



FORUM

WHAT IS ADVOCACY?

What comes to your mind when you hear the word “advocacy?” In doing a quick Google search, a few definitions came up.

The Alliance for Justice defines advocacy as **“any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others.”**¹

According to Mind, an online mental health support organization, it means getting support from another person to help you express your views and wishes, and help you stand up for your rights. Someone who helps you in this way is called “your advocate.”²

It can be challenging to find a single, simple definition of advocacy in the context of the Cutaneous Lymphoma Foundation and how we strive to advocate as one of our strategic goals: Have a strong influence over health service, regulatory and policy decisions that impact on the lives of people with cutaneous lymphoma.

Stronger Together

When we use the term “advocacy,” the first thing that may come to mind are actions related to governmental policy and regulations. While frequently used interchangeably, policy is the making of the “rules,” while regulations help ensure that the rules are followed (see page 6).

The CL Foundation engages in many policy initiatives, both in the U.S. and abroad, to help bring the cutaneous lymphoma patients' views to the issues. Working with other patient advocacy organizations helps us to stay on top of the issues and provides a better understanding of the implications that any policy or regulatory proposal may have specifically on our patient community.

This collaborative engagement can also help make us aware of potential future problems for our community, like changes to insurance reimbursements, and how we might help individuals navigate them. It can also help shine a light on where the patient community as a whole may face common challenges, and by joining our voices we can strengthen our message on issues that impact those living with a rare disease.



Bringing your stories to Capitol Hill

Advocacy...continued on page 6

2023 Issue 4 - Advocacy Edition

Have a strong influence over health service, regulatory and policy decisions that impact on the lives of people with cutaneous lymphoma.

From the President and the Chief Executive Officer	3	CL Foundation Advocacy - Behind the Scenes.....	8
Board of Director News.....	3	Frequently Asked Questions	10
My Cutaneous Lymphoma Journey	5	Emerging Topics in Patient Advocacy.....	11
Avenues of Advocacy.....	7		

CUTANEOUS LYMPHOMA FOUNDATION

*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

MEDICAL ADVISORY COUNCIL

Michi Shinohara, MD (Chair)	University of Washington
Wei Ai, MD	University of California San Francisco
Kim Bohjanen, 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 Lintz Loffreda	Education Manager
Sue McCann, MSN, RN, DNC	Services Manager
Deb Van Zegeren	Special Projects Manager
Susette Arnot	Programs and Services Assistant
Bandna Viridi	Office Assistant

What Is Cutaneous Lymphoma?

Cutaneous lymphomas are cancers of lymphocytes (white blood cells) that primarily involve the skin. Classification is based on lymphocyte type: B-lymphocytes (B-cell) or T-lymphocytes (T-cell). Cutaneous T-cell lymphoma (CTCL) is the most common type of cutaneous lymphoma that typically presents with red, scaly patches or thickened plaques of skin that often mimic eczema or chronic dermatitis. Progression from limited skin involvement is variable and may be accompanied by tumor formation, ulceration and exfoliation, complicated by itching and infections. Advanced stages are defined by involvement of lymph nodes, peripheral blood, and internal organs. 🌸

FORUM

The newsletter of the Cutaneous Lymphoma Foundation
ALL RIGHTS RESERVED

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

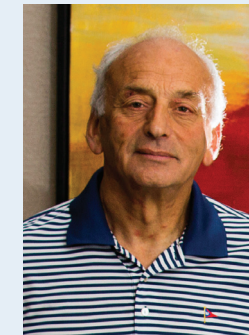


FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

Laurel Carlson, Board President; Susan Thornton, CEO

BOARD OF DIRECTORS NEWS

The Cutaneous Lymphoma Foundation bids farewell to two members of our Board of Directors.



Jeff Ward

The Foundation sends a heartfelt thank you to Jeffrey Ward for his many years of service. Jeff joined the Board in 2011 after being diagnosed with cutaneous lymphoma in 2007. Throughout his time with the Foundation, he has served as the Foundation's Treasurer, and has been committed to creating a sustainability plan and advancing research in cutaneous lymphomas. To say Jeff is leaving the Foundation in a better place than when he joined would be an understatement. We are grateful for his passion, dedication, and attention to detail. True to who he is, Jeff has agreed to continue serving on the Finance committee to ensure a smooth transition.



