%

Table 1. Reported duration of fatigue symptoms stratified across IL and AL. Those with AL reported a longer period than those with AL (p<0.001).

The areas of functioning affected by fatigue were Mood (49%-55%), Physical activities (51%-53%), Social activities (41%-44%) and...

## Communication and help provided by...

Those with IL discussed fatigue with their... AL.

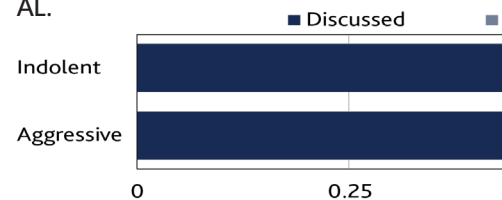


Figure 5. Respondents with IL had significantly more interaction with healthcare providers than those with AL (p<0.01).



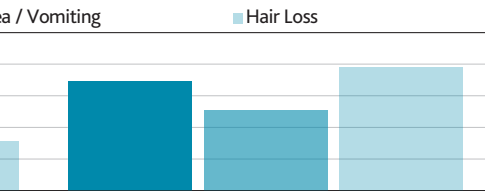
# Cross-Sectional Study

# LYMPHOMA COALITION

## Abstract #3537

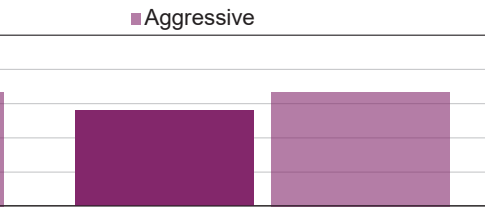
Lymphoma Coalition, Mississauga, ON, Canada

attributable to treatment and was  
to IL\*\*\*



er cent of IL and AL respondents respectively (p = 0.001).  
ent in the AL group relative to the IL group (p < 0.001).

life  
n those with AL relative to those with IL.



ate whereas respondents with AL classify their fatigue as

ose with IL relative to those with AL.

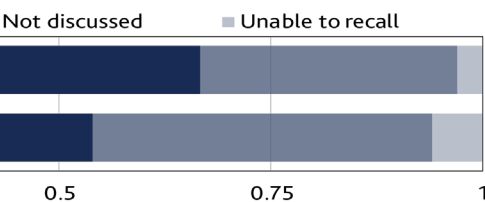
2<5 Years	5<8 Years	>8 Years
27%	13%	17%
23%	5%	8%

and AL demonstrate that those with IL cope with fatigue for a

e included: General activities (62%-62%),  
-59%), General work around the home  
and Enjoyment of life (36%-37%).

### by physicians

treating physician more than those with



n their treating physician regarding the issue of fatigue relative to

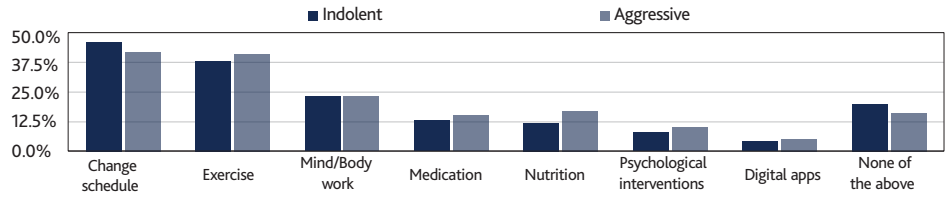


Figure 6. Respondents favoured alterations to schedules and exercise as the predominant ways of coping with fatigue.

### Conclusions

The results show that fatigue is the leading physical issue affecting the well-being of patients with indolent and aggressive lymphomas. However, some differences exist in how patients may experience fatigue in terms of fatigue severity and duration. These differences may be because aggressive and indolent lymphomas often differ in symptom presentation, severity, treatment type or whether patients communicate their fatigue with their doctor. Over 50% of all patients reported that when they expressed their fatigue to their doctor, they felt it was not addressed or followed up. Given the multifactorial nature of fatigue, there is no standard treatment, and interventions that may help improve fatigue must be explored to treat underlying causes. The data highlights that regardless of lymphoma type, fatigue needs to be recognized and treated at all stages of a patient's disease, according to standard clinical practice guidelines. Healthcare providers and patients need to improve their communication about fatigue.

