CUTANEOUS
LYMPHOMA
FOUNDATION

IMPACT REPORT

July 2024 – June 2025

I am new to MF as a patient. As a bioscientist, I’m also interested in this disease. This conference was a good balance between those objectives, and organized and implemented with great care for patients and families, with participation from excellent medical practitioners knowledgeable about CTCL.

- Conference Attendee

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Letter from the CEO and Board President

Fiscal Year 2025 (July 2024 - June 2025) marked a significant phase in the evolution of the Cutaneous Lymphoma Foundation as we navigated various changes and challenges while continuing to provide the essential programs and services our community relies on.

This year, we expanded our global reach and launched new initiatives, including Coffee & Community: Cutaneous Lymphoma Conversations podcast. We remained committed to empowering, advocating for, and uniting the cutaneous lymphoma community.

Connecting with individuals affected by rare diseases often poses challenges. In this Impact Report, you will see how the Foundation has grown our global community while engaging in international initiatives to stay informed about new policies or events that may impact us. Being the voice of this rare disease for all stakeholders is crucial to raising awareness and ensuring that the experiences of patients and care partners are represented in decision-making processes.

It's essential to bring community members forward to share their lived experiences with policymakers, clinicians, researchers, and therapy developers, ensuring that patients and care partners remain at the center of these discussions. Despite the shifting landscape, the CL Foundation continuously keeps our core vision in focus - **achieving a life free from the burdens of cutaneous lymphomas.**

Our daily work would not be possible without the invaluable support of our donors and the incredible volunteers who dedicate their time and talents to bringing the Foundation's mission to life. We also extend our gratitude to our fantastic staff, whose skills and dedication have made our accomplishments possible.

We invite you to enjoy the highlights of the year and recognize that much more has been achieved than can be captured on these few pages.

Thank you for being a part of this ongoing journey!

Susan

Susan Thornton
CEO

David

David Elefant
Board President

About the Foundation

Mission

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

- **Empowers people with cutaneous lymphomas and their care partners through impactful education and support services**
- **Influences decisions that can transform lives**
- **Promotes research focused on addressing the most critical unmet needs**

Vision

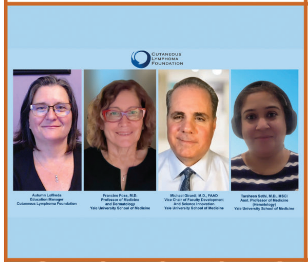
A life free from the burdens of cutaneous lymphomas

Values

The following values are the core principles and beliefs that guide CL Foundation's behavior, decisions, and culture:

- **Community: Compassion, collaboration, inclusivity**
- **Organization: Leadership, transparency, evidence-based action**

Year in Review

July	August	Septmeber	October	November	December
Patient Educational Forum Virtual	Attended American Academy of Dermatology Innovation Conference	International Patient Conference Virtual			Forum Newsletter Published
	Instagram Launched		Attended Lymphoma Coalition Global Summit Rome, Italy		Answers from the Experts: Open Q&A Virtual
	Patient Education Forum Seattle, WA	Facebook Networking Group Launched		Patient Educational Forum Orlando, FL	Attended American Society of Hematology Annual Meeting – Presented Young Investigator Award
		Forum Newsletter Published	Attended National Organization for Rare Disorders (NORD) Breakthrough Summit		

I don't feel alone and I have a lot of hope for the future. The depth of knowledge, expertise, commitment, and

January	February	March	April	May	June
		Attended United States Cutaneous Lymphoma Consortium Annual Conference		Advocates at Coalition of Skin Diseases Hill Day Washington, DC	
			Coffee & Community: Cutaneous Lymphoma Conversations Podcast Launches		Patients Seminar Cutaneous Lymphoma Dublin, Ireland
Spanish Language Patient Educational Forum Virtual	Advocates at Rare Disease Week Washington, DC	Attended Academy of Dermatology Conference Orlando, FL			Attended International Conference on Malignant Lymphoma – Presented Young Investigator Award
	Answers from Experts: Open Q&A Virtual		Annual Patient Conference Philadelphia, PA	Attended GlobalSkin Conference and RareDerm Workshop Prague, Czech Republic	

compassion of the doctors and professionals in the cutaneous lymphoma community is awe inspiring. **- PEF Attendee**

Programs & Services

Education & Support

Annual Patient Conference

- The annual Patient Conference in Philadelphia brought together 126 attendees, including 53 in-person participants and 73 virtual attendees from nine countries. The event featured expert-led sessions on cutaneous lymphoma diagnosis, treatment, and research, along with engaging breakout activities like laugh yoga to promote well-being. To increase accessibility, all clinical presentations were livestreamed. Post-event surveys showed a strong impact, with 88% of respondents learning something new and 82% expressing interest in future programs.