Michael W. Young

The Cutaneous Lymphoma Foundation sends special thanks to Michael W. Young for his 22 years of dedication to the Foundation and the people we serve. Michael became involved in the Foundation in 2002 and was part of the first Board of Directors formed in early 2003. Michael brought his deep passion and appreciation for people affected by cutaneous lymphomas and his knowledge and expertise in drug development. He was integral in bringing visibility to cutaneous lymphoma, the Cutaneous Lymphoma Foundation, and elevating the patient's voice across the clinical and industry communities.

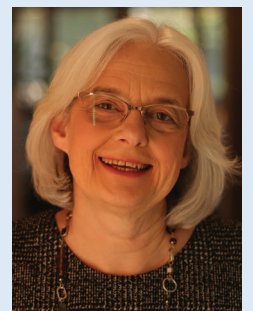
Throughout his years with the Foundation, Michael has served in many roles, including President and Industry Advisor. Regardless of his title, Michael has always been willing to step in wherever needed. We are fortunate for Michael's years of Board service, including his unwavering passion and dedication to championing all people affected by cutaneous lymphomas. Thank you, Michael; we are deeply grateful for your time and commitment - we wouldn't be here without you.

Celebrate How Far We Have Come & Looking to the Future

The annual holiday season is here again. However, this December is notable for the Cutaneous Lymphoma Foundation. We officially turned 25 on December 11, the date when our original Articles of Incorporation were filed in 1998. Making it to 25 is a big deal. The National Center on Charitable Statistics reports that about 30 percent of all nonprofits will close within ten years.

As 2023 comes to a close, we are taking time to reflect on how far the Foundation has come and how many people's lives have been impacted by our programs and services. It's mind-blowing to think that the seeds of the current Foundation were planted when Judy Jones had the idea to connect people who had been diagnosed with the same disease via the internet. From the basement of her home in Michigan, Judy started an email-based listserv that grew into the Mycosis Fungoides Foundation with 501(c)(3) nonprofit status. The Mycosis Fungoides Foundation evolved into the Cutaneous Lymphoma Foundation and has grown into a thriving international organization, leveraging technology to make sure everyone who gets a cutaneous lymphoma diagnosis has credible resources and support for their journey. Each of you has been an essential part of this evolution, and our work feels like it is only beginning.

While proud of our accomplishments over the past 25 years, we have our eyes on the future. Advocacy is one of the pillars of our new strategic plan which is why it is the focus of this issue of the Forum. Advocacy means different things to different people, so we wanted to share how the Foundation approaches advocacy and provide insight into why this is so important, especially as we look ahead. As you read this issue, you'll see that we are engaged in multiple areas of advocacy. Our advocacy efforts include: promoting the inclusion of the patient perspective as part of the clinical trial process to help ensure that new therapies for rare diseases, like cutaneous lymphoma, have the best chance of



Laurel Carlson



Susan Thornton

From the Board...continued on page 4

From the Board...continued from pg 3

passing through clinical trials and regulatory approval; helping to collect and share data about our community’s lived experience with clinicians to provide insight into better ways to deliver care and treatment; making use of available communication channels to inform clinicians, researchers, and the public that cutaneous lymphoma is a rare disease and is often misdiagnosed - an awareness that is critical to ensuring everyone is diagnosed as early as possible and adequately. All of these efforts fall under the umbrella of “advocacy.”

And then there is also personal, individual advocacy. How do you or your care partners become well-informed and confident with your understanding of this complex disease to engage in a dialogue with your healthcare providers to make the best care and treatment decisions for you? That’s where the Foundation has played a critical role in bringing education and knowledge to our community. Whether it’s the live Answers from the Experts Q&As held online every other month, the printed Forum quarterly newsletter, or updated clinical content on the website, we strive to find the best ways to deliver information to you so you can become an empowered person, comfortable and confident in advocating for your own care.

Throughout the following year, we will be celebrating 25

years of serving our community and looking for new ways to broaden and deepen our connections with you in order to serve your needs every step of the way.

We hope you will celebrate with us this year. We will be hosting a fun Saturday evening event as part of our annual 2-day Patient Conference to be held in April in Pasadena, California. We hope you can join us.

Finally, we would be remiss if we didn’t mention two incredible advocates transitioning from our Board of Directors, Michael W. Young and Jeff Ward. Michael and Jeff have served for many years in their Board capacities and many other ways as advocates beyond their dedication to Board service. Deep gratitude to both for their passion for the work of the Foundation and their commitment to service.

Enjoy this issue and know that your voice is essential; you are heard, and we take you with us everywhere we go.

MY CUTANEOUS LYMPHOMA JOURNEY

Shared by Candi S.

Cutaneous lymphoma is a unique disease, and no two patients share the exact same journey. Some patients face adversity more than others; however, similarities regarding symptoms, access to care, barriers to care, and treatment options are commonly shared among patients with this diagnosis.



