

## OUR INTERNATIONAL COMMUNITY

In this edition of the Forum, you will take a deeper look into the work being done across the globe impacting the cutaneous lymphoma community. As you know, cutaneous lymphomas are a subset of lymphomas and are also considered rare diseases. Not only are they rare, but they also cross both dermatology (skin) and hematology (lymphoma). These three distinctions (rare, skin and lymphoma) make the need for collaboration, especially international collaboration, that much more important.

The following pages include information on ways your experiences have advanced, and can continue to advance, research through patient survey opportunities. We are also excited to introduce two new alliances that are forming, as well as our new “sister” cutaneous lymphoma organization, and how they will help support patients across the globe.

As we hope you’ll see, these international efforts allow us to bring the cutaneous lymphoma global voice together as one to advance research, raise awareness, empower individuals through education and support, as well as advocate on your behalf.

## GLOBALSKIN - GLOBAL RESEARCH ON THE IMPACT OF DERMATOLOGICAL DISEASES

Individuals with cutaneous lymphoma are in the unique situation of having a rare disease that is both a cancer (lymphoma) and a condition that affects their skin. Depending on your situation, you may focus on one aspect of the disease more than another - for instance, on your skin. Does the condition of your skin, due to your cutaneous lymphoma, affect your day-to-day life? Do you ever feel the need to cover visible patches, plaques, or tumors in order to not bring attention to yourself? Do you deal with depression because of how your life has changed due to your diagnosis or treatment? If so, you are not alone. Dermatological conditions can have a significant impact on an individual’s well-being, beyond just the physical symptoms of their condition. Additionally, the availability of care and treatment can be difficult to access because the impact of “skin conditions”

*GRIDD...continued on page 10*

### 2023 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.*

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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. ❧

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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.

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## FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

Laurel Carlson, Board President; Susan Thornton, CEO

### BOARD OF DIRECTORS NEWS

The Cutaneous Lymphoma Foundation (CL Foundation) is pleased to introduce two new members to our Board of Directors, Rich Tolsma and Bryon Vielehr.



**Rich Tolsma**

An active member of the CL Foundation community since 2017, Rich is looking forward to contributing his abilities in communications, fundraising and education as a Board Director.



**Bryon Vielehr**

Bryon joins the Board with a passion for helping individuals deal with their cancer diagnosis, bringing with him an extensive background in both business leadership and non-profit experience.

We are thrilled to welcome Rich and Bryon to our Board of Directors and look forward to working together to the benefit of the cutaneous lymphoma community.

To learn more about Rich and Bryon, or our other Board members, visit our website at [www.clfoundation.org/board-of-directors](http://www.clfoundation.org/board-of-directors).

inspired us to take this leap is our sister organization in the Netherlands. Last year in this issue, Paul's journey was highlighted. This year, we will collaborate with Stichting Huidlymfoom (Cutaneous Lymphoma Foundation, the Netherlands) to host a patient symposium in Leiden immediately following the European Organisation for Research and Treatment of Cancer (EORTC) Cutaneous Lymphoma Tumor Group scientific meeting.

These efforts enable us, collectively, to reach more people living with cutaneous lymphoma wherever they may live and, importantly, bring the global patient voice to stakeholders engaged in research, clinical practice, and the regulators and government agencies who approve new therapies.

***With regard to access to quality healthcare, people with a rare disease often find themselves isolated by health and support systems designed for more common diseases. This results in inequalities in accessing diagnoses, care, and treatments. People living with a rare disease also face discrimination at work, school and leisure.<sup>1</sup>***

Welcome back from the summer holiday season!

As the fall season kicks into gear, we are focusing this issue of the Forum on our international community. Although the Cutaneous Lymphoma Foundation has always engaged globally in various ways, over the last few years, we have embarked more proactively to engage, support, and connect with patients and clinicians worldwide.

Perhaps the pandemic that shut down the world for nearly two years pushed the envelope for all of us to embrace the power of connecting virtually, or maybe the cutaneous lymphoma community was ready to expand. Either way, we have taken a bold step forward to do our part to bring the global community together. It's imperative to fulfilling our vision:

#### **A life free from the burdens of cutaneous lymphoma.**

In the pages of this issue, you will read about AELIC, a newly formed patient organization in Spain, along with the founding members' personal stories. Learn about our efforts to bring together the clinical community of nurses worldwide. It updates our efforts to create a network of patient organizations around the world that are dedicated to serving cutaneous lymphoma patients and their loved ones in their countries. One of the new patient organizations that has



**Laurel Carlson**



**Susan Thornton**

*From the Board...continued on page 4*

## MEET THE NEW MEMBERS OF OUR TEAM

The Cutaneous Lymphoma Foundation is excited to grow our team with the addition of two new members.



**Sue McCann**

Some of our community may already be familiar with our new Services Manager, Sue McCann. Sue was a member of the University of Pittsburgh Medical Center's cutaneous lymphoma team as a nurse for many years prior to joining the Foundation. She will be managing our online networking groups and community.



