

PATIENT EMPOWERMENT: FINDING THE SUPPORT YOU NEED

Previously, we spoke with Leora Lowenthal, a licensed clinical social worker who has training and special interest and expertise in oncology, about patient empowerment. She has been working the past 26 years in the oncology world with a special focus on the experience of people diagnosed with cancer, their friends, their loved ones, and also communities like the Cutaneous Lymphoma Foundation.

Leora works with medical oncologists, radiation oncologists, surgeons, nurses, physical therapists and nutritionists to name a few. They work together to take care of patients and their families who come to the cancer center for treatment. This involves a lot of counseling, both individual, family and group, and also a lot of work to help people get connected to resources in the community. It can be hard to cope with some of the practical challenges that come up with any diagnosis, and certainly any cancer diagnosis.

Here are some of the highlights of Leora's conversation with Susan Thornton, CEO of the Cutaneous Lymphoma Foundation.

Susan:

How do you engage with a social worker? I know for me personally, I didn't realize that this kind of service and support even existed, and no one told me. So maybe you can talk a little bit about from a patient perspective, how would they connect with someone like you in your position?

Leora:

That's a great question and it comes up quite a bit for the cutaneous lymphoma community. There is often such a focus, at least initially, on dermatology as opposed to hematology. I think because so many people are first coming through dermatology offices, they're less likely to come into contact with oncology social workers. You are generally more likely to be around an oncology social worker where there is a dedicated cancer center, but fortunately there are many wonderful community organizations that provide oncology social work services.

Let's say you're somebody who has early-stage cutaneous T-cell lymphoma and you're not seeing a hematologist, or you see one but you see them once a year and don't want to make that a place where you go frequently. Maybe you went to a specialist, but that person is quite far away and you need

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What Is Cutaneous Lymphoma?

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

FORUM

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

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FROM THE BOARD PRESIDENT

Laurel Carlson

I hope you are enjoying the summer; the warmer weather (or at least surviving the warmer weather) and longer days.

Did you participate in this year's Virtual Patient Conference? The data tells us there were a record number of attendees - we hope that included you. As the Board President, and a patient, it warms my heart to know more and more people affected by cutaneous lymphomas are getting education and support each year. If you didn't get a chance to participate, most of the sessions were recorded and are available on the Foundation's Youtube channel. There is some really great content - check it out.

As we look ahead to what's left of summer and we jump into the fall, we hope to see you at an upcoming Answers From the Experts program, webinar, one of the Networking Groups, in the Community (Connections Community), or at our Virtual International Conference being held on September 10, 2022. You may recall, September is a BIG month for our cutaneous lymphoma community - it is Blood Cancer Awareness Month, World Lymphoma Awareness Day (September 15th) and Rare Cancer Day (September 30th). Because September is such a big month with so much to honor, raise awareness of, and celebrate, we will be hosting a Cutaneous Lymphoma Care-A-Thon from September 10 - 18. This event is designed to raise funds to support people affected by cutaneous lymphomas. Mark your calendars and stay tuned for more details about how you can participate.

As we strive to offer with all our programming, this issue of the Forum is packed with lots of good information. As you dive in, you'll find great articles on orphan drugs, nutrition and physical activity, as well as our always popular "frequently asked questions" section and more. Hopefully we've covered something for everyone, but especially you. We look forward to hearing what you think.

Wishing you a wonderful rest of your summer and a safe, happy and healthy fall. We look forward to connecting with you. Make sure to reach out if you need anything along your cutaneous lymphoma journey.

"...it warms my heart to know more and more people affected by cutaneous lymphomas are getting education and support each year."

Laurel Carlson

FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton



"...It's more than a disease community. It's a family."

Susan Thornton

"Avocado Time: The moment when we have the chance to connect, to be in sync, to bring out the best in each other - that's time worth cherishing."

- Seth Godin

That quote is how I feel about this year's annual Virtual Patient Conference. While we had hoped to host everyone in person, COVID had a different plan. And yet, the time we spent together over those precious hours is genuinely worth cherishing. It makes our work unique here at the CL Foundation because we get to create the space for each of you to enjoy a little "avocado time."

As I reflect on 2022 so far, I feel grateful that we have been able to bring a wide variety of programs, services and, most of all, opportunities to connect with you. That connection makes all the difference, whether

during a monthly networking group or a one-on-one conversation. It's the core of why the CL Foundation exists and was the original vision of our founders.

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EVERYTHING YOU NEED TO KNOW ABOUT ORPHAN DRUGS

What is an orphan drug?