Patient Educational Forum - Orlando/Seattle/Virtual

- Patient Educational Forums (PEFs) are one-day events providing credible, up-to-date information directly from practicing clinicians, as well as opportunities to connect with peers. Attendees consistently find these events empowering and reassuring, gaining clarity on treatment options, research developments, and ways to improve their quality of life. Just as importantly, PEFs foster a sense of connection and community, reminding participants that they are not alone on their journey.

Answers From the Experts: Open Q&A

- Answers From the Experts (AFTEs) are among our most popular programs, offered virtually every other month as open Q&A sessions with expert clinicians. These sessions can cover a wide range of topics, including variants, treatments, itch management, skincare, nutrition, and more. Over the fiscal year, clinicians answered more than 104 questions—averaging 26 per session. Recordings are available on our YouTube channel, https://bit.ly/CutaneousLymphomaFnd, and rank among our most-viewed content.

Monthly Networking Groups

- The Cutaneous Lymphoma Foundation hosts two online peer-to-peer networking groups monthly. Group members engage in discussions centered on education, emotional resilience, and practical self-care. A recurring theme is the power of shared experience - finding strength in connecting with others facing similar challenges, gaining reassurance, and learning new coping strategies. Hearing from others and sharing their own stories helps members feel empowered, informed, and less alone in their journey.

Online Networking Group

"Whether you're newly diagnosed, a long time sufferer or a care giver, this is a very useful group to attend to gain extra knowledge from others on the journey" - Attendee

> The CL Foundation’s website and events have become a very important source of information and comfort to me and my son who is dealing with MF. We both thank you so much for all you do to improve our level of knowledge, our feeling of community and our overall “mental health.” Thank you for being there for us!! **- Donor**

Community Outreach

Podcast: Coffee & Community Conversations

- In April 2025, we introduced our Coffee & Community: Cutaneous Lymphoma Conversations podcast. The podcast brings together the many voices of the cutaneous lymphoma community to share both their experiences and knowledge about cutaneous lymphomas. From conversations with individuals living with the disease to clinicians and researchers actively pursuing a better understanding of the disease and its impact, the podcast is one more way to keep the cutaneous lymphoma community well informed. Since April, the podcast has been downloaded over 1,000 times across more than 40 countries.

Forum

- Published three times a year, the Forum newsletter features in-depth articles on topics that matter to the cutaneous lymphoma community. This year, we introduced a refreshed look—including a redesigned cover—and a renewed editorial focus: ensuring every article answers the question, “Why does this matter to our community?” By listening closely to patients and care partners through their questions and conversations, we aimed to deliver content that’s both useful and meaningful.

  Over 21,000 print copies were delivered to mailboxes, and over 9000 electronic copies arrived in inboxes around the world. This doesn’t account for the hundreds of copies downloaded or viewed from the website.