Candi is from the Pittsburgh area and has lived there her entire life. Like many others, her journey began in 2020 with a rash and itching that was not improving. She was diagnosed with eczema and then psoriasis, and failed numerous therapies that are commonly prescribed to treat these conditions. With growing

frustration and no improvement, a biopsy was performed a year and a half later, and she was finally diagnosed with mycosis fungoides. Candi was fortunate to establish her care in Pittsburgh with a cutaneous lymphoma expert.

Candi has had her share of struggles in managing her mycosis fungoides. She has tried multiple treatments commonly used for the treatment of mycosis fungoides including extracorporeal photopheresis, methotrexate, and topical steroids. Candi faced further barriers to care regarding ineligibility for numerous clinical trials due to past diagnoses of tongue cancer (2017) and breast cancer (2018) for which she received radiation treatment and ongoing antineoplastic therapy.

As Candi’s symptoms and disease continued to progress, she was prescribed mogamulizumab. As many others with this

disease have learned, treatments can be incredibly expensive, and Candi was devastated to learn that she would not be able to afford the copay even with Medicare insurance. Candi did not let this stop her. Candi, her physician assistant, and the rest of her supportive treatment team advocated to get Candi any financial assistance that she would qualify for. Persistence and advocacy on her behalf allowed Candi to have her mogamulizumab treatments free of charge. She is forever grateful for that experience, and amazingly had great relief from that treatment for a period of time.

After a year of mogamulizumab treatments, Candi was doing so well that her physician decided she could stop therapy. Candi was without treatment for a year before her mycosis fungoides started to relapse. Candi was hopeful she could restart mogamulizumab as it had worked in the past; however, this time she learned she cannot afford the medication copays, AND she no longer qualifies for copay assistance as the pharmaceutical company's requirements have changed.

Candi would like others to know that many pharmaceutical companies have a nurse navigator that will work with patients and their treatment team to navigate patient assistance programs. The type and amount of assistance given to patients will vary program to program. Candi reached out to multiple organizations for assistance, with no luck at this time. She has not given up hope and is currently working with her physician, treatment team, and patient assistance programs to find a treatment that will not only help but is also affordable. Advocacy, as Candi learned, is an ongoing process, with ongoing hurdles. However, it is imperative to never give up. ✨



PLANNING AHEAD TO MAKE AN IMPACT

A bequest, or gift through your will, is one of the simplest ways to make a lasting gift to the Cutaneous Lymphoma Foundation.

To learn more about planned giving or estate planning, please visit our website at: <https://bit.ly/CLPlannedGiving> or use the QR code at right.



Or please contact us by phone at (248) 644-9014 or email info@clfoundation.org

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



**Stay Up-To-Date With
The Cutaneous Lymphoma Foundation**
Subscribe to the Foundation's YouTube channel (CutaneousLymphomaFnd) and follow us on Facebook and LinkedIn.

Celebrating 25 Years Together



**25th Anniversary Celebration
and
Patient Conference**

Pasadena, CA
April 13 -14, 2024

**Plan now to join us! Watch for more
details on our website:**
www.clfoundation.org/upcoming-events
or scan the QR-code.



Advocacy...continued from pg 1

Raising Awareness of Cutaneous Lymphoma

In addition to keeping us informed, our active involvement with other patient organizations and scientific/clinical stakeholder groups helps to raise awareness of cutaneous lymphoma itself in the broader community. This is another reason why we attend member meetings, conferences, and sit on coalition boards and committees. While this type of engagement may not be what is immediately thought of as “advocacy,” raising awareness of cutaneous lymphoma is an important part of the CL Foundation’s advocacy goals.



Bringing your voice to the table

Developing Your Voice

Another side of advocacy is the CL Foundation’s support and education of our community to develop their “patient voice.” A well-informed individual is more empowered to advocate on their own behalf, whether in discussions with their healthcare providers or when tackling an insurance issue. The purpose of advocacy, as described by Applied Development, LLC, is to “help people to: express their views, thoughts, and concerns; and have access to information and guidance in a way they can understand.”³ This is what we strive to do for our community by providing information about the disease itself, available treatments, research and clinical trials, managing skin care, and many other topics related to living an excellent life while having a cutaneous lymphoma diagnosis.

Advocacy as a Strategic Goal

To summarize advocacy as a strategic goal, we see the CL Foundation’s role as supporting an individual to be an advocate in their disease journey; and, serving the entire patient and care partner community as one voice to bring change through public awareness, influencing policies, and making sure the cutaneous lymphoma collective voice is heard.