According to the United States Food and Drug Administration (FDA), an orphan drug intends to treat rare diseases or conditions, specifically those affecting fewer than 200,000 persons in the United States.

Orphan drug research provides a pipeline for new treatments for rare diseases. According to the National Institutes of Health, more than 7,000 rare diseases affect around 30 million Americans, but only a few hundred of these rare diseases currently have approved treatments.¹

Why does a drug need orphan status?

Years ago, pharmaceutical companies were reluctant to invest research dollars into rare disease research because they affected so few people. Even with successful drug development, there would not be enough “buyers” for the developers to earn a return on their investment. However, the Orphan Drug Act incentivized rare disease drug development, and many new treatments followed.

The year 2023 will mark the Orphan Drug Act’s 40th anniversary! Before the 1983 Act, people with rare diseases had little hope for new drug development.

The Orphan Drug Act was signed into law by President Ronald Reagan on January 4, 1983. In his signing speech, President Reagan noted how the United States “has led the world in developing new drugs that have saved millions of lives. That is a gift to mankind that we can be very proud of. Yet the sad fact remains that many diseases still cripple or kill hundreds of thousands of Americans, as well as citizens

of other countries, because no drugs have yet been developed.”⁴

Has the Orphan Drug Act been successful?

According to a 2021 article in the Orphanet Journal of Rare Diseases, 5,099 drugs and biologics received orphan drug designation between 1983 and 2019. Oncology drugs received the most designations 37% (1,910), followed by neurology and infectious disease drugs. These orphan products may have gone untested had it not been for the incentives provided by the Orphan Drug Act.

As of December 2019, 724 (14%) of the 5,099 orphan drugs had at least one associated approval and there were 878 total approvals - meaning some orphan drugs prove useful for more than one condition.⁵

Is cutaneous T-cell lymphoma (CTCL) an orphan condition?

Yes! Because CTCL is a rare disease with no cure, it has designation as an orphan condition.

The National Organization for Rare Disorders (NORD) is a patient advocacy organization dedicated to individuals with rare diseases and the organizations that serve them. According to NORD, there are approximately 1,000 new skin lymphoma cases each year in the United States. About 16,000-20,000 Americans have the classic presentation of CTCL known as mycosis fungoides.²

By contrast, some estimates suggest up to 50% of adult Americans have high blood pressure, making it the most common health condition in the United States.

“When Daddy Warbucks gave Little Orphan Annie some attention, it transformed her life. Similarly, when pharmaceutical companies turn their attention to rare and often neglected diseases, they have the potential to touch the lives of people that often have no alternatives. To encourage development of these types of drugs, the FDA has developed several incentives. In fact, we have a name for these drugs – orphan drugs.”
– 2012 FDA Newsletter⁶



How do you find orphan drug studies?

All clinical trials enrolling in the United States are listed on the National Institutes of Health (NIH) website: www.ClinicalTrials.gov.

This user-friendly site allows you to search by condition, disease, or other keywords and provides a list of upcoming and currently enrolling trials.

Many orphan drug studies happen in academic medical centers in larger cities. However, limited access to these trial sites creates a challenge (known as an enrollment barrier) for those who do not live where these trials are enrolling.

Are there CTCL orphan drug studies happening now or in the near future?

Yes! Let’s take a closer look at two orphan drug studies:

- Canada’s Trillium Therapeutics TT1-621 received orphan drug status in 2018. A phase 1 study injected TT1-621 directly into CTCL lesions and showed some promise, according to a published study in the journal *Lancet Haematology*.³ Pfizer, an American multinational pharmaceutical and biotechnology corporation headquartered in New York, acquired Trillium Therapeutics in the fall of 2021. Planning for continued early phase TT1-621 studies is ongoing.
- Innate Pharma, a global, oncology-focused biotech company based in France, received orphan drug status for IPH4102 (Lacutamab) in 2017. Innate Pharma is currently enrolling subjects into a phase 2, open-label study to evaluate Lacutamab, an intravenously administered monoclonal antibody. The current trial aims to evaluate the clinical activity and the safety of Lacutamab in both Sézary syndrome and mycosis fungoides. Early data presented in 2021 appears encouraging.

Why does it take so long for new CTCL drugs to get approved?

A rigorous process exists for drug testing in the United States. This process was fast-tracked, with accelerated development and approval processes, for some COVID treatments. As a result, urgently needed drugs gained approval more quickly. Hopefully, this will result in other non-COVID drugs coming through the pipeline faster.

In rare diseases, however, the problem of finding enough patients to participate in clinical trials remains a challenge.

Finding ways to bring the trials directly to the patients, rather than having the patients come to the trial, might be a way forward.

