



QUALITY OF LIFE: REVISITED

“Patients may joke about having “blown up” or otherwise broken more than one vacuum cleaner because of the daily use in cleaning up fallen, dead skin. Between the lines, these patients are reporting a burden experienced by themselves and their family that goes far beyond the sweeper (vacuum cleaner).”² p. 429 This is an observation written for Nursing Clinics of North America about 15 years ago, based upon the insight I gained as I sat alongside patients and their families living with cutaneous lymphoma (CL). It still rings with truth about how the quality of life (QoL) of people with cutaneous lymphoma can be so greatly affected. Since that time, QoL issues affecting people with CL have become an ever-increasing part of the conversation between patients and health care providers. Thankfully, global research efforts continue to expand availability of resources and the knowledge base through more frequent assessments of this critical topic.

What is clear from reviewing the literature is that more work remains to be done. A recent clinical trial has shed in-depth, additional light on the factors impacting QoL for people affected by CL. This qualitative study is entitled “Current measures are not sufficient: an interview-based qualitative assessment of quality of life in cutaneous T-cell lymphoma”¹. Qualitative studies involve first-hand interviews, face-to-face discussions, and focus groups, among other techniques. This trial examined the QoL of 18 patients diagnosed/living with CTCL from one specialty treatment center. Of these 18 patients, 13 were non-Hispanic white, and 5 were non-Hispanic black. The median age was 62, with 10 females and 8 males. Eleven patients had early stage (61%) and 7 had advanced stage disease (39%).



Several advantages to this study were that their treating physician verified the stage of each included patient and the in-depth interviews lasting an average time of 43 minutes revealing meaningful information important to patients across all disease stages. Thus, more specific, validated information was obtained from patients with verified advanced (IIB-IV stage) disease than had previously been learned from prior QoL studies. Interviews for all participants took place over the phone or in private hospital rooms and were conducted by the same experienced researcher who used a formal interview guide to help navigate the discussion. Enrollment continued until no new themes were identified during the interviews¹.

Quality of Life...continued on page 8

2022 Issue 3

From the President and the Chief Executive Officer	3	Frequently Asked Questions	6
My Journey With Cutaneous Lymphoma	4	Qualified Charitable Distributions	7
Legislative Days Recap	5	Thank You	Back

What Is Cutaneous Lymphoma?

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

Cutaneous Lymphoma Foundation is a 501(c)(3) non-profit organization. Donations are tax deductible to the extent allowed by law.

BOARD OF DIRECTORS

OFFICERS

Laurel Carlson	President
David Elefant	Vice President
Jeff Ward	Treasurer
Marianne Tawa, RN, MSN, ANP	Secretary

DIRECTORS

Steven Horwitz, MD	Director
Youn Kim, MD	Director
Michael W. Young	Director
Susan Thornton	Chief Executive Officer

RESEARCH ADVISORY COUNCIL

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

FORUM

The newsletter of the Cutaneous Lymphoma Foundation
ALL RIGHTS RESERVED

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

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

Disclaimer

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

The Cutaneous Lymphoma Foundation's patient educational newsletter, Forum, has been made possible in part thanks to the following generous supporters:

MEDICAL ADVISORY COUNCIL

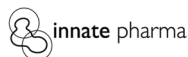
Michi Shinohara, MD (Chair)	University of Washington
Wei Ai, MD	University of California San Francisco
Kim Bohjanan, MD	University of Minnesota
Francine Foss, MD	Yale University
Richard Hoppe, MD	Stanford Cancer Center
Erick Lansigan, MD	Dartmouth-Hitchcock Medical Center
Cecilia Larocca, MD	Dana-Farber/Brigham and Women's Cancer Center
Leora Lowenthal, LICSW, OSW-C, MPA	Beth Israel Deaconess Medical Center
Sue McCann, MSN, RN, DNC	University of Pittsburgh
Amy Musiek, MD	Washington University School of Medicine
Steve Rosen, MD, FACP	City of Hope
Debjani Sahnii, 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	Education Manager
Deb Van Zegeren	Special Projects Manager
Susette Arnot	Programs and Services Assistant
Jaren Williams	Office Assistant



FROM THE BOARD PRESIDENT

Laurel Carlson

It seems since the pandemic began, we have anticipated that each year would be another step closer to some degree of normalcy. For some of you reading this, you didn't expect returning to normalcy would include a cancer diagnosis, especially one you'd never heard of before. But, here you are, dealing with a life event that isn't very normal.