**Bandna Virdi**

We also welcome Bandna Virdi as our new Office Assistant. Bandna brings a strong background in administrative skills and client relationships to her new role with the Foundation.

You can learn more about these newest members of our team on our website at [www.clfoundation.org/cutaneous-lymphoma-foundation-staff](http://www.clfoundation.org/cutaneous-lymphoma-foundation-staff)

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

To capture our collective experiences, we also participate in other global initiatives with umbrella nonprofit patient organizations. You will learn more about the new Global Research on the Impact of Dermatological Diseases (GRIDD) project launched in June. Your responses to the survey are critical to providing the cutaneous lymphoma patient experience, alongside other dermatology patient voices. This data will be shared with policymakers at the global and national levels to show the true life impact on people living with a skin condition in order to raise awareness, more funding for research, and more access to clinicians and therapies. Additionally, the 2024 Lymphoma Coalition Global Patient Survey will launch in January. This valuable data collection tool has enabled us to share real-life patient experiences with the clinical community, highlighting areas for further research into better managing the quality of life issues facing cutaneous lymphoma patients.

### Your voice matters. Your experience matters.

We can change lives by joining forces and bringing together our patient community globally.

Enjoy this international issue - look for more news about our work worldwide.

Power to the patient!



#### Reference

1 EURORDIS - Rare Disease Europe (n.d.) *Rare Disease Day 2023: Our global community comes together for a more equitable world.* <https://www.eurordis.org/rare-disease-day-2023-our-global-community-comes-together/#:~:text=With%20regard%20to%20their%20access,diagnoses%2C%20care%2C%20and%20treatments.>

## Find Your Community!

Are you looking for a way to connect with others who also have cutaneous lymphoma? Or do you have a family member or friend who has the disease and you would like to connect with other care partners?

Then we invite you to join the Cutaneous Lymphoma Community, a place where you can interact online with others facing the same or similar experiences as you.

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



### Stay Up-To-Date With The Cutaneous Lymphoma Foundation

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

# AN INTERNATIONAL ALLIANCE FOR CUTANEOUS LYMPHOMA

In this edition of the Forum, we are focusing on the international community. Cutaneous lymphoma knows no borders, and neither does the Foundation. Advocacy and awareness are key components of our mission statement. We hope you find this edition of interest.

One of the questions that we hear is how to best serve cutaneous lymphoma (CL) patients worldwide. With that in mind, the Cutaneous Lymphoma Foundation convened a meeting of representatives of patient organizations across various countries with an interest in cutaneous lymphoma.

## Why did we do this?

We wanted to learn from each other's experience in supporting and advocating for people affected by CL and explore the value of international collaboration between patient organizations with an interest in CL.

## Who attended?

There were 11 participants from around the world. The countries represented were Austria, Finland, Germany, Italy, the Netherlands, Portugal, Spain, Switzerland, the United Kingdom, and the United States.

## What was discussed?

- The existing resources across the different organizations
- Key challenges of people affected by cutaneous lymphoma
- Key challenges faced by patient organizations in CL
- Establishing an international cutaneous lymphoma patient network

## What would be the benefits of an international cutaneous lymphoma patient network?

- Sharing of resources
- The ability to learn from each other and share experiences
- Help support new groups
- Launch an international symptom campaign to promote more timely diagnosis
- Facilitate connections with CL specialists including dermatologists and hematologists
- Promote CL research

## Next Steps

The group will reconvene in Madrid in October 2023, following the Lymphoma Coalition's annual meeting. The workshop will build on the original meeting, as well as the follow-up virtual meeting held in June where the group discussed resources that have been created and collaborative efforts to engage the local patient community in a more targeted way. Additionally, the workshop will discuss the structure of the coalition going forward, the scope of the work needed to be done, and how the collective group wants to manage the projects going forward. ❖



Seated (left to right)  
Lorna Warwick, Lymphoma Coalition, Canada; Susan Thornton, Cutaneous Lymphoma Foundation, United States

Standing (left to right):  
Tara Steeds, Lymphoma Action, United Kingdom; Kathy Redmond, facilitator, Redmond Consulting, Switzerland; Holly Priebe, Cutaneous Lymphoma Foundation, United States; Rosmarie Pfau, Lymphoma CH, Switzerland; Matti Järvinen, Syopapotilaat, (Lymphoma), Finland

On screen: (left to right)  
Enzo Bottazzi, Associazione Italiana Contro Leucemie Linfomi E Mieloma, Italy; Mieke & Ton de Leewu, Skin Lymphoma Foundation, Netherlands; Joaquin Diez, AELIC, Spain

Attended but not in the photo: Lara Cuna, APCL, Portugal



The AELIC and Journey articles are available to read in the original Spanish here.

# AELIC - SPANISH ASSOCIATION OF CUTANEOUS LYMPHOMA PATIENTS

Hello! We are AELIC - Spanish Association of Cutaneous Lymphoma Patients - and today we want to tell you our story.

AELIC is a non-profit organization, transparent and independent, which was constituted on August 1, 2022, and registered in Spain's National Registry of Associations of the Ministry of Interior on December 14, 2022, with the number 625435.