#### Notes

\*Indolent Lymphomas: CLL/SLL, Cutaneous, Follicular, Marginal zone (all subtypes), Mucosa-Associated Lymphoid Tissue (MALT), Mycosis Fungoides, Sézary Syndrome, WM/LPL

\*Aggressive Lymphomas: Angioimmunoblastic T-cell, Adult T-cell, Breast Implant-Associated Anaplastic large cell, Burkitt's, DLBCL (all subtypes), Extranodal killer T-cell, Hairy cell, Hodgkin lymphoma (HL), Nodular lymphocyte predominant HL, Peripheral T-cell

\*\* Newly diagnosed, On maintenance therapy, Post-treatment but not in remission, Relapsed or refractory disease but not in treatment, Palliative and Others

\*\*\* Question asked to those who have received treatment only.

### CONFLICT-OF-INTEREST DISCLOSURES AND CONTACT INFORMATION

Study was sponsored by Pfizer Inc, AbbVie Corporation, Roche, BMS, Pharmacyclis and Takeda Oncology.

None of the authors benefited personally from the research.

For further details on the LC 2022 GPS, please scan the QR code or visit:  
<https://lymphomacoalition.org/global-patient-survey>.

Please direct any queries to C.Bates, Head of Research at Lymphoma Coalition: [cherie@lymphomacoalition.org](mailto:cherie@lymphomacoalition.org)



Artificial Intelligence...continued from pg 1

tions based on specific patterns. For cutaneous lymphoma, digital pathology images, clinical data, radiology data and outcomes can be “fed” into a computer program and used to predict outcomes in a specific patient. Increasing the details of the information given to the computer can make the “output” more accurate and specific. This concept is being evaluated in CL for the following purposes:

- Distinction of cutaneous lymphoma (a malignant process) v.s. reactive infiltrates (a collection of inflammatory cells in reaction to infection or injury). Sometimes it is difficult to distinguish between the two clinically as they can look very similar
- Classification of cutaneous lymphomas and various subtypes
- Identification of biomarkers for progression and survival – this may incorporate thickness of the lymphoid infiltrate, PET images for tumor volume evaluation, and clinical data from known databases to predict outcomes
- Identification and quantification of biomarkers for therapy (e.g., CD30 expression on tumor samples)

Another use for AI is digital pathology. Digital pathology (DP) allows whole slide imaging of biopsy specimens. It digitally scans tissue slides from biopsies of lesions and stores them. They can then be used by pathologists as needed for diagnosis or research. The use of digital pathology has already been studied for primary diagnosis of skin conditions and it can reliably distinguish between benign dermatosis and skin cancers with remarkable accuracy. This is of immense importance in centers where specific specialists in dermatopathology are not available. Similar programs are available to capture radiology data from PET scans and other imaging modalities.

**Dr. Luttwak:** The utilization of AI in the field of cutaneous lymphoma (CL) is in its initial stages. Currently, AI primarily contributes to pathology, showing promise in various aspects such as disease diagnosis, subclassification, cancer detection, and predicting treatment outcomes in CL cases.

AI, particularly through digital pathology and deep learning algorithms, can aid pathologists in diagnosing cutaneous lymphomas. It helps identify morphological features - in

other words, the form and related structures - differentiating between various subtypes, and enhancing accuracy.

AI has the potential to predict disease progression, survival, and therapy response. It can also assist in identifying genomic profiles, helping personalize treatment plans. In the future, AI might play a crucial role in predicting responses to specific therapies and improving overall treatment outcomes.