Our reliance on internet resources has probably never been greater, and there is a good chance that one of them led you to the Cutaneous Lymphoma Foundation. Doctors often caution our patients to not explore their disease on the internet because it is replete with overwhelming information and misguided advice that could scare and confuse a newly diagnosed patient. Fortunately, though, you found us, an organization created exclusively to help those with cutaneous lymphomas. Before you discovered our organization and its extremely resourceful website,

I wonder if you imagined you would find one place that would have the answers to so many of your questions; one place that would provide help and resources from medical professionals, friendly and knowledgeable staff, and fellow patients - real people for you to connect with. Whether you expected to find a place like the Cutaneous Lymphoma Foundation or not, every day we hear sighs of relief and gratitude from patients and their care partners. For each of them, finding us made a huge difference in their ability to deal with their disease. I hope that finding us, a community dedicated to helping you be able to make the best decisions to manage your diagnosis, has made a difference in your life too.



"...you found us, an organization created exclusively to help those with cutaneous lymphomas."

Laurel Carlson

From the Board President...continued on page 11

FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton



"And as our world changes, we must look forward and transform ourselves to meet the needs and expectations of our global community."

Susan Thornton

I am so thankful for.....

YOU!

As we approach the end of 2022 and look back over the year that has gone by, I have deep gratitude.

Gratitude to everyone who showed up and participated in some way this year. You joined one of our virtual programs. Or took the leap of faith and came to our education program in Philadelphia in person. Or supported our work by providing a financial donation or your time.

Thank You!

The Board and staff have been diligently developing a new strategic plan to take the Foundation through the next 3-5 years. Supporting our growing patient and care partner community with services, education, and new programs that can travel with you through your journey living with a cutaneous lymphoma diagnosis. Our world is changing, and the Foundation needs to change as well. Looking at the larger ecosystem the Foundation lives in, there are new opportunities to reach more people living with cutaneous lymphoma. New ways to bring the collective patient experience to researchers, regulators, and healthcare providers. Together we can enhance the availability of treatments, move research forward and connect those living with this rare group of diseases together to support each other.

The Foundation exists for you, your family member, your neighbor, or your colleague impacted by this disease. The mission is a special one, one that is unique to us and the people we serve. And as our world changes, we must look forward and trans-

From the CEO...continued on page 11

MY JOURNEY WITH CUTANEOUS LYMPHOMA

Shared by Ricky K.

As I looked over my “Personal Journey” article in the patient Forum from 2011, I really reflected on what a journey it has been so far, both personally and professionally. I am very grateful to have an opportunity to describe my own personal journey with cutaneous lymphoma.



Eleven years ago, I spoke about the newness and understanding of this journey. In these last few years, I have had opportunities to meet others who have this disease and learn of their journey as well. I have also met quite a few doctors along the way, and I am grateful for all of them.

For a long time, I did not need further treatments after my initial few rounds of UVB and some months of bexarotene topical treatments. I recently experienced a new flare in a similar area but it has done well with treatment.

Since my last journey update, I graduated with my Master of Social Work. I have used the experience and knowledge I’ve gained to further my work with students, as well as with patients, in the area of medical social work. I was very grateful for my internship with the Cancer Support Community, which gave me a great experience in learning more about how to support patients in their individual journey.

I am so grateful for many of the life changes and opportunities I’ve experienced and for the many individuals I have met along the way. I am thankful to have become well acquainted with Susan Thornton and the staff at the Cutaneous Lymphoma Foundation and am excited by the work they are doing. And, I am always encouraged by seeing Judy Jones, the Foundation’s founder whom I first met via phone when I was diagnosed, still involved

I am grateful to the Cutaneous Lymphoma Foundation for allowing me to be involved in their programs. I had the opportunity to speak about wellness during the 2016 2-Day Patient conference in Chicago. In 2020, I was privileged to proctor a wonderful online networking session for newly diagnosed patients. More recently, I joined Autumn Lintz, the Foundation’s education manager, for a webinar to support parents and students with chronic and acute illnesses, and spoke about resources parents can access to help their child. I am grateful to be added to the many resources the Cutaneous Lymphoma Foundation has on its website, and am hopeful that my contributions have been able to help at least one individual on their journey with cutaneous lymphoma.