AELIC was born from the need to find support and answers to our concerns as patients and relatives of those with cutaneous lymphoma, to meet other people who are in our same situation, to form a support network, and to give visibility to cutaneous lymphomas.

This path of search began with Susana, a mother of a young patient diagnosed with cutaneous lymphoma, was later joined by Almudena and Joaquin, also patients with cutaneous lymphoma, and Dr. Pablo Ortiz Romero, a specialist in cutaneous lymphoma and promoter of this project, and our common desire to learn how to manage our own diagnosis and to help others with the same disease. With great enthusiasm and full of emotions, we set out to raise awareness of this minority and unknown disease.

We began to take the first steps to form the association in 2018. We did not know where to start, and thanks to Dr. Pablo Ortiz we were lucky to meet Susan Thornton and the Cutaneous Lymphoma Foundation. Susan has been our teacher; she sheds light and guidance when we don't see where to go. Susan, thank you from the depths of our hearts!

After a pandemic and a few setbacks, finally in the summer of 2022 we were able to celebrate the constitution of the association, and here we are!

From AELIC we want to reduce the impact caused by this rare disease and improve the welfare of patients. We want to work side by side with other cutaneous lymphoma patient organizations, specialized professionals, and patients and their relatives, with the aim of:

- learning,
- spreading the knowledge of cutaneous lymphomas,
- keeping a real record of the number of patients,
- moving for the designation of reference centers,
- promoting research that allows early diagnoses and advanced treatments,
- knowing the real needs of patients, and
- creating a support network for the improvement of our quality of life.

We have a long way to go, but we are sure that together we will go further. Thank you very much Cutaneous Lymphoma Foundation!

A big hug,  
Almudena Montejo  
President

Susana Díaz-Guirado  
Secretary

Joaquín Díez  
Treasurer

# OUR JOURNEYS WITH CUTANEOUS LYMPHOMA

Hello,

I am Almudena, a mycosis fungoides (MF) patient. I live in Spain and today I will talk to you about my disease.

In 2014 my skin lesions appeared, first as spots on my back and upper body and later purplish red plaques that spread over the extremities and in the face. In addition to the appearance of these lesions, the most striking aspect was the intense itching, even in areas where there was no apparent lesion.

After several years of multiple biopsies with non-specific results, uncertain diagnosis and treatments and no improvement, finally in 2017, the diagnosis of MF was confirmed. I became aware of the importance of the disease when the doctor told me "I'm sorry" when he gave me the diagnosis. A thousand questions, concerns and emotions surfaced overnight.

My case is peculiar because I have developed a total intolerance to ultraviolet radiation, and this led me to have to use more aggressive treatments. Today I am at a cycling stage, sometimes with more lesions, sometimes less, and always with treatment.

For me, the most difficult thing to manage is when the facial lesions appear. I am very affected by the radical change of my face and by the intense itching that this disease produces. When this happens to me, what helps me is to stop, try not to get overwhelmed and seek help from my friend and family environment and trusted professionals.

It also helps me to understand the behavior of this disease, to learn about situations that may favor the appearance of the outbreak and itching, as well as habits and remedies that help me to take care of myself, relieve myself, and have a more positive attitude.

I am fortunate to be a healthcare professional; this is helping me a lot. I trust the doctors who treat me a lot, and I also want to help other patients and learn with them. I trust in the progress of science.

I think that patients have a lot to contribute - giving a voice to this rare disease, promoting training so that the disease is detected at earlier stages, and promoting research that facilitates access to advanced treatments that improve our quality of life and that of our families.

I encourage you to keep fighting.



*Almudena*

My story with cutaneous lymphoma began in the fall of 2018. For no apparent reason, I experienced intense itching in my legs, a discomfort that seemed relentless. I didn't notice or remember identifying patches, spots or irregularities on my skin, just a ceaseless itch.

At that time, I didn't think it necessary to go to a doctor or dermatologist. Living in Madrid, the pollution, the city's dry environment, or even a change in my shower gel, seemed like potential causes of my discomfort.

It wasn't until February 2019, when several eczemas emerged on my right arm and torso, that I decided to visit my family doctor. I was diagnosed with pityriasis rosea, and the recommended treatment was medium-strength corticosteroids for two weeks. The relief was palpable, the eczemas disappeared, but upon ceasing the treatment, they reemerged.



*Joaquin*

*Our Journeys...continued on page 8*

## Our Journeys...continued from pg 7

Despite several visits to the doctor, the diagnosis remained unchanged, not taking into account the persistent itching in my legs. In May, my partner identified four large oval patches on my thighs and buttocks. Her insistence led me to seek immediate consultation with a dermatologist. Given that wait times in the public health system in Spain can be lengthy, I opted for a private specialist.

The dermatologist I initially consulted attributed my condition to a stress-induced skin condition. She prescribed me medium-high potency topical corticosteroids, but the cycle of relief and recurrence continued, and the persistent itch on my legs did not cease.