Sometimes, we don’t always do the best job of sharing the behind-the-scenes work we are doing on behalf of the community; it’s our goal to share more of that work with you and provide ways that you can become engaged beyond becoming your own best advocate. Sharing your personal experience of how you have empowered yourself to navigate your journey by being a member of the online CL Community or the monthly networking groups, is a great place to inspire and enable others as they begin their path. New opportunities for broader engagement in our policy and legislative work, sharing your views and experiences via focus groups, or input on clinical developments are also ways we hope to engage more of our community members in the future.

As we always say, knowledge is power. We are poised to take the next step in bringing that collective knowledge to impact broader change in the cutaneous lymphoma ecosystem, one person at a time. ✨

References:

- 1 Bolder Advocacy - Alliance for Justice. *Terminology*. (n.d.). <https://bolderadvocacy.org/resource-library/terminology/#:~:text=Advocacy%20is%20any%20action%20that,pleads%20on%20behalf%20of%20others>
- 2 Mind. *Advocacy in Mental Health*. (n.d.). <https://www.mind.org.uk/information-support/guides-to-support-and-services/advocacy/what-is-advocacy/>
- 3 Applied Development, LLC. *What is the Purpose of Advocacy?* (2022, August 15). <https://applied-dev.com/what-is-the-purpose-of-advocacy/>

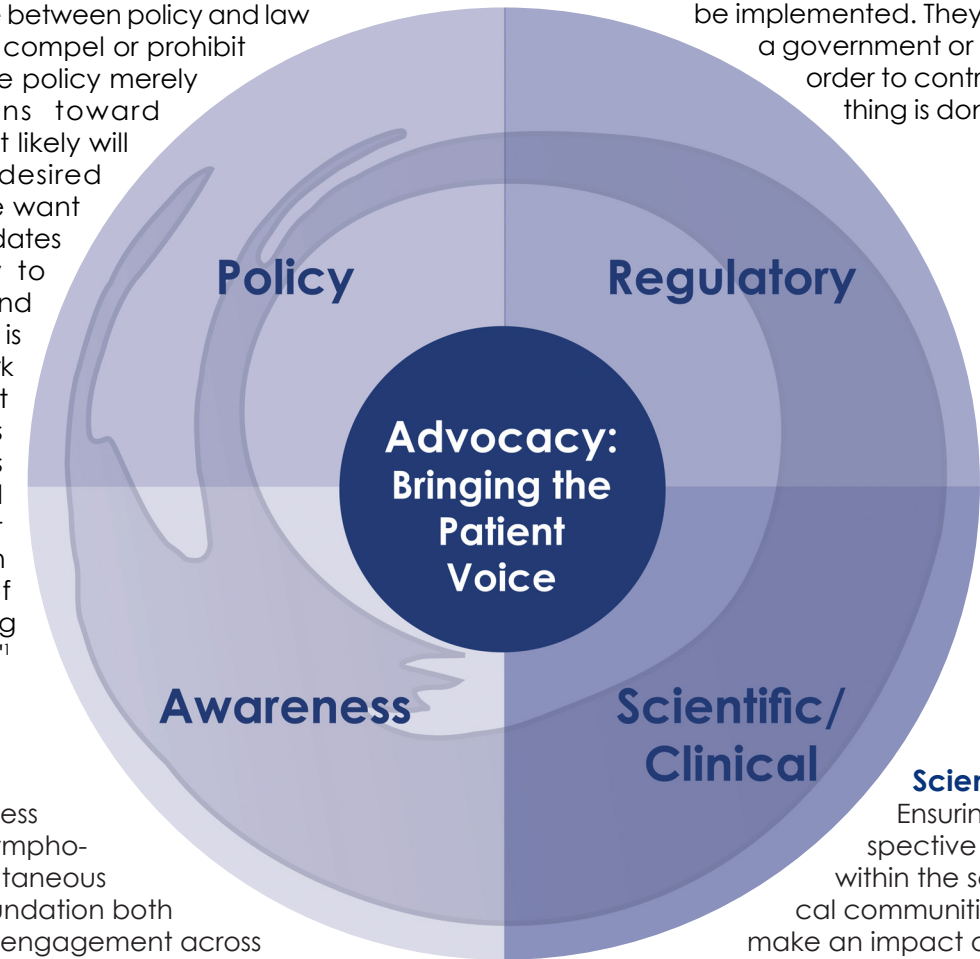
AVENUES OF ADVOCACY

Policy

From the article, *What is the Difference Between Law, Policy and Regulation, According to 7 Experts*, policy precedes law and is typically informed by how people would like to see things be or be improved. “The main difference between policy and law is that law can compel or prohibit behaviors, while policy merely guides actions toward those that most likely will achieve the desired outcome. If we want to create mandates for the policy to be followed, and implications if it is not, we can work with our district representatives and senators to draft bill language that can begin the process of transforming policy into law.”¹