I have also been privileged over time to continue to work as an intervention specialist and recently just obtained my second graduate degree in Education Administration, as I move forward in my education and social work career. I mentioned my first overseas trip in my original article. I continue to consult and speak with educational professionals and students in the country of Honduras, providing support in the areas of special education and mental health. And, using my medical social work background and experience, I hope to continue to volunteer and speak for the betterment of others. I also look forward to continuing to support the Cutaneous Lymphoma Foundation in the future in any way I can.

I am grateful and extremely proud of my family with my wife and son, who have always been supportive of me. My son continues his university studies in IT and my wife and I support him. I continue to enjoy hiking and pursuing the outdoors, and we hope to travel more in the near future as we are trying to get more active once again.



Thanks for the privilege of checking in and I hope to perhaps see some of you in the future.

Take Care,
Ricky

LEGISLATIVE DAYS: AADA AND COALITION OF SKIN DISEASES - SEPTEMBER 20 & 22, 2022

Thank you to the American Academy of Dermatology Association (AADA) for the continued opportunity to participate in the AADA Legislative Conference. After two years of virtual visits to Capitol Hill, we were able to return in person to Washington, DC, this year. Similar to last year, over 200 dermatologists and 35 patient advocates visited Capitol Hill together - participating in more than 220 meetings across the United States Senate and Congress. We joined together as advocates to deliver important messages and share the impact legislators' decisions have on patients; specifically, access to treatments and care, which directly impact both a patient's health, as well as their quality of life.

Removing Barriers to Treatments and Care

Reduce Prior Authorization Burdens (S 3018, H.R. 3173/H.R. 8487, H.R. 7995)

Prior authorization policies can fundamentally interfere with the patient-physician relationship and are counter to the practice of personalized medicine. Prior authorization processes are one, time-consuming, and two, siphon resources away from patient care and unfairly question a physician's clinical judgment. Furthermore, prior authorizations can cause delays in care and negative patient health outcomes

Reform Step Therapy Protocols (S 464/H.R. 2163)

Step therapy practices require patients to try and fail one or more treatments before the insurer will cover originally prescribed treatment. Too often, this leads to delays in proper treatment, worsened health outcomes, and contributes to higher healthcare costs. The Safe Step Act legislation has been re-introduced in the Senate as S464 and the House as H.R. 2163. The Act would require insurers to implement a clear and transparent process for a patient or healthcare provider to request an exception to the step therapy protocol and require group health plans to grant exceptions if a certain protocol is met.

Ensure Medicare Stability for Patients and Physicians

Medicare physician reimbursement has failed to keep up with inflation, threatening the viability of medical practices. The current payment structure has contributed to consolidation and increased hospital ownership of physician practices, which are more costly, reduce competi-

tion, and typically are less patient-centered. Year-over-year cuts to Medicare reimbursement jeopardize physicians' ability to keep their doors open and care for patients in our communities. Action is needed to prevent Medicare physician payment cuts which will ultimately impact a patient's access to care.

Two days after our time with the American Academy of Dermatology Association, we returned to Capitol Hill with the Coalition of Skin Diseases (CSD), this time meeting with different members of Congress. We joined 24 other patient advocacy organizations, representing 84,000,000 people affected by skin diseases, and took your stories to the legislators. Our "asks" had some overlap to our prior visit, but also focused on specific issues identified across the Coalition's membership.

Funding Research

We asked for focused funding for medical research through the National Institutes of Health (NIH), as well as funding for education and awareness through the Centers for Disease Control and Prevention (CDC). We also had several "asks" addressing the ongoing access issues facing people affected by skin diseases.

Like with AADA, we addressed the Safe Step Act (S 464/H.R. 2163) for step therapy, but we also asked for assistance with the following:

HELP Copays Act (H.R. 5801)

This bill requires health insurance plans to apply certain payments made by, or on behalf of, a plan enrollee toward a plan's cost-sharing requirements. Specifically, plans must apply third-party payments, financial assistance, discounts, product vouchers, and other reductions in out-of-pocket expenses towards the requirements.



Foundation staff members, Autumn Lintz (left) and Holly Priebe, at this year's Legislative days.

Frequently Asked Questions

The following questions and responses are from an “Answers From the Experts: Open Q&A” event held in August 2022 with Drs. Theresa Pacheco and Brad Haverkos.

What is the outlook for early-stage folliculotropic mycosis fungoides (FMF)? Where can I find good research on this?