In July, my dermatologist decided to proceed with a biopsy. By the end of August, I received the results, and the impact of that visit still lingers in my memory. Her lack of experience in treating patients with mycosis fungoides resulted in unfortunate communication. She could barely answer my questions, and her sparse words were lymphoma and cancer. She handed me some printed sheets with technical information, but it felt like everything was beyond my understanding.

The emotions that invade after receiving such news are overwhelming. I felt crushed, and the feeling of distress intensified when searching for information about the disease. I was expecting a child in a few months, and now I was faced with this challenge.

With the support of my partner, I embarked on a journey to get more information and seek help. I visited my family doctor again, delivering the diagnosis and requesting that he refer me to dermatologists specializing in cutaneous lymphoma in the public health system. I spent countless hours on the Internet, reading every article and visiting forums, looking for everything that could help me understand what was happening to me.

It was at that moment when I realized the scarcity of information in Spanish about cutaneous lymphoma, and fortunately, I found the Cutaneous Lymphoma Foundation. Their message, that although there is no known cure and many years can be lived with this disease if treated by specialists, was encouraging. Additionally, I found a list of doctors specializing in cutaneous lymphoma in Spain, including Dr. Ortiz, who was located close to my home.

A few minutes later, I had an appointment with Dr. Ortiz for

the following Thursday. This visit marked a turning point. After evaluating my lesions, he confirmed the diagnosis of mycosis fungoides and asked me what I had read about it.

I replied: "It's a disease with no cure, but it's very likely that it won't kill me."

"Exactly, that's it, and that's what you have to keep in mind. Now let's talk about the next steps," said Dr. Ortiz.

Since then, it has been four years, we have been fighting to keep the disease at bay and especially to limit the annoying symptoms, the itching, and the lesions.

These have been four years of highs and lows. Every day, I use topical corticosteroids at the appearance of each lesion. In the winter, I have three weekly UVB sessions, and in the

summer, 20 minutes of daily sun exposure whenever possible. And, when the outbreaks are more severe and affect a larger portion of the skin, I resort to oral corticosteroids.

I have learned that the quality of life is what is most affected, an aspect that, frankly, the doctors did not warn me about. I also understand that this disease affects each patient in a different way. But above all, I've learned that I must coexist with this condition and be disciplined in taking care of my skin and

minimizing moments of discomfort.

After expressing my frustration to Dr. Ortiz about the lack of information in Spanish about cutaneous lymphoma, he introduced me to Susana and Almudena. From this connection, the idea for AELIC.org emerged, a project to fill this void and provide support to those who have been diagnosed with cutaneous lymphoma and who possibly feel the same as we did when receiving our diagnosis.

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**I've learned that I must coexist with this condition and be disciplined in taking care of my skin and minimizing moments of discomfort.**

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Susana

Our story began in July 2018. Fran, my eldest son, who was 11 years old at the time, had five or six lesions that looked like insect bites on the back of his left leg. Days went by and we saw no improvement, on the contrary, the lesions got worse, so we went to the doctor and without further ado, they told us they were bites and prescribed topical corticoids and antibiotics.

Approximately a month later, not only had the lesions not improved, but we could also see that Fran had many more on his legs and arms. We started to seriously worry, especially when we saw that some small lesions on his hand began to grow, to join together to form a plaque that oozed a clear liquid, and there was no way to cure it.

We went to the doctor again, this time to the dermatologist who had seen us in August, and without giving us any explanation as to what it could be, because she didn't know, she set about doing a biopsy on the largest lesion, the one on his hand. Weeks later, the Anatomical Pathology report was inconclusive. We were sent home and told that if the lesions persisted, we should come back and they would continue to study them.

As a mother, I felt an anguish that I cannot explain, as time went by and my son had more and more lesions and they became more and more unpleasant to look at. The new school year would start in September and this could be a problem.

I went to the medical insurance company and they got me an appointment with another dermatologist was already September. This dermatologist took Fran's case as a challenge, so he got down to work. We started again with biopsies, more creams... and meanwhile, Fran went to school with the larger lesions covered up, as they oozed and sometimes bled.

In the meantime, I became pregnant with my third child, and the first three months were very difficult as the stress and anxiety caused by Fran's situation meant that I had complications during the pregnancy, and I even had to take time off work. Finally in October, the dermatologist phoned us and asked us to come to his office, as he already had the results of

the biopsies. We were surprised when we heard "lymphomatoid papulosis." We had no idea what it could be, but it didn't sound good. I will never forget the doctor's words: "As bad as it is, it is not the worst, but as good as it is, it is not the best."

Faced with the name of a disease unknown to us, with no cure, that really told us, what was the next step? Well, the next step was to research on the Internet, and it was discouraging. There was little information about lymphomatoid papulosis, but we did find Dr. Pablo Ortiz, professor and dermatologist specializing in the cutaneous lymphoma unit of the Hospital 12 de Octubre in Madrid. I contacted him and we went to Madrid, and that was one of the greatest decisions we were able to make, as we were finally talking to a person who knew about this disease. He reassured us a lot because he told us that despite being a cutaneous lymphoma, it is benign, it has no cure, no treatment, medication can only numb the outbreaks, space them out, shorten them....