Regulatory

From the same article mentioned in Policy, “once a law has been passed, implementation of the law is the next step. A regulation is a rule within a law that specifies how the ideas of the law are actually going to be implemented. They are rules made by a government or other authority in order to control the way something is done.”¹



Awareness

Raising awareness of cutaneous lymphoma and the Cutaneous Lymphoma Foundation both through active engagement across different channels with collaborative partners or alone with the goal of impacting outcomes for our community.

Scientific/Clinical

Ensuring the patient perspective is being provided within the scientific and clinical communities wherever it can make an impact on accessibility to care, treatments, and quality of life for patients and their care partners.

Common Acronyms

- | | |
|--|--|
| CDC - (U.S.) Centers for Disease Control and Prevention | IEEPO - International Experience Exchange with Patient Organisations |
| CMS - (U.S.) Centers for Medicare & Medicaid Services | NCCN - (U.S.) National Comprehensive Cancer Network |
| EMA - European Medicines Agency | NIH - (U.S.) National Health Institute |
| EORTC- CLTG - European Organisation for Research and Treatment of Cancer - Cutaneous Lymphoma Task Group | NORD - (U.S.) National Organization for Rare Disorders |
| FDA - (U.S.) Food and Drug Administration | RDLA - (U.S.) Rare Disease Legislative Advocates |
| IDEOM - International Dermatology Outcome Measures | WHO - World Health Organization |

References

- 1 Upjourney. *What is the Difference Between Law, Policy and Regulation, According to 7 Experts*. (2023, March 21). <https://upjourney.com/what-is-the-difference-between-law-policy-and-regulation>

“Alone we are strong, together we are stronger”

Source Unknown

CUTANEOUS LYMPHOMA FOUNDATION

In addition to providing our programs and services, the Cutaneous Lymphoma Foundation team is actively working to ensure our community's voice is present where decisions are made that may impact access to care, treatment, and quality of life. Your voice and experiences are shared across a broad spectrum of initiatives and events in many ways. Here are just a few:

National Comprehensive Cancer Network (NCCN)

The National Comprehensive Cancer Network has developed the NCCN Guidelines® - the recognized standards for accepted clinical practice guidelines for cancer care, including cutaneous lymphoma.¹ The guidelines provide clinicians with a roadmap for diagnosing, staging, and therapeutic recommendations across all cutaneous lymphoma subtypes. These clinically created and annually reviewed guidelines are also used when insurance coverage is questioned for therapy, providing patients and providers with evidence to support treatment decisions.

The NCCN, for the first time, invited a patient expert to participate in this year's T-cell/Cutaneous Lymphomas review panel. CL Foundation CEO Susan Thornton was invited to be the panel's patient expert. This role includes reading through all of the currently published clinical guidelines for cutaneous and other T-cell lymphomas, reviewing the recommended updates, and participating in a one-day clinical review meeting with clinical experts representing the 33 NCCN cancer center member institutions. While the guideline content is quite clinical and scientific, having an opportunity to share the patient's perspective brings additional value to the review process.

The updated T-Cell/Cutaneous Lymphoma Guidelines will be published in 2024. Work is also being done to engage patient experts in the review process for the European Organisation for Research and Treatment of Cancer (EORTC) Cutaneous Lymphoma Task Force, which creates the clinical guidelines for Europe.

Legislative Policy - HEART Act and PROTECT Rare Act

Moving from the clinical advocacy perspective to U.S. legislative policy, the CL Foundation is a member of two specific umbrella groups that focus on the impact of legislation for rare and ultra-rare diseases, the Haystack Project and the Protecting Innovation in Rare Cancers Coalition.

The Haystack Project (<https://haystackproject.org/>) successfully included the HEART (Helping Experts Accelerate Rare Treatments) Act into the Senate HELP Committee User Fee Package at the end of 2022. In a nutshell, the HEART Act "advocates for patients and experts to have an increased role during the FDA review process for treatments for rare diseases."²

While a significant achievement, the hard part is now ensuring the implementation of the HEART Act is accomplished. In November, the CL Foundation joined other patient advocates at a meeting with the U.S. Government Accountability Office (GAO) to share the views of patients regarding the effectiveness of the Food and Drug Administration's (FDA) policies and practices related to incorporating patient experience data into their review process. Haystack has also requested meetings with the FDA regarding the HEART Act requirements for more visibility of the FDA's inclusion of patient experience data and knowledge into their processes, especially for rare and ultra-rare diseases. These are important ongoing advocacy activities to make sure the outcomes from the initial legislative policy are enacted.