CUTANEOUS
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FORUM

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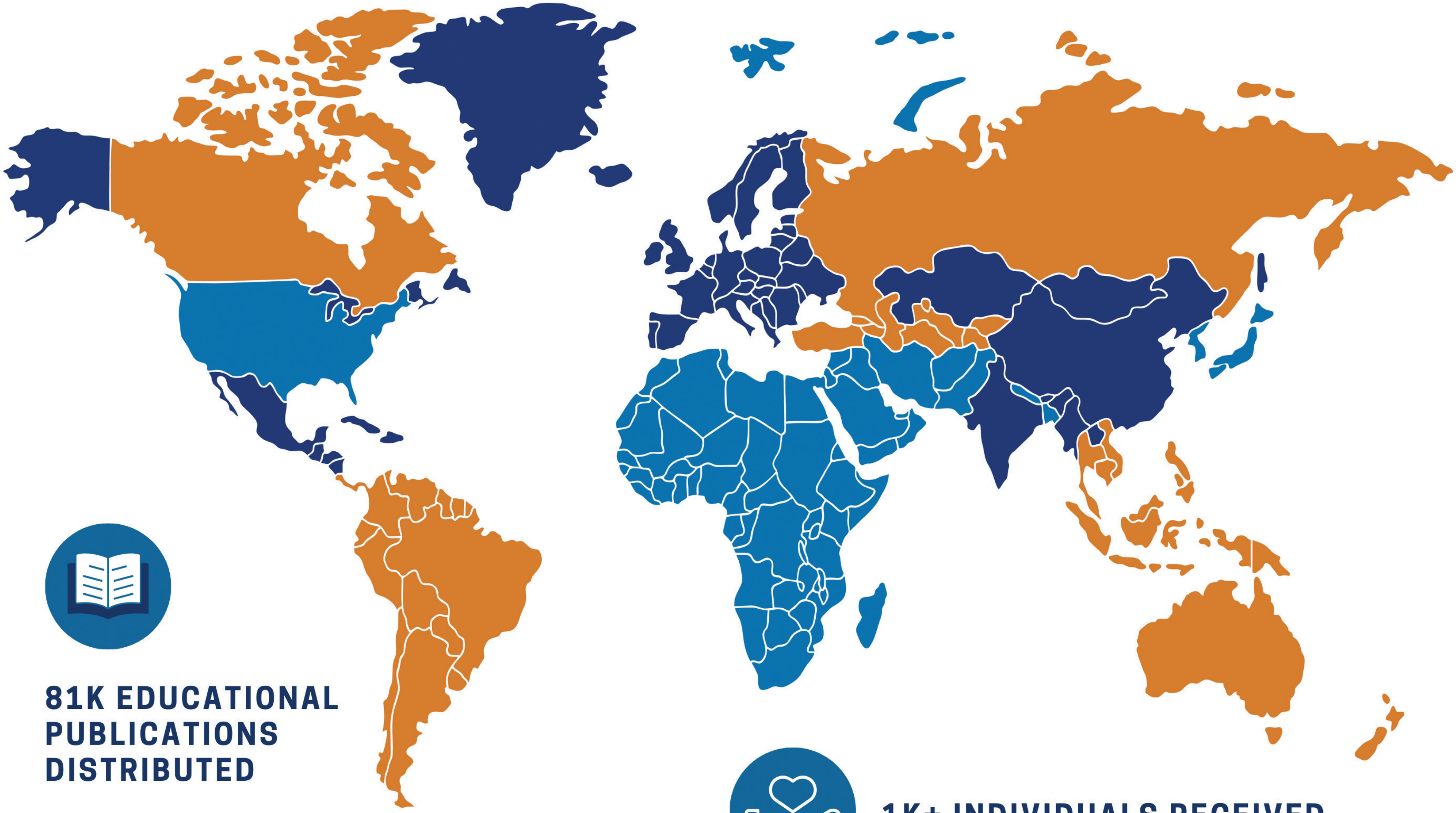
eNews

- Each month, our eNews was sent to nearly 3,500 inboxes. That’s over 42,000 newsletters sent in FY2025 to keep the community informed. They shared important news, invited people to educational events, and highlighted ways to get involved in advocacy, research, and fundraising. The eNews is a great way to stay current with what is going on in the cutaneous lymphoma world.

ONLINE LEARNING CENTER: 114K USERS FROM 175 COUNTRIES



81K EDUCATIONAL PUBLICATIONS DISTRIBUTED

1K+ INDIVIDUALS RECEIVED ONE-TO-ONE OR PEER SUPPORT

Advocacy & Awareness

The Cutaneous Lymphoma Foundation advocates on behalf of people living with cutaneous lymphomas to affect positive change on many important fronts. We also empower our community members to advocate for themselves. Highlighted below are some of the advocacy and awareness events and programs we engaged in this past fiscal year.

Legislative Days and Awareness Campaigns

Members of the cutaneous lymphoma community joined staff at the following advocacy events to bring their stories and shared concerns to the attention of members of Congress to help advance positive changes.