It is hard to receive such a diagnosis as a patient, but I assure you that receiving it as the patient's mother is horrible, and the lack of knowledge and uncertainty about the evolution of this disease makes you live in a state of constant vigilance and alarm.

Dr. Ortiz encouraged me to do something to raise awareness of cutaneous lymphomas, but I didn't know what I could do, although I needed to meet more patients., Fran wasn't going to be the only one, and I needed to know more. The best idea I had was to create a cutaneous lymphoma group on Facebook, and it was surprising how little by little patients from both Spain and America joined.

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**Our aim is to give support to patients and their families, calm their anguish and answer the many doubts that arise after being diagnosed with this disease.**

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As a result of this initiative, Pablo put me in touch with Almudena and Joaquín, and that was the beginning of our adventure with AELIC, the Spanish Association of Cutaneous Lymphoma Patients. Our aim is to give support to patients and their families, calm their anguish and answer the many doubts that arise after being diagnosed with this disease. We want to raise awareness of cutaneous lymphoma to promote research and also the training of healthcare personnel, so that the diagnosis period is not so long.

We do not know what the future holds, but we will fight to improve the quality of life and achieve our goals.

## GRIDD...continued from pg 1

frequently isn't seen by decision makers as being as serious as other conditions.

GlobalSkin's goal is to shed an accurate light on the impact of dermatological conditions through its GRIDD survey. GRIDD stands for Global Research on the Impact of Dermatological Diseases, and it isn't just another acronym. It is the first global patient impact project in the history of dermatology. It aims to collect global data on the impact of dermatological diseases directly from patients.<sup>1</sup>

### Background

GRIDD was developed through the efforts of the International Alliance of Dermatology Patient Organizations (GlobalSkin), in partnership with Cardiff University (UK) and University Medical Centre Hamburg-Eppendorf (Germany). GlobalSkin was established in June 2015 when 125 delegates from 25 countries, representing 60 skin patient organizations, met and agreed to "the establishment of a global umbrella organization to serve the needs of people living with dermatological conditions."<sup>2</sup>

As GlobalSkin explored how it and its member organizations could improve their advocacy efforts for their constituents, it became clear patient-reported data was key. However, while decision makers and Health Technology Assessments (HTA) see the value in patient-reported data, most of what existed at the time was anecdotal, and decision making criteria requires measurable data.

GlobalSkin and its member patient leaders asked: What if there was a quality of life measurement tool that was developed by patients? What if a credible patient voice could be built upon verifiable data? And, what might it mean if policymakers wouldn't ever make a decision without including

a patient-led measure?<sup>3</sup>

Thus began the multi-year project to develop the Patient-Reported Impact of Dermatological Diseases (PRIDD). From the very beginning, PRIDD was built with patient involvement, beginning with a survey of over 2490+ patients globally to find out how dermatological conditions impact their lives. From the 263 unique impacts that were shared across all conditions, the researchers refined the survey down to 16 questions which capture data related to the impact of dermatological conditions on the physical, psychological, social, and life responsibilities areas of a patient's life.

In order to be introduced as a credible tool for collecting patient-reported data for clinicians and researchers, PRIDD underwent evaluation by COSMIN - the "gold" standard for evaluating health measurement tools.<sup>4</sup> In five of the seven areas tested by COSMIN, PRIDD scored as high, if not higher, than other existing skin-related measures currently used by the medical and research community. The two remaining areas require additional data before the COSMIN evaluation can be completed, which is where GRIDD comes in.

### What is GRIDD and why is it worth 20 minutes of your time?

The GRIDD study is GlobalSkin's survey that includes both the PRIDD questions, plus demographic information and dermatologic questions that were captured through the process of developing PRIDD. The goal of GRIDD is to collect data from at least 10,000 patients which will provide sufficient data for the researchers to complete the COSMIN evaluation. Once validated through the COSMIN evaluation, GlobalSkin will publish its findings and begin promoting PRIDD to clinicians and researchers as a more sensitive



**PRIDD data will help inform the world that dermatological conditions can rob people of their quality of life and emotional wellbeing and that solutions are needed to deliver a higher quality of service and treatment to dermatology patients around the world.<sup>5</sup>**

measure of patient experience, which is especially important in clinical trials and testing for the effectiveness of treatments.

In addition to validating PRIDD, the GRIDD results will be shared with patient organizations to help with their advocacy for better care and treatments. It can also help raise awareness of the actual impact of living with dermatologic conditions - providing condition-specific data as available. Imagine being able to share with decision makers the actual impact cutaneous lymphoma has on individuals' lives using quantifiable data.

**Except for where cited, information for this article was sourced from the following:**

Global Skin. (June 3, 2023). *Changing How the World Measures and Understands Dermatological Diseases*. GRIDD Presentation - GlobalSkin Elevate 2023 Conference. [https://youtu.be/yHXuiCvt\\_fo](https://youtu.be/yHXuiCvt_fo)

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1 Global Skin. (2023). *GRIDD Global Research on the Impact of Dermatological Diseases*. <https://globalskin.org/research/gridd-about>

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The survey will take about 20 minutes to complete, a relatively small “investment of time which is an investment in improved life.”<sup>3</sup>

To participate in this important research, please follow this link: <https://globalskin.org/GRIDDStudy>

The online survey is open from June 5 to September 28, 2023.