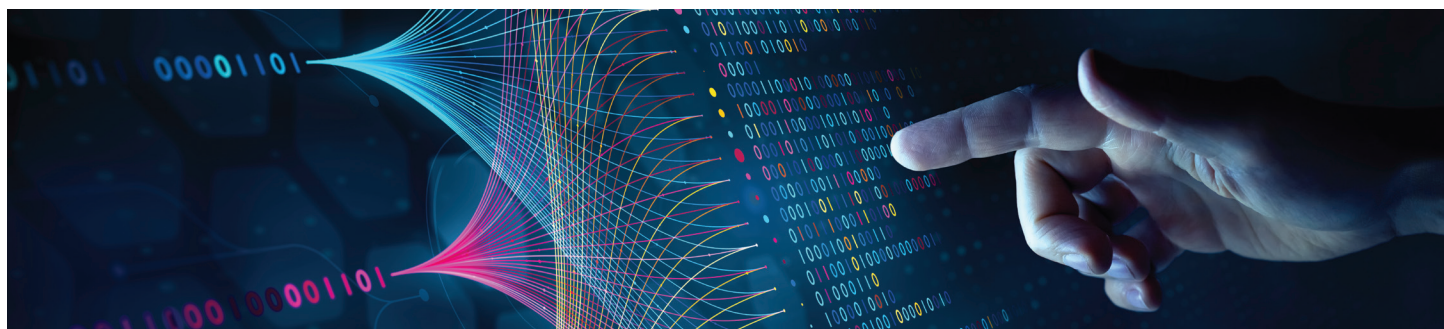
What kind of data has value in furthering the goals above? How is it acquired?

**Dr. Luttwak:** As Dr. Zain explained, data such as histopathological slides of skin biopsies and lesion images are valuable. The first step is to create digital representations of entire glass slides, a process known as whole slide imaging. This is done using specialized scanners that capture high-resolution images of the entire tissue section, preserving the details present on the glass slide. The digitized images go through various preprocessing steps to enhance clarity and quality. This may involve adjusting brightness, contrast, and color balance to ensure optimal visualization of the tissue features.

Deep Learning (DL), a subset of machine learning, employs multilayered neural networks. These networks are trained on large datasets of annotated pathology images. In the case of cutaneous lymphoma, the neural networks learn to recognize patterns and features associated with different subtypes, disease states, or specific characteristics indicative of the condition.

DL algorithms excel at recognizing complex patterns and features within the digitized pathology images. In the context of cutaneous lymphoma, this could involve identifying unique cellular structures, variations in cell morphology, or specific markers associated with the disease.

**Dr. Zain:** Currently, AI and deep learning methodologies are being used in research only, and rely on retrospective databases at centers that have detailed information on patients with CL, including diagnostic slides, radiology data and outcomes. I believe that it has been most helpful in challenging diagnostic cases. One major drawback is these tools have not been



validated in prospective studies, which limits their current usefulness.

Having said this, ChatGPT and various other chatbots are being used by patients and other individuals to get information about CL. These bots are using data and information that is already present on the web to synthesize information according to the needs of the person making the inquiry. For example I asked ChatGPT to “tell me about CL and the use of AI in this disease,” and I got an answer that was pretty close to what I have described above.

### Should patients be concerned about allowing access to their medical records and/or QoL experiences? Do you have recommendations for how patients can determine credible “data banks” and those to avoid?

**Dr. Zain:** Data breaches are becoming more common, and no one is immune to these attempts by hackers and other entities that have malicious intent for the use of personal data. I encourage patients to discuss this concern with their providers and to find out about the safety protocols in place to safeguard their personal data. It is the institution’s responsibility to inform patients if there is a data breach and any contingency plans they have. Lastly, be aware of phishing attempts, do not disclose any information to an unrecognized source, and always make sure that you read and sign a consent form before giving any information to anyone, including your doctor.

**Dr. Luttwak:** Access to medical records is essential for research and improving patient outcomes. To ensure credibility, patients should choose data banks affiliated with reputable medical institutions, and research organizations that follow data protection regulations.