Having any medical condition challenges us. However, having a rare medical condition presents an even more significant challenge. As you navigate opportunities for treatment with orphan drugs, or if you are considering participating in an orphan drug clinical trial, the Cutaneous Lymphoma Foundation welcomes your questions and strives to support you on your forward journey.

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NUTRITION & PHYSICAL ACTIVITY: A LIFESTYLE MEDICINE APPROACH

My name is Karla Rodriguez and I have been a registered nurse for 23 years and teach at Rory Meyers NYU College of Nursing. I am a certified nurse educator, and I am also certified in Lifestyle Medicine since 2020. How we conduct ourselves in our day-to-day lives has a profound impact on our health. At the American College of Lifestyle Medicine, we focus on six pillars: plant-strong nutrition, physical activity, stress management, cessation of risky substances, sleep, and engaging in positive social connections.¹ I want to preface by saying, please always consult with your health care provider before making any changes to your lifestyle behaviors that may impact your health.

I was diagnosed with mycosis fungoides for about ten years now. My oncologist is from Memorial Sloan Cancer Center; I have seen the same doctor on and off for 10 years. It was not officially confirmed at first, but I was eventually diagnosed with Stage IB. I have been using phototherapy and using the topical cream, triamcinolone acetonide. I mostly have it on the inner aspects of my arms at this time; they usually travel around different parts of my body. They are not raised nor are they itchy; however, it is scary not knowing when or how it will progress, or just fear of the unknown. For those of you who are part of the Cutaneous Lymphoma Foundation networking groups are aware, no two people are alike when it comes to this condition. I am thankful for the Cutaneous Lymphoma Foundation for providing a support network for us to connect with one another, at least virtually.

Nutrition

I have always been interested in nutrition. I was very overweight growing up; I stopped weighing myself when the scale tipped to 160 pounds. Somehow, I found a way to eating healthier even though I felt the odds were against me. I am 52 years old, and, at this age, I feel we are all on a journey.

There is no denying that we are facing an obesity epidemic. As countries around the world have adopted a diet of processed foods, chronic diseases follow. Based on data from the USDA's Economic Research Service, the average person in the United States gets:

- 64% of their calories from processed foods
- 23% from animal foods (primarily beef, chicken, pork, cheese and milk), and
- 13% from whole plant foods²

Everywhere you go, there are advertisements for mostly processed foods, complements from the food industry. For

instance, upon entering the grocery store, aisles are filled with packaged foods which are not good for us, all the while sending subliminal messages to our brain. In the past, I did not believe that what we eat can produce a whole host of conditions for people such as Type 2 diabetes, arthritis, thyroid conditions, fatty liver disease, and yes, even some cancers.⁴ However, the research is replete with evidence supporting these claims. I will never forget what my hematologist from the New York Blood and Cancer Center said three years ago. I went for a flow cytometry blood level test and it was my first encounter with him. The first thing he said was, "Eat whole plant-based foods; a lot of people are eating processed foods and too much sugar."

At that time, I was already plant-based but could have done a better job at consuming less vegan junk foods. I do not consume any foods derived from animals as this is my personal choice. The research is replete showing how eating high fat foods and processed foods can produce inflammation in the body. For the most part, having an unhealthy microbiome produces cells which thrive on sugar and, in turn, can produce significant inflammation in the body over time.



The world's longest-lived people adopt diets that have helped sustain their longevity. They live in regions called the Blue Zones (there are five) such as Loma Linda, California; Ikaria, Greece; Nicoya Peninsula, Costa Rica; Sardinia, Italy; and Okinawa, Japan (Willett et al., 2019)³. Although these people consume foods endemic to their region such as lean meats and fish, it is not part of the main course. The common foods they eat are leafy greens, beans, sweet potatoes, whole grains, fruits, nuts, seeds, and olive oil. Cow's milk is not part of

any Blue Zones diet. Eggs come from chickens that range freely and do not receive hormones or antibiotics.

If you find yourself wanting to make a change in your food plan, then this message is for you. The idea is not about restricting foods, but what can you add to your food plan such as more fruits, vegetables, and whole grains. The problem is not so much the carbohydrates as it is the lack of fiber. There are processed foods which have little to no fiber, and then there's the sweet potato which contains fiber, minerals, and nutrients. We all have different food plans but the idea is to add more whole grain, plant fiber in our diet to produce a healthy microbiome in our gut. It's the fiber that will carry out the toxins and added cholesterol that we have out of our body.