Haverkos: FMF can be a challenging subtype of mycosis fungoides to treat. There are some individuals that have a more challenging time to get into remission, more often require systemic therapies and just may have a more difficult disease to treat. Historically, there have been more FMF patients that have a more difficult disease to treat. Some people think that it carries a worse prognosis. With that said, we have lots of FMF individuals who do very well and have early-stage disease and respond well to therapies. At the end of the day, it really is very individualized to the patients and it's hard to generalize too much about these other studies because on the patient level side, all that really matters is what happens to that individual person. If you have favorable FMF that does well and responds well to therapy, there's no reason to think that it's going to become this terrible disease and be difficult to treat.

I think there are lots of reasons to be optimistic and still hopeful that you're going to respond well to therapies. With that said, I will say that we sometimes, because of the historical data that suggests that maybe these patients sometimes can be more difficult to treat, sometimes we keep a little bit closer eye on them, at least initially, to make sure that they get into remission. We may be even a little bit more aggressive in starting them on both skin-directed and a systemic therapy until they get into remission and then back off or talk about backing off on either the systemic drug or the light.

I think this is the challenging thing about trying to generalize too much about these prior studies. The important thing also to remember is that these are old studies and we don't know that necessarily those will hold true in the future with all the new, exciting therapies that we have. It may be irrelevant what subtype you have. We may find therapies that work much better for certain subtypes. For example, Sézary syndrome, we now have mogamulizumab, which can be a great drug for individuals. It has changed the outlook for many individuals with what historically was a bad, very difficult disease and

sometimes it can be so difficult to treat. Just give that example, maybe some ray of hope.

Can cutaneous T-cell lymphoma go into remission?

Haverkos: Cutaneous T-cell lymphoma (CTCL) can go into remission. We have lots of potential therapies, both skin-directed therapies that are focused on the skin and other systemic therapies. Any number of these therapies can lead to a remission. Remission can be defined as complete remission where all the skin lesions go away or partial remission. One of our goals is usually to get someone into a complete remission, and certainly that's possible with the number of different therapies that we can offer.

Pacheco: We stage disease based on the amount of skin involvement and it's fair to say that if you have early-stage disease with limited skin involvement, it's fairly easy to get patients into remission. We have skin-directed therapies like phototherapy, topical medications, localized radiation. There are lots of treatments for early-stage disease, and it's very likely that patients can go into remission with early stage.

Do you have any comments or elaboration on the use of topical steroids and different potency of them and when we use them and how they may be helpful.

Pacheco: Topical steroids are first line therapy for mycosis fungoides. There are seven groups of steroids, and group one is the strongest and group seven is the weakest. We tend to favor the high-potency topical steroids like group one, two, and three. There are different names, and they come in creams or they come in ointment. They can be used for active lesions and active lesions that itch. When people present with this disease, they have a red patch or plaque and often their skin is pruritic, itchy. The topical steroids work to help reduce inflammation and the itch. Topical steroids treat the symptoms but not the disease. If you stop the topical steroids, the lesion will come back and it does require another skin-directed therapy or systemic therapy or all the tools that we have in the toolbox to treat this disease.

HELP ENSURE THE FUTURE OF THE CUTANEOUS LYMPHOMA FOUNDATION: QUALIFIED CHARITABLE DISTRIBUTIONS

2022 has brought the highest inflation in decades, rising interest rates, and volatile financial markets. Nevertheless, many donors have maintained their charitable giving, on which charities such as the Cutaneous Lymphoma Foundation so urgently depend. No matter when you make a gift to the Cutaneous Lymphoma Foundation, it is always tremendously appreciated; however, with some planning, and by making smart and strategic choices about how you donate, you can maximize tax savings for yourself.

In previous articles, we have discussed:

- Donating appreciated non-cash assets (such as stock) instead of cash. The Cutaneous Lymphoma Foundation will then receive 100% of the value of the stock donated and you will receive a tax deduction for the full value of the gift (subject to limits), without any reduction for capital gains;
- Bunching donations into one year so you can itemize deductions and realize income tax savings;
- Establishing a Donor Advised Fund;
- Naming the Cutaneous Lymphoma Foundation as beneficiary in your Will or Trust, or as beneficiary of a life insurance policy or retirement plan.

Another very effective and very easy way to benefit the Cutaneous Lymphoma Foundation is to make a “Qualified Charitable Distribution” (QCD). A QCD is a direct transfer of funds from your IRA custodian to the Cutaneous Lymphoma Foundation. It is counted towards satisfying your required mini-

imum distributions, and the amount contributed is excluded from your taxable income. There are several requirements, including that you must be age 70 1/2 to be eligible to make a QCD, the maximum annual amount is \$100,000, it must be completed by December 31, and other rules.