### Are you currently using AI as part of your treatment of cutaneous lymphoma patients?

**Dr. Zain:** We are not using AI as part of our treatment planning for patients with CTCL. However, this may change as more data emerges on the use of AI and machine learning as it relates to diagnosis and evaluation of prognostic markers in patients with CTCL. For example, after evaluating a newly diagnosed patient with CTCL, I may use AI tools to integrate pathologic and radiology data to assess prognosis and then choose treatment options based on this information. Or, the use of AI may help in assessing tumor markers like CD30 and PD-1 expression or others that may help in tailoring appropriate treatments for patients

**Dr. Luttwak:** At present, artificial intelligence remains in the research phase and isn’t yet implemented in practical settings.

Nevertheless, there is considerable potential for AI to contribute to the diagnosis, prognosis prediction, and customization of treatment plans for individuals with cutaneous lymphoma.

### What concerns, if any, do you have about the use of AI related to cutaneous lymphoma?

**Dr. Luttwak:** This field is still very limited in clinical use and still there are many limitations. The studies are mostly retrospective and small, which may limit the confirmation of the clinical impact of DL-based models. Prospective studies are needed to validate the effectiveness of these models in real-world clinical settings. Collaborations between pathology institutions are essential to encourage data sharing, increase dataset sizes, and overcome inter-institutional and inter-regional variations.

**Dr. Zain:** My current concern is about the misuse of AI and its tools by patients and caregivers. AI is available to any one who wants to use it. Most common tools are ChatGPT and other bots like Bing, etc. Patients can access information from these sources, but just like the standard internet, the information may be incorrect or incorrectly interpreted. For example, prognostic information may be incorrect and can lead to undue anxiety and distress in a patient. It is best to get guidance from individual providers or specific sources like the Cutaneous Lymphoma Foundation to ensure that the correct information is being generated for a particular patient. ✨

### Contributors

Efrat Luttwak, MD MPH  
Advanced Fellow | Lymphoma | Medical Oncology & Hematology  
Memorial Sloan Kettering Cancer Center

Jasmine Zain, MD  
Director T-Cell Lymphoma Program  
Clinical Professor  
- Hematology and Hematopoietic Stem Cell Transplantation  
Associate Program Director  
- Hematology/Oncology Fellowship Program  
City of Hope Medical Center

### Reference

NORD Breakthrough Summit (2023), *Harnessing the Power of AI: From Data to Diagnosis and Improved Outcomes*. Recording not publicly available as of February 2023.

# INTERNATIONAL DERMATOLOGY OUTCOME MEASURES (IDEOM): CUTANEOUS LYMPHOMA PROJECT

An introduction to an initiative to improve the quality of life for people living with cutaneous lymphoma.

## Background

There is a general need for more evidence or consensus on standardized measurement tools to demonstrate patient outcomes across dermatology treatments. This is often a problem for patients and can prevent them from accessing the best and most effective treatment options for their skin conditions. Without standardized data, there are no critical criteria for making effective treatment recommendations and assessing the effect on a patient's disease. The lack of data can also affect what treatments insurance covers.

IDEOM is a nonprofit group, primarily of dermatologists, with a shared goal of developing evidence-based outcome measures for patients with skin diseases. They bring together a broad group of stakeholders to develop this evidence to measure outcomes for dermatological diseases and provide a space for specific disease workgroups to develop these evidence-based, consensus-driven measures and tools.

The mission of IDEOM is: "To establish patient-centered outcome measures to enhance research and treatment for those with dermatologic diseases." To succeed in this endeavor, a broad group of stakeholders (including patients, physicians, industry, payers, government, and health economists) must participate in the process to ensure the outcomes will be helpful to achieve the intended results. Currently, there are ten individual disease workgroups. Cutaneous lymphoma is one of the newest groups that started this work in 2022.

To understand the work of IDEOM and the individual workgroups, some background in this research and measurement development area will help provide you with a general understanding of the framework.

An outcome is any health change resulting from a particular intervention/treatment. In some sense, it is any "action" that results from that intervention/treatment. An "outcome measure" is a tool or process developed by doctors, scientists, and patients to measure and quantify that action.

## What is the issue when there is no agreed-upon outcome measure?

When outcome measures are not standardized or agreed upon, especially when included in clinical trials, it becomes difficult to compare outcomes across clinical studies. In some cases, results are only relevant to the patient population that the therapy is being used to treat. This makes it difficult to draw definitive conclusions about the effectiveness and safety of a medication in treating a condition and whether the patient found it improved their quality of life.