- Rare Disease Week in DC - February 2025
- Coalition of Skin Diseases Hill Day in DC - May 2025

Patient Opinion Leader

Patient opinion leaders are people with detailed knowledge of a health-related topic, as patients themselves or as care partners, and have the ability to influence healthcare decision making. The Foundation's CEO, Susan Thornton, has responded to requests by both collaborative partners, clinician researchers, and industry partners to help advance better care and treatments for cutaneous lymphoma.

- National Comprehensive Cancer Network T-Cell/Cutaneous Lymphoma Panel - Patient Expert Representative
- International Dermatology Outcome Measures Cutaneous Lymphoma Workgroup - Patient Expert Representative
- Industry Sponsored Study PROSPER: Prospective Research Based Observational Study of Poteligeo Experience in the Real World - Patient Expert Partner
- Industry Sponsored CTCL Forum for Healthcare Professionals - Patient Expert Keynote Presentation

Representation in Global Coalitions

The CL Foundation joins global coalitions to help achieve our mission and strategic goals. We have represented the cutaneous lymphoma patient voice and perspective through our engagement with the following organizations:

- Coalition of Skin Diseases*
- Cutaneous Lymphoma International Nurses Network*
- European Organisation for Research and Treatment of Cancer (EORTC)
- GlobalSkin*
- International Cutaneous Lymphoma Coalition*
- International Experience Exchange with Patient Organisations (IEEPO)*
- International Society for Cutaneous Lymphomas
- Lymphoma Canada
- Lymphoma Coalition*
- National Organization for Rare Disorders
- RareDERM*
- Rare Cancer Coalition
- Rare Diseases International
- United States Cutaneous Lymphoma Consortium (USCLC)
- World Skin Health Coalition*

*Foundation leadership held position in leadership, committee or as a workgroup member.

Quality of Life Collaborative Efforts

Throughout the year, we requested individuals affected by cutaneous lymphoma and their care partners to participate in surveys and studies to share the impact cutaneous lymphoma has on their day-to-day life. The goal of these surveys is to ultimately improve the quality of life of those living with cutaneous lymphoma.

- Financial Impact and Challenges of Cutaneous Lymphoma: A Patient's Perspective survey - Dr. Gregg Murray and Dr. Kevin Molloy, Department of Dermatology, Tallaght University Hospital
- Prescription Drug Affordability - Patient Inclusion Council
- Industry Sponsored Study PROSPER: Prospective Research Based Observational Study of Poteligeo Experience in the Real World

The Foundation supported the efforts of our collaborative partners' resolutions to the World Health Agency (WHA) to raise awareness of the impact of, and improve treatment globally for, both skin and rare diseases. Both resolutions were passed.

- Rare Diseases International - the WHA Resolution on Rare Diseases
- GlobalSkin - WHA Resolution "Skin Diseases as a Global Public Health Priority"

Research

Young Investigator Award

The CL Foundation continues to advance research and support researchers in cutaneous lymphoma through its Young Investigator Award, which has helped cultivate a lasting community of researchers in the field. Recipients of the $1,500 award must be presenting cutaneous lymphoma specific research at a major medical meeting. We provided awards to the following medical meetings:

- International Conference on Malignant Lymphoma – June 2025
- American Society of Hematology Annual Meeting – December 2024

Patient-Reported Data

Another component of our research awards program is participation in patient-reported data collection to improve treatments, care, and speed up accurate diagnoses. We are grateful to our community members for participating in the following:

- Lymphoma Coalition - Global Patient Survey (342 responses in 2024)
- International Dermatology Outcome Measures (IDEOM) - Health-Related Quality of Life in CTCL Patient Survey
- GlobalSkin - Patient-Reported Impact of Dermatological Diseases (PRIDD) tool
- University of Washington/Dr. Michi Shinohara - A Qualitative Study on the Experience of Sexual and Gender Minorities with Cutaneous T-cell Lymphoma
- Cutaneous Lymphoma Patient Story Abstracts
- And other specific patient input requests throughout the year

T-cell Lymphomas International Scientific Workshop

Through a generation donation, the Foundation was able to sponsor the cutaneous lymphoma track at the Lymphoma Research Foundation's T-cell Lymphomas International Scientific Workshop held in May 2025. The workshop brought together the world's leading T-cell lymphoma experts to discuss the latest research findings, plan future studies, foster collaboration within the research community, and create a research agenda, which in turn could prioritize T-cell lymphoma research and improve outcomes. CL Foundation leadership served on the steering committee for the workshop.