The Haystack Project also successfully introduced the PROTECT Rare Act, H.R. 6094, this year. This bipartisan bill levels the playing field for rare disease patients seeking medically necessary care and off-label access to treatment by expanding the guidelines for medically acceptable use to include peer-reviewed literature and clinical guidelines.³

While these policy initiatives can be complex and challenging to understand, our membership in the Haystack Project can help provide clarity, while allowing the CL Foundation to add our voices and share examples from actual patients who are impacted.

Legislative Policy - Inflation Reduction Act

The CL Foundation was recently invited to participate in a newly formed umbrella group targeting the implementation of the Inflation Reduction Act. The Protecting Innovation in Rare Cancers (PIRC) Coalition is "a multi-stakeholder group that fosters collaboration and promotes evidence-based policy decisions. By amplifying the voices of those affected by rare cancers and combining their collective expertise, the Coalition will work toward raising awareness, advocating for policy

ADVOCACY - BEHIND THE SCENES

changes, and shaping regulations that prioritize the needs of the rare cancer community."⁴

The current focus of the Coalition is asking the Centers for Medicare & Medicaid Services (CMS) for several refinements to the proposed Medicare Prescription Payment Plan Program implementation. Previously known as the "smoothing" provisions of the Inflation Reduction Act (IRA), the program is intended to help Medicare patients spread the cost of their prescriptions over a plan year.

However, PIRC members highlighted several areas where CMS could still improve upon the program, including:

- An interactive 'calculator' to help patients calculate their monthly costs.
- A process to allow patients to sign up for the program at the pharmacy (i.e., point-of-sale or POS) rather than directly with the Part D plan.
- Greater clarity on out-of-pocket (OOP) obligations in specific scenarios like returns (e.g., due to side effects, etc.)
- Uniformity of forms, notices, etc., options for participating in the new program through an 800# (number), paper and electronic means, and simplicity of instructions and communications.⁵

The work on these initiatives is ongoing, requiring continued meetings and follow-up to engage with CMS about these concerns. Keep an eye on communications with updates as they occur going forward.

World Skin Health Coalition

Finally, the CL Foundation is one of the inaugural members of the World Skin Health Coalition. The Coalition was established in January 2022 and publicly announced later that spring at the World Health Assembly in Geneva, Switzerland. The Coalition is an informal, multi-stakeholder collaboration among independent organizations, societies, groups, networks, institutions, and companies. The mission of this group is:

To harness our collective power to raise awareness about the global impact of dermatological diseases/conditions and increase their health policy prioritization⁶

Over the last year, the Coalition developed two workgroups to focus on specific issues related to skin conditions. The advocacy work group is focused on the importance of skin conditions at the global level, targeting a resolution to the World Health Assembly. While this may sound easy, navigat-

ing the global health landscape will require significant effort on the group's part. The second workgroup is focusing on the creation of a Global Awareness Campaign. Proposed to launch in early 2024, the campaign will raise awareness around the world of the impact of living with a skin condition.

Both projects are significant undertakings, and the CL Foundation actively participates in both, bringing the perspective of the cutaneous lymphoma patient experience to these initiatives. Look for more about these two projects unfolding over the next several years. You can read more about the Coalition at: <https://bit.ly/WorldSkinHealthCoalition>

Summary

These are the highlights of a few "behind-the-scenes" projects the CL Foundation is engaged in on your behalf. As an active partner in these initiatives, the CL Foundation advocates for the cutaneous lymphoma community. By joining forces with others, nationally and internationally, we can help ensure the patient and their care partner's voices are amplified and heard. ✨

References

1 NCCN. *About Clinical Practices Guidelines*. (n.d.). <https://www.nccn.org/guidelines/guidelines-process/about-nccn-clinical-practice-guidelines#:~:text=The%20NCCN%20Guidelines%20are%20a,patients%20in%20the%20United%20States>