Of course, the above estate planning techniques are most effective for larger contributions and the bulk of our contributions are under \$500. These are our lifeblood and are critical to our continued success. We are so very appreciative of your continued support, as without you we couldn't do the important work we are doing.

Remember, charitable gifting must be completed by December 31, and some of the techniques mentioned above take time to implement, so start now! The future of the Cutaneous Lymphoma Foundation depends on you!

Finally, a friendly reminder that we have moved. Please be sure your records and any account you might have directly connected to us are up to date. (Cutaneous Lymphoma Foundation, PO Box 969, Warren, MI 48090).

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 and your personal estate planning attorney. Thank you again for your support - we can't do it without you!

Is combining phototherapy and regular sun exposure recommended?

Pacheco: Before we were able to get home phototherapy units and patients did not have access to a hospital-based or clinic-based phototherapy unit, we would often counsel on getting natural sun exposure during peak hours. So peak hours are between 10:00 a.m. and 3:00 p.m. and anywhere from 10 to 20 minutes of full body exposure. The entire legs or the entire back or the entire front side of natural sun exposure is thought to be therapeutic for patients with certain skin diseases, not just cutaneous T-cell lymphoma. Phototherapy is often a specific wavelength of light, like narrowband UVB is 311 nanometers. We prefer that, and we prefer protecting the normal skin from regular sun exposure, which is the entire spectrum of UVB and UVA and potentially some UVC.

Brad Haverkos, MD, MPH, MS
Associate Professor, Medicine-Hematology
University of Colorado

Theresa Pacheco, MD
Associate Professor, Dermatology
University of Colorado

Questions and responses taken from the recording of our “Answers From the Experts: Quarterly Q&A - August 2022” webinar. Find the full-length recording here: <https://youtu.be/PfBzSqO-Sho>



Specific patient-reported concerns and themes emerged from the de-identified interviews; these were coded and analyzed, using inductive thematic analysis¹. The performed analysis involved different researchers than the one performing the interviews to help reduce the subjective bias that is an inherent weakness of qualitative research. Another reported weakness of the study is its small sample size from one NCI designated-comprehensive cancer center that may limit its generalizability to other CTCL centers or patients both nationally and internationally.

From the interviews, multiple clinical symptoms were identified. Up to half of the participants in this study reported they were bothered by the following symptoms (number in parenthesis indicates the total out of 18 being bothered by this symptom): itch (16); pain (12); fatigue (12); sleep disturbance (11); open skin areas/fissures (11); and shedding/flaking (10). Other bothersome symptoms reported less frequently included redness (8) and dryness of the skin (6), problems with maintaining body temperature (6), constitutional symptoms (other body systems being affected) (3), hair loss (2), concentration issues (2), loss of weight (2), watery eyes (1), and wrinkled skin (1).

Thus, the major themes extrapolated from the participant interviews included 1) clinical symptoms, 2) psychological and social functioning - with 3 associated subthemes, and 3) treatment burden. Table 3 (see pg 9-10) details these major themes and subthemes along with excerpts from the participant interviews which vividly and powerfully illustrates the QoL burden experienced in this group of patients^{1, p15-16}.

The authors further went on to compare the currently used QoL instruments, such as the SkinDex-29, the MF/SS-CTCL QoL, and the Dermatology Life Quality Index, to determine how each instrument assessed the identified concerns/themes found in this study of patients with CTCL. They found that

while these QoL instruments addressed some/many of the QoL issues, none of them reviewed by the authors were found to fully assess/address patient concerns identified in their qualitative analysis, indicating more work needs to be done on the development of a comprehensive QoL instrument¹.

Thus, it is essential to continually re-examine the issues surrounding QoL for patients experiencing a cancer diagnosis involving a cutaneous lymphoma. At its core, health care providers have a responsibility to address the overall QoL of those entrusted to their care and to try to improve patients' QoL while providing treatment for the illness³. More conversations need to occur between the patient/family and their physician, nurse practitioner, physician assistant, and the nurse to ensure the provision of patient-centered care. Keeping the patients' and families' QoL concerns and experience front and center is one strategy for improving how a person experiences and lives with their disease. As such, the QoL experienced by those diagnosed with CL is worth revisiting now and into the future! Stay tuned for Part 2 of this mini-series on QoL.