To address this challenge, there needs to be a defined process to develop the standardized outcome measures, and this requires the workgroup to engage in three high-level steps:

1. Select relevant outcomes
2. Standardize outcomes measured (by consensus)
3. Create a core outcome set(s)

## What is the definition of a core outcome set?

A core outcome set is the minimum set of outcomes to be measured and reported in all clinical trials in a specific condition.

A detailed, specific process must happen to finalize this core outcome set to establish this minimum set of core outcomes. The steps in this process are:

### Step 1: Determine **what** to measure

- Literature search to identify which outcomes are commonly measured
- Ask patients and other stakeholders which other outcomes are essential
- Consensus process (a Delphi study) to agree on the most critical outcomes
- Consensus meeting to agree on the final outcomes selected for the core domain set

### Step 2: Determine **how** to measure

- Find existing measures
- Assess the quality of measures - "measurement properties"
- Generate recommendations for the core outcome set

## Why is this an essential project in cutaneous lymphoma?

The scope of current research in cutaneous lymphoma is limited (based on existing tools that are not specific to cutaneous lymphoma), the number of patients is small (based on the rarity of cutaneous lymphoma and the wide range of disease iterations among patients), and the geography of patients worldwide necessitates a multi-center collaborative approach. There is no assessment of the current set of quality-of-life tools commonly used in cutaneous lymphoma clinics to evaluate patient outcomes.

The tools currently used are not specifically focused on cutaneous lymphoma and may overlook some critical areas important to patients' quality of life. Due to the complexity and wide range of disease experiences among the patients (early stage versus advanced stage, mycosis fungoides versus Sézary Syndrome or other rare subtypes), patients may feel the need for a broad range of priorities. This is an opportune moment in the history of cutaneous lymphoma to bring together a multi-stakeholder workgroup on this project.

## What is the project?

To design interventions that enhance quality of life, it is crucial to understand what is essential to patients and how to measure it best. The Cutaneous Lymphoma Quality of Life (CL-QL) workgroup aims to create a core set of patient-reported outcome measures that describe clinical benefit using patient-centered endpoint measurements.

The CL-QL workgroup aims to optimize care for patients with cutaneous T-cell lymphoma by identifying the best way to measure patient-reported outcomes to improve the quality of life for those diagnosed and living with cutaneous lymphoma.

To meet those goals, the objectives of the workgroup are to:

- Develop a core outcomes measure set for cutaneous lymphoma
- Determine (or develop) the best instrument (surveys) to capture health-related quality of life (HRQoL) for cutaneous lymphoma at various stages for clinical trials and clinical practice
- Educate and engage key stakeholders throughout the process

## Who is involved?

The Cutaneous Lymphoma Quality of Life Consortium Steering Committee was formed in 2022. It is a multidisciplinary group of clinicians and patients worldwide.


A complicated and unique set of tasks must be completed, with each successive step building upon the previous one, to achieve the ultimate objective of a global agreement for a core suite of outcome measurements that will be incorporated into clinical trials and contribute to clinical practice.

The steering committee has completed the following over the last year:

- Protocol methodology for core outcome set development
- Systematic literature review (#1) to identify candidate domain identification
- Qualitative study for candidate domain development - patient engagement
- Content validity study on leading HRQoL tool in CTCL patient engagement (evaluate Skindex and others)
- Systemic literature review (#2) of patient-reported outcome measures in CTCL

The tasks targeted for completion in 2024 will include beginning the core domain Delphi exercise, which incorporates a detailed survey of healthcare providers to gather their input, and a similar activity for the patient community to gather their insights. From there, an in-depth data analysis will inform the next steps in the process, which will continue through 2025 and beyond.

The dedication of the workgroup team to tackle this critical initiative is inspiring. It speaks to the deep desire to improve cutaneous lymphoma patients' lives. By having a core set of outcome measures incorporated into all clinical studies, the data compared and evaluated across studies and over time will provide important insights into ways to change clinical care and quality of life for those diagnosed and living with cutaneous lymphoma worldwide.