❖

## LC GLOBAL PATIENT SURVEY - GATHERING DATA FOR CUTANEOUS LYMPHOMAS IN LYMPHOMAS (HEMATOLOGY)

The Cutaneous Lymphoma Foundation has enjoyed a long and valuable relationship with the Lymphoma Coalition (LC). The Coalition is a global network of patient advocacy organizations dedicated to lymphomas and chronic lymphocytic leukemia (CLL). It has over 80 member organizations in more than 50 countries. The Coalition provides a space where member organizations can share their best practices and what works to successfully meet the needs of their patient community. Another focus is advocacy - the Lymphoma Coalition “is committed to bringing equity in lymphoma across borders.”<sup>1</sup> As expressed by LC CEO Lorna Warwick in her presentation for the CL Foundation’s 2021 International Patient Conference, the Lymphoma Coalition uses the knowledge and strength of its membership to “influence changes to the health care systems to ultimately get better care for patients.”<sup>2</sup>

Every two years, the LC circulates its Global Patient Survey on Lymphomas & CLL (GPS) through its member organizations for their constituents’ participation. The survey was first introduced in 2008 and “seeks to understand patient experience in lymphomas as well as the impact of treatment and care.”<sup>1</sup> This collected patient/care partner data allows the Coalition and its member organizations to more accurately represent the impact of living with lymphoma or CLL when working with health care professionals, researchers, industry and others. The information is also invaluable when speaking with policymakers, as the CL Foundation does in its advocacy efforts.

Ms. Warwick presented cutaneous lymphoma specific outcomes from the 2022 Global Patient Survey at the CL

*LC Global Survey...continued on page 15*



# CUTANEOUS LYMPHOMA

## *Who we are and how we got here...*

The Cutaneous Lymphoma International Nurses Network aka “CLINN” hosted its inaugural webinar on June 6, 2023. This milestone event did not come to fruition without a back story, of course. Four dedicated cutaneous oncology nursing professionals, along with Susan Thornton, CEO of the Cutaneous Lymphoma Foundation, clearly understood there was a scarcity of nursing centered resources and networking opportunities for our colleagues caring for this challenging disease, both within the US and across the globe.

The timeline for the CLINN commenced around 2016 when Australian Lymphoma Nurse Practitioner, Odette Buelens, reached out to US counterparts Marianne Tawa, RN, MSN, NP, and Sue McCann, MSN, RN, DNC, looking to connect for advice on a difficult cutaneous lymphoma T-cell (CTCL) case. She wanted to examine alter-

native therapeutic approaches to wound care, which are unique to the advanced tumors of CTCL. It was at that moment that we all understood we needed to expand our reach. In 2017, Marianne, Sue, and Susan Thornton designed and participated in a joint case-based educational program with British Dermatology and Oncology Nurses at the EORTC meeting in London. The thrill of sharing best practice for cutaneous lymphoma (CL) patients was a unifying theme. Since that time, the CLINN initial core of Marianne, Odette, and Sue has expanded with the addition of Claire Lusted, Advanced Nurse Practitioner from the United Kingdom. The group met virtually throughout the pandemic, culminating with a live webinar on June 6th.

## *Why meet?*

In the summer of 2022, the CLINN group set out to develop a survey aimed at gathering data on clinical practice for nurses caring for cutaneous lymphoma patients, and to further understand gaps in education across the globe. Identifying nursing colleagues in CL practice proved to be a challenge, as many of us practice within our individual disease centers, community or private practices, inpatient, phototherapy, photopheresis, radiation and research settings. With the generous assistance of the Cutaneous Lymphoma Foundation, physician and pharma partners, and word of mouth, we were able to create a mailing list for the survey. The survey landed in nurses’ inboxes in the fall of 2022. We were thrilled to have 128 total respondents from the USA, UK, Australia, Switzerland, and Canada. Practice settings ranged from Dermatology/Hematology/ Multi-Disciplinary, urban- academic to rural and home-based care. 25% of the respondents returned to participate in the live webinar.

## *What did we learn?*

Key insights derived from the survey were nurses desire to connect within an organized clinical community; nurses perceive limited education resources: nurses want to leverage and share skills, knowledge, and experience within the treating community. Key themes generated from the survey were that nurses are interested in expanding essential disease-related education (pathogenesis/ therapies, clinical trials), acute and chronic nursing care, symptom management, skin and wound care, patient education, and quality of life measurements. Additionally, they expressed a strong interest in creating an avenue for networking and engagement via access to in-person and online educational programming.

## *Now what?*

After careful review of the survey responses and feedback from key stakeholders, the CLINN priorities fell nicely into place. The consensus was to prioritize two projects.

1 - Creation of a repository for CL nursing education to include a collection of nursing guidelines or platform for evidence-based nursing literature; powerpoints on disease state; quick reference guides on symptom management; forum for Q&A and problem solving.