Sue McCann, MSN, RN, DNC
Cutaneous Lymphoma Practice
University of Pittsburgh Medical Center

References

1. Bhat T, Herbosa B, Rosenberg A, Sogade B, Jeffe D, Mehta-Shah N, Semenov Y, and Musiek A. Current measures are not sufficient: an interview-based qualitative assessment of quality of life in cutaneous t-cell lymphoma. *Br J Dermatol*. 2021;184(2):310-318. Doi:10.1111/bjd.19298.
2. McCann S. Cutaneous T-Cell Lymphoma: Overview and Nursing Perspectives. In: Jones J, editor. *Dermatologic Nursing*. Nursing Clinics of North America. 2007;42(3):421-455.
3. Tawa M. and McCann S. Quality of Life: A Nursing Perspective. *Cutaneous Lymphoma Foundation Forum*. 2020; 2: 1,9.

Table 3

Key Theme: Clinical symptoms and associated concerns
<p>Pruritus</p> <p>“It’s like if you went camping for 2 weeks and you were around a lot of mosquitoes and weeds and wasn’t able to bathe, that’s what it felt like to me. Like you had a 100-fold more poison ivy than a normal person would have.” (P12, female)</p> <p>“I mean, the itching is, like, your back, your neck, your head, your arms, your leg, your—I mean, it’s just like—to describe it, just say, “fire ants.”...Fire ants all over your body... you find anything to scrape, to scrape your arm, your legs, your body with.” (P13, male)</p>
<p>Pain</p> <p>“...It’s too painful for me to be on my feet... the pain is kind of, uh, sharp... It’s almost like a spear or something.” (P4, female)</p> <p>“I was in pain all of the time because my skin always felt like somebody was striking matches on it.” (P9, female)</p>
<p>Skin breaks (fissuring, lacerations, sores), often causing pain</p> <p>“I get my spots [and] they start to open and crack and pus. And they are very uncomfortable. I mean, they hurt when they get to that point because they’re infected. And if I bump it on something it hurts incredibly. It’s like hitting your funny bone times 100. It’s so very painful.” (P5, female)</p> <p>“...If that area gets really dry and cracked to where you got splits...your earlobes will feel like they’re splitting off, and they feel like paper cuts... it’s a non-stopping, constant like burning, just like you would slice yourself with a piece of paper... and then you got the other places, like an ulcerated tumor area... you hit it on something, and then it’s pretty agonizing, a stabbing type of pain.” (P8, male)</p>
<p>Insomnia, secondary to other clinical symptoms and worry about disease</p> <p>“[CTCL] doesn’t let you sleep at night because you’re just constantly fixated on what’s going wrong, what could go wrong, how it affects the people that are close to you, all those kinds of things.” (P7, male)</p> <p>“Middle of the night, I wake up itching, so it’s like every day, all day... Last night, I woke up, like, five times itching.” (P14, female)</p> <p>“And then the pain, I wake up in the middle of night sometimes with the pain... It feels like needles sticking in your body... And sometimes it’s so bad, like I said, I wake up with it.” (P10, female)</p>
<p>Skin flaking</p> <p>“I can’t get certain jobs because I have to wear a hat. And I flake so much, I can’t be around food. So, yeah, jobs are kind of limited.” (P14, female)</p> <p>“Literally, in the bathroom every morning, [my wife] would sweep up a—I’m not lying—a cupful of skin...I have piles of skin on the carpet, on the floor of the car... 'Cause there’d just be so much skin sloughing off. Dust everywhere.” (P16, male)</p>
Key Theme: Psychological and social functioning
Subtheme: Lack of understanding and awareness in the community
<p>Lack of understanding in community compared to other diseases</p> <p>“You tell people you have cancer, they think you - you’ve got a tumor so that an operation will fix it.” (P4, female)</p> <p>“If you say skin cancer, people have other things and not the thing that you have...And so people will go, ‘Oh, is it like melanoma?’ No, not like that, you know.” (P6, female)</p>
<p>Lack of media coverage</p> <p>“There’s not commercials for it...it’s kind of like a mystery disease.” (P6, female)</p> <p>“You’re always seeing advertisements on TV for this kind of cancer, that kind of cancer, and you go, okay, but I’ve got cancer, and they don’t talk about any of my stuff.” (P9, female)</p>
<p>Misconception as contagious</p> <p>“...People thought I had chicken pox... I had to have documentation that my skin issues were not contagious...other coaches and teams were afraid that they were gonna get something.” (P5, female)</p> <p>“They might think you kind of have some – something that’s catching or whatever.” (P17, male)</p>
Subtheme: Self-image and concern about appearance
<p>Concern about appearance and awareness of scrutiny</p> <p>“I had a procedure done... and I’m in the wheelchair, and [this man] said, “Oh, you were in the hospital for your face”... it was pointed out to me... I mean, I had a surgery that was a lot more extensive than this... then it was like, oh, thanks, if I don’t have enough pain with this, then you have to point out my face.” (P2, female)</p> <p>“You know they’re detecting, and they’re looking at everything that’s going on... I feel like what a leper must’ve felt like” (P3, male)</p> <p>“I realized that I was the person that people were trying not to look at, but everybody was looking at... you recognized right away that people were trying not to look you in the face, you know? And at the same time, you’d turn your head and everybody’d be looking at you.” (P4, female)</p>