As the project unfolds, updates will be shared, and you will be invited to engage in the process. Nothing about us without us! 

**“The true finish line is when the patient gets to the right doctor and the right treatment and their disease has minimal to no impact on their quality of life.”**

Alice Gottlieb, MD, PhD  
President of IDEOM

# Frequently Asked Questions

The following questions and responses are from an “Answers From the Experts: Open Q&A” event with Drs. Jori Hardin and Debjani Sahni and a past International Conference Clinical Q&A with Prof. Maarten Vermeer and Prof. Pietro Quaglino.

## Do you consider CTCL patients to be moderately or severely immunocompromised?

**Hardin:** There is such a huge spectrum of disease in patients who have cutaneous T-cell lymphoma. I would say in early-stage disease there is a small kind of immune dysregulation, but I wouldn't consider those patients who are achieving only skin directed-therapy to have severe immunosuppression.

As we get towards more advanced stages of CTCL and with Sézary syndrome, there is a shift in the immune balance and the body's ability to regulate sort of a normal immune response. So, yes, in patients with Sézary syndrome or advanced cutaneous T-cell lymphoma, I would consider them in an immunocompromised or an immunodeficient state because their immune system isn't function normally and the blood cells that are being produced are not functioning as normal blood cells would in terms of fighting infection.

I also would note that patients who have extensive involvement of their skin are at a major sort of potential source of infection because with skin breakdown and barrier dysfunction the potential for pathogens or infections to come through the skin is much higher. From that perspective, I would say there is immunodeficiency because our main barrier toward infection from the skin is impaired.

## Do all of your spots, including the originals, have to be gone to be considered in remission?

**Bohjanen:** From the skin standpoint, to be in clinical remission you really would want to have all the spots gone, but remember, sometimes you can get hyperpigmentation or just kind of dark patches or different colored patches on the skin left over after the original rash is gone. These may take many months to fade down. They are not active disease, just some leftover pigment in the skin. So, you might be in clinical remission, meaning you don't have any active disease in your skin, but you still have some patches of pigment change on the skin. That's not active disease.

## What are the mandatory tests for diagnosing and staging Sézary syndrome?

**Street:** With Sézary syndrome, the most important thing is that you are evaluated by a specialist that is familiar with the diagnosis and knows how to make this diagnosis. It can be very challenging. I have encountered many patients that quite likely have had Sézary for several years prior to meeting me and it's just been simply too difficult to establish a diagnosis when providers are less familiar with this very rare subtype of skin cancer. The most important thing is to first identify the skin infiltration; and so, the classic textbook pictures of total body erythroderma, or redness of the skin, and perhaps many of you who have skin lymphoma have already looked up on the Internet what that might look like (and there are a few representative pictures), that by no means represents how all patients actually present with their skin erythroderma. Many patients with different skin tones or skin colors based on genetics and ethnicity have a different appearance to their skin. It may not be as classic bright red as others, so that's where it's really important to have a provider who's familiar with assessing the skin.

Many patients might have simply flaking or infiltration or almost swelling of the superficial layers of the skin that we're able to identify. It may not be as classically total body red and may also initially not involve the whole body. We've had many patients who present first with redness or infiltration of their skin to their face or upper torso before it becomes all over their body. The first thing is a really careful skin exam. The next thing that's very challenging is evaluating whether an individual has circulating Sézary cells in the bloodstream.

This requires a specialized test called flow cytometry and also a very coordinated approach with your laboratory colleagues or pathologists who work in the flow cytometry lab to provide an adequate assessment of the individual blood cells to see if they are Sézary cells or not. It's important to know that patients can have Sézary without necessarily having an absolute rise in their lymphocyte count as identified on a simple blood count in the lab. Rather, you need the flow cytometry machine or assessment to identify the clone of Sézary cells and then enumerate them to see if an individual meets the criteria for Sézary syndrome

In summary, I would say that to evaluate or diagnose a patient with Sézary, you both need an expert skin assessment and an expert blood assessment to establish that diagnosis.