# INTERNATIONAL NURSES NETWORK

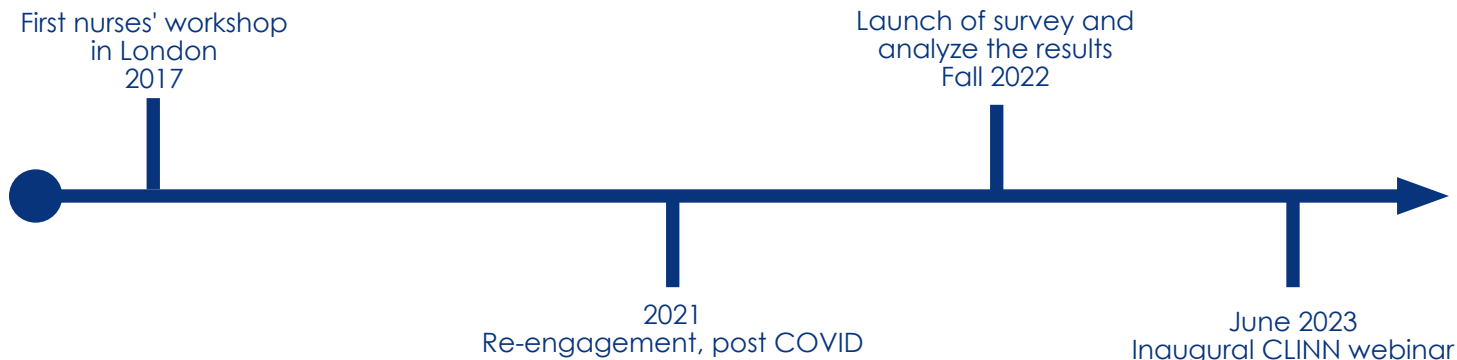
2 - Wound care education package tailored to cutaneous lymphoma patient population. What literature is available; what will an online wound care educational program look like; challenges inherent to the development of international guidelines.

### *What does the near future hold?*

The CLINN will be endeavoring to collaborate with nursing organizations within the US and internationally to promote this project. We are looking to create an innovative “home base” via a web-based platform where nurses can connect, learn from their colleagues, and ultimately improve care for the cutaneous lymphoma patient community.

Marianne Tawa, RN, MSN, ANP  
Nurse Practitioner, Cutaneous Oncology  
Dana Farber Cancer Institute, Boston, MA  
Board Member  
Cutaneous Lymphoma Foundation

### CLINN Timeline



## UPCOMING EVENTS

Plan now to join us for these upcoming educational events

### Patient Educational Forum

Denver, Colorado  
November 4, 2023

**25<sup>th</sup>**  
*Anniversary*

### and Patient Conference

Pasadena, CA  
April 13 -14, 2024

#### Visit

[www.clfoundation.org/upcoming-events](http://www.clfoundation.org/upcoming-events)  
or scan the QR-code  
to more learn about upcoming events.



# The Cutaneous Lymphoma Foundation Needs Your Continued Support

Help the Cutaneous Lymphoma Foundation provide the services and programs you've come to rely on. There are so many ways you can support the Cutaneous Lymphoma Foundation:

## To make an immediate impact:

- Make a gift to the Cutaneous Lymphoma Foundation in cash. Your gift may be increased if your employer has a matching program.
- Make a gift to the Cutaneous Lymphoma Foundation of appreciated assets, such as stock or mutual funds, which will provide you with a charitable deduction for the full current fair market value of your gift regardless of what you paid for the stock or mutual fund.

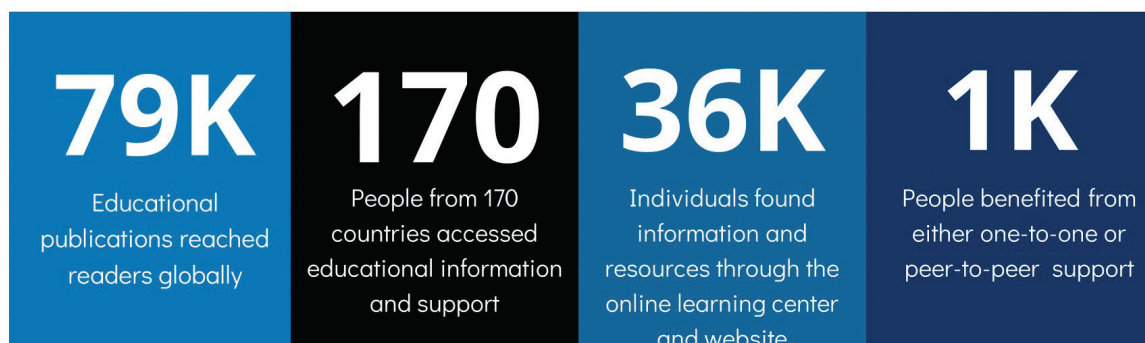


## To make a future gift to the Cutaneous Lymphoma Foundation:

- Make a gift to the Cutaneous Lymphoma Foundation in your estate plan through your Will or Trust.
- Make a gift to the Cutaneous Lymphoma Foundation by naming the Cutaneous Lymphoma Foundation as a beneficiary, in part or for all of your retirement plan. (Note the Cutaneous Lymphoma Foundation will receive the retirement plan funds completely tax free, whereas an individual beneficiary will be subject to income tax.)
- Make a gift to the Cutaneous Lymphoma Foundation by naming the Cutaneous Lymphoma Foundation as a beneficiary, in part or for all, of a life insurance policy.
- Make a gift to the Cutaneous Lymphoma Foundation by naming the Cutaneous Lymphoma Foundation as a beneficiary of a bank account or brokerage account upon your death.