Together Online

How Our Community Stays Connected

Facebook Community
500+ Members

Facebook
4.15K+ followers, 44K reach

Instagram
294K Followers, 3K reach

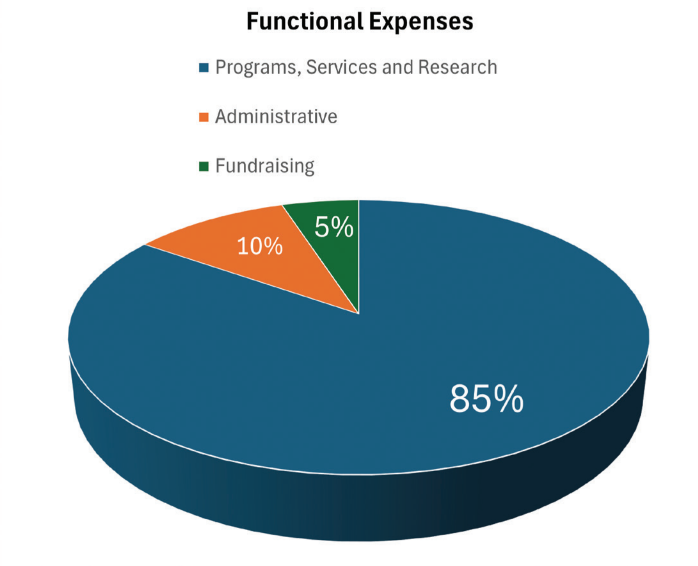
LinkedIn
929 Followers,
69.5K impressions

YouTube
3.4K+ Subscribers
394 videos, 439K views

Financial Overview

STATEMENT OF ACTIVITIES • YEAR ENDED JUNE 30, 2025

	Unrestricted	Temporarily Restricted	Total
SUPPORT AND REVENUE:			
Contributions and grants	235,593	589,360	824,953
Interest income	11,880	0	11,880
TOTAL SUPPORT AND REVENUE	247,473	589,360	836,833
NET ASSETS RELEASED FROM TEMPORARY RESTRICTIONS	535,999	(535,999)	0
	783,472	53,361	836,833
FUNCTIONAL EXPENSES:			
Program	913,760	0	913,760
Management and general	110,815	0	110,815
Fundraising	54,339	0	54,339
TOTAL FUNCTIONAL EXPENSES	1,078,914	0	1,078,914
CHANGE IN NET ASSETS	(295,442)	53,361	(242,081)
NET ASSETS - Beginning of year	595,403	533,686	1,129,089
NET ASSETS - End of year	$299,961	$587,047	$887,008



STATEMENT OF FINANCIAL POSITION • YEAR ENDING JUNE 30, 2025 AND 2024

	2025	2024
ASSETS		
CURRENT ASSETS		
Cash and cash equivalents	565,933	752,007
Certificate of deposits	248,002	239,480
Promises to give	82,382	126,155
Total current assets	896,317	1,117,642
FIXED ASSETS		
Property and equipment	150,951	150,951
Right of Use Asset	36,416	57,624
Less: Accumulated depreciation	148,835	134,940
Total fixed assets	38,532	73,635
OTHER ASSETS		
Prepaid expenses	0	10,973
Security deposit	1,706	1,706
Total other assets	1,706	12,679
TOTAL ASSETS	$936,555	$1,203,956

	2025	2024
LIABILITIES AND NET ASSETS		
CURRENT LIABILITIES		
Accounts payable	13,131	17,243
Lease payable - current	19,800	19,069
Total current liabilities	32,931	36,312
LONG TERM LIABILITIES		
Lease payable - long term	16,616	38,555
Total long term liabilities	16,616	38,555
Total liabilities	49,547	74,867
NET ASSETS		
Net assets without restrictions	299,960	595,403
Net assets with restrictions	587,048	533,686
Total net assets	887,008	1,129,089
TOTAL LIABILITIES AND NET ASSETS	$936,555	$1,203,956

Looking Ahead

As we look ahead to 2026 and beyond, several key initiatives are being developed to advance our mission and improve outcomes for individuals affected by cutaneous lymphoma. These efforts reflect a strategic focus on collaboration, patient-centered innovation, and long-term impact. The following summary outlines the major projects currently in planning or early development stages.