2 Haystack Project. *HEART Act*. (n.d.). <https://haystackproject.org/heart-act>

3 Haystack Project. *PROTECT Rare Act*. (n.d.). <https://haystackproject.org/protectrare>

4 Protecting Innovation in Rare Cancers (PIRC) Coalition. *Homepage*. (n.d.). <https://rarecancerira.org/>

5 CLL Society. *Protecting Innovation to Rare Cancers (PIRC) Coalition Asks CMS For Several Refinements to Proposed Implementation Details of the Medicare Prescription Payment Plan Program*. (2023, September 20). <https://cllsociety.org/2023/09/medicare-prescription-payment-plan-program/>

6 International Alliance of Dermatology Patient Organizations. *World Skin Health Coalition*. (n.d.). <https://globalskin.org/component/content/article/78-gs-2019-content/535-global-dermatology-coalition-new?Itemid=1710>

Frequently Asked Questions

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

What is a recommended diet for someone with cutaneous lymphoma?

Sahni: I've been asked that multiple times. I always tell my patients, a good, healthy, balanced diet is the correct diet. There's nothing that we know that definitely predisposes, that makes it worse or better, and the treatments can cause side effects themselves. The condition is something that takes quite a bit out of the patient. So I think looking after yourself and having a balanced diet is key.

Lansigan: A lot of our patients do come in with questions about supplements during chemotherapy, and so we would review those and you should review those with your treating physician if you are on active chemotherapy. What I like to do is use an opportunity to talk about diet as a state of general health and to improve diet and your eating habits, and increasing the amount of antioxidant type foods in your diet can have some benefit. We usually go into conversations about health because diet just isn't a treatment for cancers, but it can improve overall health if you pay attention to your own diet

What is light therapy and how long can you do light therapy?

Vermeer: I'll start with telling you a little bit about the types of UV treatment that we use, and it's important to realize that UVB therapy is the penetration of light into skin. It is relatively low so it can be an effective therapy for thin patches or maybe patches that are on the brink of becoming a plaque. Typically the light will penetrate just a little bit below the basal membrane so not just in a superficial layer of the skin. If your malignant cells are in that layer then UVB can be an effective therapy. If lesions get a little bit thicker and tend to be more infiltrated plaques or in particular in those patients that have folliculotropic mycosis fungoides where the tumor cell infiltrates are located a little bit deeper in the dermis around the hair follicles, then you would need a light therapy that can penetrate deeper into the skin and then PUVA therapies, psoralen combined with UVA, is preferred because that treatment penetrates deeper into skin.

The second question is how long can you use this treatment, and that's a difficult one. I think it should always be tightly administered and tailor-made for individual patients. We get this question often from dermatologists that are accustomed to giving light therapy for eczema or psoriasis and they have the regimen that they will treat, at least in the Netherlands, for up to three months and then they will stop. For cutaneous lymphoma is a completely different disease and if a patient is profiting from the treatment, we tend to use it longer, maybe four months or even five months or even a little bit longer, but of course at a certain point you want to stop it because you do not want to have someone in light therapy indefinitely for practical reasons and also because of cumulative toxicity.

You can use UV treatment in a clever way, such as to use it in the winter months and then, in the summer months, we will stop treatment as patients can profit from the natural sunlight. This will make it a little bit easier for patients because it's very difficult and limiting of course. You have to go to the clinic once or twice a week.

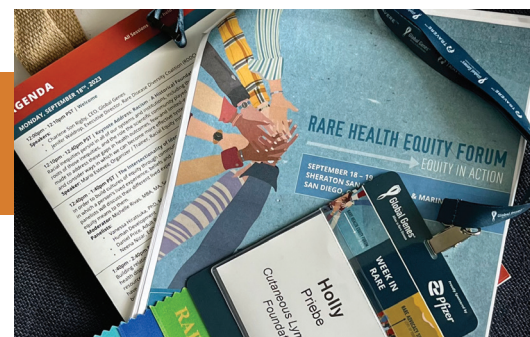
Quaglino: I think it is important to highlight the fact that UV, either UVB or UVA, represents one of the most common treatments for early phase mycosis fungoides, and indeed are very effective. A lot of times patients ask me “why don't you give me a systemic treatment?” In the majority of cases phototherapy is highly effective and more effective than systemic treatment for early phases cases. I think it's very important, this disease originating and present in the skin and using directed therapies like phototherapy are very, very effective. Also, in the majority of cases it's associated with less severe side effects and toxicity with respect to systemic therapy. 🌟

Erick Lansigan, MD
Geisel School of Medicine, Dartmouth

Debjani Sahni, MD
Boston University
Chobanian & Avedisian School of Medicine

Prof. Maarten Vermeer
Leiden University Medical Center, the Netherlands

Prof. Pietro Quaglino
University of Turin, Italy



EMERGING TOPICS IN PATIENT ADVOCACY

As you likely know, bringing the cutaneous lymphoma voice to the table, as well as staying up-to-date with what's happening in the rare disease, skin disease, and lymphoma spaces is all part of our advocacy efforts. Our alliance partners and our participation in the broader communities' activities allow us to achieve these objectives.