Funds received by the Cutaneous Lymphoma Foundation have been used to further our mission to support medical research in Cutaneous Lymphoma and to provide patient education and support.

## 2022 Impact



If you have any questions or would like to discuss this further, please contact the Cutaneous Lymphoma Foundation at 248-644-9014 or [info@clfoundation.org](mailto:info@clfoundation.org) and your personal tax adviser or attorney for more information. Thank you again for your support - we can't do it without you! ❖

## LC Global Patient Survey...continued from pg 11

Foundation's International Patient Conference, held virtually in September 2022. 518 individuals with cutaneous lymphoma representing 29 countries responded to the survey, as did 53 caregivers. Some of the survey findings include:

- Almost 50% of the respondents waited 12 months or more to seek medical care after originally experiencing symptoms.
- Unique to cutaneous lymphoma when compared to the other lymphomas, for almost 50% of the respondents, it took 12 months or more after their initial medical appointment to be formally diagnosed - partially due to the similarity of the symptoms to other conditions.
- 66% of the respondents were given a different diagnosis before their CL was confirmed.
- Symptoms that most affected quality of life were skin rashes/lesions, itchy skin and fatigue. Fatigue showed up as both a symptom of the disease and the number one side effect of treatment.<sup>3</sup>

What is the value of this patient and care partner reported data? While global analysis provides an overall view of the patient/care partner experience, countries with 100 respondents or more prompt a region specific data analysis so that reported issues can be addressed on a local level. Equally important to what can be done with the survey data is how and where the data has already been used. The results from past surveys have been published in research papers and included in medical conference presentations and posters to broaden the knowledge of medical professionals, researchers and industry to the real impact lymphomas have on patient lives. Below is a brief list of some of the presentations<sup>4</sup> that have included cutaneous lymphoma data and where they were presented:

European Organisation For Research and Treatment of Cancer (EORTC) Meeting

- *A Cross-Sectional Study Examining the Diagnosis and*

*Psychosocial Experiences of Patients with Cutaneous Lymphomas* - 15 October 2021 (In collaboration with the Cutaneous Lymphoma Foundation)

American Society of Hematology (ASH) Annual Meetings

- *Patient Reported Experience with Fatigue, a Cross-Sectional Study Examining Indolent and Aggressive Lymphomas* - December 10-13 2022
- *A comparative analysis of patient experience and patient-doctor communication in patients with lymphoma and CLL: Clinical trials versus non-Clinical trials* - December 2021
- *Age-Related Differences in the Informational Experiences and Needs of Patients with Lymphoma: Results from the 2020 Lymphoma Coalition Global Patient Survey* - December 2021

American Society for Clinical Oncology (ASCO) Annual Meeting Abstract

- *A Comparative Study of Unmet Information Needs of Patients with Lymphoma and CLL: North America and Europe* - June 2022

European Hematology Association (EHA) Congress

- *A Comparative Study of the impact of Countries Health Expenditure on the diagnosis experiences of patients with lymphoma and CLL in Europe* - June 2022

Your next opportunity to participate in the Global Patient Survey is coming up in 2024. Wherever you may reside, your experience as an individual with cutaneous lymphoma or as their care partner is vitally important - it can help ensure better care and treatments, but also a more equitable access to the same care and treatment that is available to others. ❖

**Except for where cited, information for this article was sourced from the following:**

Lymphoma Coalition. (2023). *2022 Global Patient Survey on Lymphoma & CLL*.

[https://lymphomacoalition.org/wp-content/uploads/GPS-2022-Global\\_Report\\_-Nov-22-final.pdf](https://lymphomacoalition.org/wp-content/uploads/GPS-2022-Global_Report_-Nov-22-final.pdf)

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TIME SENSITIVE MATERIALS ENCLOSED



## Cutaneous Lymphoma Care-A-Thon

Text: 2023CARE to 53-555

As a part of Blood Cancer Month, World Lymphoma Awareness Day (September 15) and Rare Cancer Day (September 30):

**September = Cutaneous Lymphoma Awareness Month**

Show someone you care by participating in the **2023 Care-A-Thon** for cutaneous lymphomas.

Your gift goes a long way to providing **education, support, advocacy, awareness and funding research** for you and the next person with a cutaneous lymphoma diagnosis.

Don't wait, text: **2023CARE** to **53-555** to make a donation, start a fundraiser or both!



Together, we make a  
difference in  
cutaneous lymphomas!

***Together we will make a difference for people affected by cutaneous lymphoma!***