### I am doing UVB light treatments. My skin gets so scaly and dry and itchy, especially when I increase the time in the light box. Is this normal?

Hardin: Yes definitely, and unfortunately phototherapy is one of our main treatment modalities for skin directed therapy for early-stage cutaneous T-cell lymphoma. One of the tricky parts of phototherapy is that it does initially make your skin more dry and itchy, and this is when we really go back to basics in terms of skin health.

What I suggest is bathing everyday, and while most adults don't like taking a bath, taking a bath is good for the skin. If you take a 10 minute bath in lukewarm water, and then I call it the soak and smear where you just get out of the bath and pat yourself dry, you can leave your skin wet, take a very thick kind of cream or ointment-based moisturizer (one that you have to scoop out of a jar), and put it all over your body. Then put on warm cozy cotton pajamas and then go to bed. This will allow the barrier function and the normal kind of differentiation of the layers of the skin to normalize and help restore moisture to the skin.

Phototherapy can often be very drying, so dry itchy is definitely a product of phototherapy. Often, as you go that gets better, especially with some of the tips that I've mentioned. If you're burning after phototherapy or your skin is red beyond 24 hours, then you're getting too much energy and that can certainly cause dryness and itch in the skin. Be mindful that you're getting the appropriate dose of phototherapy.

### When should a mycosis fungoides patient see an oncologist?

Ghione: I would say whenever a patient feels like their dermatologist is starting to think that there's a need for a treatment other than just skin-directed. That's where probably the dermatologist starts having a role where they want to include a hematologist as well. But, I think it would be good to see a hematologist anyways from the get-go and then they will decide the pace at which they want to see you. It can be that you see the dermatologist more often than the hematologist and the hematologist can see you just once a year or every two years. ✨

Kimberly Bohjanen, MD  
Dermatology Clinic at University of Minnesota  
Minneapolis, Minnesota

Paola Ghione, MD  
Memorial Sloan Kettering Cancer Center  
New York, New York

Jori Hardin, MD,  
Richmond Road Diagnostic and  
Treatment Centre Cutaneous Lymphoma Clinic  
Alberta, Canada

Lesley Street, MD  
Alberta Health Services  
Alberta, Canada

"Thank you for the work the CL Foundation does. I always find your site and newsletters interesting and have suggested to my dermatologist and oncology staff to recommend your site as a reference for their patients."

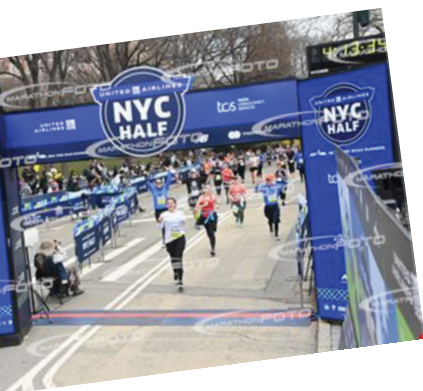
We can't do it without you!  
Please consider supporting the CL Foundation today!  
[www.clfoundation.org/giving-online](http://www.clfoundation.org/giving-online)



CUTANEOUS LYMPHOMA FOUNDATION  
PO BOX 969  
WARREN, MI 48090

TIME SENSITIVE MATERIALS ENCLOSED

## Spring has arrived... and people are eager to get outside!



### ***Are you preparing for an event?***

Maybe a 5k or 10k marathon, a cycling event or any other type of competition. Want to make your training even more impactful by raising awareness and funds to support cutaneous lymphomas?

Well, here's your chance to turn your hard work into support for education, research and resources.

### ***Want to learn more?***

Call (248) 644-9014 or  
email at [debra@clfoundation.org](mailto:debra@clfoundation.org)

### ***Ready to get started?***

Visit **CLFriends** using the QR code at left or  
visit <https://givebutter.com/CLFriends>  
to set up your event today!



***Thank you to all our past, present and future fundraisers -  
we can't do it without you!***