Table 3...continued on page 10

Table 3...continued from pg 9

<p>Isolation</p> <p>“Cause when you first find out you have what's basically called an orphan disease, it makes you feel like an orphan... [like] you're the only person in the world who has this problem... It's like you don't have a mommy and a daddy, and you don't have any siblings, and there you are, all alone, and you have to rely on yourself.” (P9, female)</p> <p>“Nobody really wants to hug anymore. You don't have even... the feeling of people wanting to hug you... my family doesn't want to touch me now.” (P10, female)</p>
<p>“Otherness”</p> <p>“The emotional part is extremely there because you—you're just not yourself.” (P1, male)</p> <p>“Yeah, it feels like it's either something wrong with you or something...I mean, I guess I never had that feeling before.” (P10, female)</p> <p>“I have to deal with just thinking I'm different from everybody else.” (P12, female)</p>
<p>Subtheme: Depression, hopelessness, uncertainty</p>
<p>Depression</p> <p>“Six months after I was diagnosed I went to my primary care provider and was put on Zoloft because I was so upset about the diagnosis and then the domino effect of the rest of my life... it totally just kind of wrecked our little dream life that we were having.” (P5, female)</p> <p>“I'm on anti-depressant medicine for that...I see a psychiatrist...[for] depression...Some days, I have bad days.” (P15, female)</p>
<p>Hopelessness</p> <p>“I really lost my bearings, I think. It was like I didn't know what to do... it was all pretty much finished, and you might as well just sit around and wait to die.” (P7, male)</p> <p>“This is really life-changing, not just having this but dealing with it...Every day you wake up and you think, oh, maybe this'll be a better day, and it's not. But you try to go on, and some days you forget about it, and all of a sudden you look down and you see flaking everywhere and you're like, oh great, still there.” (P10, female)</p> <p>“It was just impossible to find joy each day...because as soon as something good would happen, you'd somehow be reminded of this, and you'd be taken right back down again.” (P18, male)</p>
<p>Uncertainty</p> <p>“I wouldn't say that it's front and center, but there's always a lingering thought that, you know, what if it advances.” (P6, female)</p> <p>“[CTCL] gets you thinking about your mortality. Is this it? Or is this gonna go into something else? And that lingers to this day... Is it suddenly gonna turn a corner and suddenly gonna get bad in some way, shape, or form?” (P18, male)</p>
<p>Key Theme: Treatment burden</p>
<p>Side effects</p> <p>“Right, the laser, and then that's when I'm like, yeah, I don't think we'll be doing laser anymore...boy, it just burned the crap out of my arm.” (P11, female)</p> <p>“There have been medical – I guess, more internal side effects like my cholesterol...going through the roof and stuff like that. Now I'm on more medication just to manage that... 'cause now I've got to take medication to manage my thyroid...I've got to take medications to manage cholesterol.” (P17, male)</p>
<p>Logistical concerns associated with therapy</p> <p>“You kind of miss out on things... social things with other people. [And] date night was always Friday night for my husband and myself. But when I was at three times a week where I would go Monday, Wednesday, and Friday... you'd have to change your life a little bit to accommodate the treatment... you have to do everything else around it.” (P6, female)</p> <p>“I miss days [of work] all the time... right now I'm doing light treatments, so I got those three times a week, and every other week I got infusions and doctors' visits, so that's a good half a day there.” (P8, male)</p>
<p>Financial cost</p> <p>“When you're on a fixed income...the added expense, where I was driving three days a week from where I lived to where I get my treatments, and it's 40 miles one way. That's 80 miles round trip, where you do that three times a week. The wear and tear on your car, the added expense for gas... it's just all the little things that goes along with [treatment] that adds up.” (P3, male)</p> <p>“I'm sure you know insurance doesn't pay for everything, and it's quite expensive. On top of that, every time you come down and see a doctor it's considered a specialty visit, you gotta \$80 co-pay. Sometimes when am doing light treatments, which I am, they want an \$80 co-pay three times a week, and then you top it off with seeing two doctors that same week... You know, it's 80 times five. I mean, nobody's going to be able to do that unless you're rich... So, yeah, the medical bills pile up. You try to pay a little bit here and there, but it's a never-ending battle. You never get caught up and never can.” (P8, male)</p> <p>“No individual can afford this, even—I've got good insurance, but even with that... Now that I'm down to just two pills a day, it's around \$12,000 a month, but back when I was taking nine pills a day, it was more around 45 or \$50,000 a month.” (P9, female)</p>