This fall we were excited to participate in four very important meetings: the National Organization for Rare Disorders (NORD) Breakthrough Summit in Washington, DC; the Global Genes RARE Advocacy Summit in San Diego, California; the Lymphoma Coalition's General Annual Meeting in Madrid, Spain; and, the annual European Organisation for Research and Treatment of Cancer (EORTC) Cutaneous Lymphoma Task Group (CLTG) meeting in Leiden, the Netherlands. Each meeting had its own objectives; but interestingly, addressed very similar topics. At each, the Cutaneous Lymphoma Foundation joined attendees from other patient organizations, policy and regulatory leaders, and industry stakeholders to learn more about the critical topics that impact our community.

The following topics were addressed at each meeting:

Artificial Intelligence

Artificial Intelligence, or AI, seems to be the **hot** topic everywhere. There was a lot of excitement for the potential medical and research advances that AI can help achieve, but also a level of caution, as it is still a relatively new technology. As one panel member said: AI is so new, existing Federal law related to technology doesn't currently take it into account, and there may be a need to establish new laws to govern its use. Also, there is a need to evaluate the advantage of its use versus the risk, and whether it's being used to meet a currently unmet need. Panelists added that AI may help lead to earlier diagnosis, especially for rare diseases, and it may also help identify who may become unresponsive to treatment and how to improve their responsiveness. What can be accomplished using AI will be based on the amount, diversity, quality, and depth of data it has access to. The more layers of data (e.g., labs, imaging, etc.), the better. However, it is understood that for individuals to feel comfortable allowing access to their

medical data, education surrounding AI is needed to help dispel misunderstandings or fear of it. For all its potential, the panelists cautioned that artificial intelligence should not be seen as a replacement for the clinician and patient relationship.

Patient Histories and Registries

Patient histories and registries were another popular topic. Patient data, especially clinical, has value across all diseases in producing layers of valuable data that can benefit researchers. Clinician reported data is preferred by the regulators because it is easier to standardize and tends to be reliable. It was recommended that rare diseases consolidate their data because similarities found across diseases can help find new therapeutics that may benefit the group. It was also suggested that an individual's data should be updated to show how their condition has evolved, rather than starting at square one each time it is collected. As important and valuable as patient data is to research, it was still emphasized that patients should have ownership of their data and have the ability to withdraw it from a registry should they so choose.

Mental Health

The impact of living with a lymphoma, skin disease or rare disease on an individual's mental health is becoming increasingly recognized. Post-traumatic stress disorder (PTSD) is very common among individuals living with a rare disease. Experiencing anxiety and fear of bad things happening is “normal” when you have experienced something traumatic such as a rare disease diagnosis. The sense of uncertainty related to the disease can also be a contributing factor. Having a connection with others who share your experience is very important for both patients and care partners. Certified health psychologists are the best resource for finding help if you are having difficulties, and group therapy with a licensed counselor is reimbursable by law.

Attending these types of programs is invaluable in keeping the Foundation informed of the advances and challenges taking place in research, the regulatory and policy makers, and Industry that may play a role in an individual's access to care, and the development and availability of future treatments for cutaneous lymphoma. 🌟



CUTANEOUS LYMPHOMA FOUNDATION
PO BOX 969
WARREN, MI 48090

TIME SENSITIVE MATERIALS ENCLOSED

EMPOWER • CHAMPION • UNITE

As we launch into the Foundation's next 25 years with a new strategic plan crafted to address the needs of the cutaneous lymphoma community, we are...

- here to **EMPOWER** you through education and support - but we can't do it alone.
- dedicated to being your **CHAMPION** in advocacy and awareness - but we can't do it alone.
- committed to **UNITING** the community through research - but we can't do it alone.

We need your help!

As we fight for a life free of the burden of cutaneous lymphoma, every gift - **\$35, \$60, or any amount** - brings this vision closer to reality.

Every donation makes a difference!

DONATE TODAY -- ONLINE, BY PHONE OR BY MAIL

Online: <https://www.clfoundation.org/giving-online>

By Phone: (248) 644-9014, Ext 100

By QR Code: provided at right

By Mail: PO BOX 374, Birmingham, MI 48012

(a remittance envelope has been enclosed for your convenience)