Quality of Life Symposium (November 2026)

A landmark multi-stakeholder workshop to bring together everyone working on quality-of-life projects for those living with cutaneous lymphoma. Currently, there are many diverse stakeholders working separately on the issue. The symposium aims to bring the community together to share ideas and develop a plan for moving forward. The Cutaneous Lymphoma Foundation will serve as the host of the program, given our role in representing the patient's voice across all stakeholders.

Patient Experience Roadmaps

Throughout 2026, we will begin developing comprehensive patient experience roadmaps for the different subtypes of cutaneous lymphoma. These roadmaps will illustrate the journey from the first symptoms to living well day-to-day, given the nature of the variant. This is expected to be a multi-year project that will inform care strategies and patient support.

Key Patient Opinion Leaders Program

We are launching a major initiative to identify, train, and make available key patient opinion leaders. This project will fall under our Patient Ambassador Program with these trained individuals serving across clinical and advocacy efforts (both regulatory and policy), representing the patient's voice to meet global needs. Curriculum development and initial training will be a central focus in 2026.

Earlier Diagnosis Campaign

An advocacy and awareness campaign is in development to promote earlier diagnosis. Potential collaboration with Moffitt Cancer Center’s dermatology education series may serve as a pilot for regional clinical engagement. Additionally, we aim to support the distribution and potential open-source funding of the “A through F – Think MF” diagnostic tool created by Dr. Julia Scarisbrick and Dr. Kevin Molloy, targeting general practitioners and dermatologists among others.

All of these projects are part of a bigger plan toward achieving long-term goals such as earlier diagnosis, improved access to care, and timely, appropriate therapy. Each project contributes to a broader vision of enhancing patient outcomes and quality of life through coordinated, sustained efforts.

> The connection with other Warriors is priceless. And, to have the opportunity to listen, learn and ask questions from the attending practitioners is invaluable and important to the journey of living successfully with CTCL. **- Conference Attendee**

Get Involved

From donating to joining a networking group to writing a letter to your elected leaders, there are multiple ways for you to get involved and help the Cutaneous Lymphoma Foundation make a difference for the next person diagnosed with this rare disease.

Join the online community - Sharing your daily experiences with cutaneous lymphoma can help others feel less alone and more understood, especially when the disease is unfamiliar to those around you.

Share your story - Telling your story—from when you were diagnosed to how you live with the disease and its treatments—can give hope, help others understand, and make a big difference for you and the people who hear it.

Volunteer or become a Patient Opinion Leader - Patient opinion leaders are those with detailed knowledge of a health-related topic, as patients themselves or as care partners, who have the ability to influence healthcare decision making.

Donate or fundraise - Your support of the Cutaneous Lymphoma Foundation helps change lives by providing important resources, education, support groups, awareness programs, and research to help people facing this disease.

Participate in research and surveys - More and more, researchers and therapy developers are focusing on what patients are going through, and by sharing your story you can help improve treatments and care for others.

You can learn more about these opportunities to get involved in the work of the CL Foundation by visiting the Get Involved section of our website: **www.clfoundation.org/get-involved-0**

Acknowledgements

Donors & Supporters

The Cutaneous Lymphoma Foundation is deeply grateful to every donor who supported our mission during the 2025 fiscal year–you are the reason we can continue to grow, serve, and make a global impact. Your generosity has empowered us to reach over 114,000 individuals across 175 countries, ensuring that those affected by cutaneous lymphoma receive the information and support they deserve.

A special thank you to our first-time donors, recurring supporters, major contributors, and those who gave in honor of loved ones—we are truly grateful for your decision to support our mission.

Together, we are changing lives.