Reprinted by permission from corresponding author Trisha Bhat Scharff @ Scharff, Trisha <scharff@wustl.edu>. Bhat T, Herbosa B, Rosenberg A, Sogade B, Jeffe D, Mehta-Shah N, Semenov Y, and Musiek A. Current measures are not sufficient: an interview-based qualitative assessment of quality of life in cutaneous t-cell lymphoma. Br J Dermatol. 2021;184(2):310-318. Doi:10.1111/bjd.19298.

Legislative Days...continued from pg 5

Pharmacy Benefits Manager (PBM) Transparency Act (S 4293)

This bill would ban deceptive unfair pricing schemes; prohibit arbitrary “claw backs” of payments made to pharmacies; and require PBM’s to report to the Federal Trade Commission how much money they make through spread pricing and pharmacy fees.

While there may be repetition across efforts and some issues may span over several years, please don’t be discouraged as the process can be lengthy and requires significant effort in order to make change. We will continue to keep track of the issues you bring to us, and work to bring your voices and your stories to the table. Together, we can make a difference.

(Information related to "asks" taken from AADA 2022 Legislative Conference and CSD Legislative Agenda materials)

Your Stories Make Change Possible!

Visit our advocacy page to find resources on how to share yours:

www.clfoundation.org/advocacy

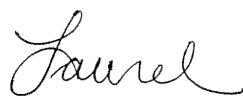
Opportunities to be an advocate come in many forms - join our mailing list to stay informed how you can participate!

www.clfoundation.org/join-mailing-list

From the Board President...continued from pg 3

As we approach the end of this not-so-normal year, I want to ask you to please consider making a donation to the Cutaneous Lymphoma Foundation so we can continue to make a difference in your life and the lives of every person affected by this disease. You are the reason we exist, and your financial support helps guarantee that we will continue to exist. We are fighting for all of us to have a life free of the burden of cutaneous lymphomas. Every gift, regardless of its amount, helps bring this vision closer to reality. Your support makes a difference today, and enables the next person who receives this diagnosis, wherever they are in the world, to get what they need tomorrow.

As a fellow patient, I thank you.



From the CEO...continued from pg 3

form ourselves to meet the needs and expectations of our global community.

With your ongoing participation and support, we can continue to connect and serve everyone impacted by cutaneous lymphoma. Whether you are newly diagnosed or have been a part of our community for many years, YOU make the Cutaneous Lymphoma Foundation who we are. It’s you that I am personally grateful for. Every conversation and every connection is precious.

Thank you for trusting us and joining us in pursuing our vision to eliminate the burden of cutaneous lymphoma for everyone impacted. Together we make a difference in the lives of people around the globe.

Have a joyous holiday season. We will see you in 2023!



**We are working on program planning for 2023
and we want to hear from you.**

Scan the QR code on the right to answer a short survey
or visit:

<https://bit.ly/3hVz7il>





CUTANEOUS LYMPHOMA FOUNDATION
PO BOX 969
WARREN, MI 48090

TIME SENSITIVE MATERIALS ENCLOSED



Thank you for being a valuable member of the cutaneous lymphoma community.

Thank you for showing up for yourself and for others affected by cutaneous lymphomas.



Thank you for trusting us to be there to fight for you and the people who support you.

And...Thank you for supporting the Cutaneous Lymphoma Foundation to ensure the doors stay open and the lights stay on for you and the next person who needs information, support, and/or resources.



Donate Today!

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

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

By Mail: PO BOX 969, Warren, MI 48090

(a remittance envelope has been enclosed for your convenience)