Corporate Partners

The Cutaneous Lymphoma Foundation wishes to thank the following corporate partners for their support:

CITIUS PHARMA

HELSINN
Building quality cancer care together

KYOWA KIRIN

Mallinckrodt
Pharmaceuticals

Ortho Dermatologics

Therakos™ LLC

Volunteers

Thank You to Our Patient and Care Partner Volunteers

We extend our deepest gratitude to the incredible patient and care partner volunteers who have generously shared their personal journeys with cutaneous lymphoma. Whether through advocacy, podcast appearances, newsletter contributions, or speaking at educational events, your voices have brought hope, understanding, and inspiration to so many. Your courage and commitment help build a stronger, more informed community, and we are truly honored to walk alongside you in this mission.

Thank you for making a difference.

Medical Professionals

We wish to thank the many medical professionals and researchers who have volunteered their time and expertise as advisors, translators, speakers, or contributors to our publications. It is due to their commitment to those living with cutaneous lymphoma that we are able to provide vetted, timely, and reliable information.

Past Advisors - Medical/Research

- **Thomas Anderson, MD**
- **Jaehyuk (Jay) Choi, MD**
- **Kevin Cooper, MD**
- **Madeleine Duvic, MD**
- **Lars French, MD**
- **Christine Eischen, PhD***
- **Sam Hwang, MD, PhD**
- **Richard Hoppe, MD**
- **Glenn Jones, MD**
- **Steven Jones, MD**
- **Barry Kacinski, MD, PhD**
- **Ellen Kim, MD***
- **Robert Knobler, MD**
- **Thomas Kupper, MD**
- **Liliane LaRoche, MD**
- **Stuart Lessin, MD***
- **Sue McCann, MSN, RN, DNC**
- **Laura McGirt, MD**
- **Amy Musiek, MD**
- **Lauren Pinter-Brown, MD**
- **David Ramsay, MD**
- **Alain Rook, MD**
- **Lucia Seminario-Vidal, MD**
- **Christopher Shipp**
- **Martin Weinstock, MD, PhD**
- **Lynn Wilson, MD, MPH**

***Council Chairs**

Translations Workgroups

American Spanish

- Abigail Martinez, MS, Project Leader
- Frank Trujillo, BS
- Miguel Aristizabal, MD
- Diana Olvera, BS
- Claudia Francia, MD
- Claudia Perez Draper, MD
- Ann Pacheco, BS
- Maria Lalama, BS

Arabic

- Dr Rasha Tawab
- Dr Jihan Younos

Hebrew

- Shamir Geller, MD

Clinical Speakers/Presenters

- Lindsay Ackerman, MD, FAAD
- Muhamad Alhaj Moustafa, MD, MS
- Stefan Barta, MD, MS, MRCP
- Erin Boh, MD, PhD, FAAD
- Odette Buelens, BN, RN, PGDipNur, MN, NP
- Jina Chung, MD
- Caitlin Crimp, MD
- Steve Daveluy, MD
- Francine Foss, MD
- Shamir Geller, MD
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- Michael Girardi, MD
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- Vincent Liu, MD
- Elizabeth Loggers, MD, PhD
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- Eric Mou, MD
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- Pablo Ortiz-Romero, MD, PhD
- Theresa Pacheco, MD
- Evangelia Papadavid, MD, PhD
- Christina Poh, MD
- Pierluigi Porcu, MD
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- Jason Sluzevich, MD
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- Rasha Tawab, MD
- Cesar Virgen, MD, PhD
- Jennifer Wang, MD
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- Jasmine Zain, MD
- Yumeng Zhang, MD

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Erick Lansigan
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Anjali Mishra, PHD
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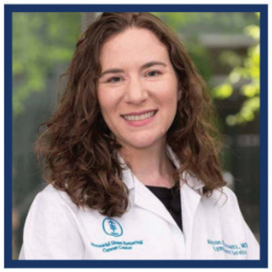
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Steven Rosen, MD
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Debjani Sahni, MD
Dermatology
Boston University Medical
Center


Sean Whittaker, MRCP
Dermatology
St. Thomas Hospital


Jasmine Zain, MD
Hematology/Oncology
Memorial Sloan Kettering
Cancer Center

The Cutaneous Lymphoma Foundation connects, empowers, unites and gives voice to those with this rare chronic condition. You will feel part of a united community--virtually, online, in person–with an international and global footprint.

- Conference Attendee

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