Things you can do to mitigate unhealthy habits: Read labels; foods with "artificial colors" can disrupt the immune system, are man-made in a lab with chemicals derived from petroleum, have been banned in countries like Norway and Australia, are contaminated with carcinogens, and have been linked to long-term health problems such as asthma, skin rashes, and migraines.³

Dispel Diet Myths: "I need my protein"

All plants contain protein and all 20 amino acids. (See chart) They also reduce the risk of dangerous diseases and can contribute to living longer. Animal protein ingestion results in a heavy acid load in the blood. This sets off a series of reactions in which calcium is released from your bones to help neutralize the acid resulting in calcium loss.⁵

"I need dairy for calcium and my bones"

Dairy products are often touted as the best way to get your calcium, but that is one of the greatest nutrition myths passed by the food industry. A systematic review from a reputable medical journal, the Lancet, analyzed 62,910 participants from 89 countries, and estimated the global prevalence of lactose intolerance to be 68%. Almost 70% of the world is intolerant of cow's milk (Willett et al., 2019).³ Many green vegetables have calcium absorption rates of over 50% compared with about 32% for milk.

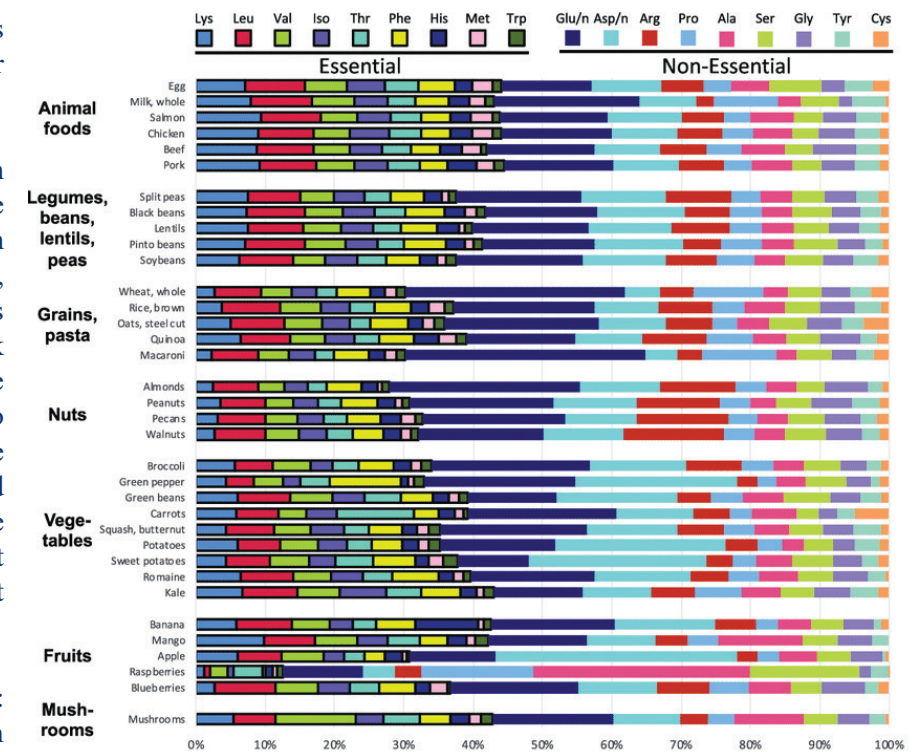


Figure: Proportions of amino acids in selected foods across food groups. Amino acids are grouped as essential or nonessential, in descending order of prevalence within food groups. (Source: Nutrition Database System for Research, University of Minnesota; <http://www.ncc.umn.edu/ndsr-database-page/>). Abbreviations: Ala, alanine; Arg, arginine; Asp/n, aspartate and asparagine; Cys, cysteine; Glu/n, glutamate and glutamine; Gly, glycine; His, histidine; Iso, isoleucine; Leu, leucine; Lys, lysine; Met, methionine; Phe, phenylalanine; Pro, proline; Ser, serine; Thr, threonine; Trp, tryptophan; Tyr, tyrosine; Val, valine. [Figure available via license: Creative Commons Attribution-NonCommercial-NoDerivatives 4.0 International]¹¹

"Soy is a hormone"

For the first time ever, the 2020-2025 USDA dietary guidelines proclaim that soy milk is nutritionally equivalent to cow's milk. Flaxseed is 4 times higher in phytoestrogens than raw soy compared to cooked or fermented soy which is even higher. Phytoestrogens lock up your estrogen receptor so when a stronger estrogen comes along, whether it's your own estrogen, DET, or environmental estrogens since it's already blocked, they cannot latch on. Phytoestrogens are weak estrogens but also act as an estrogen regulator.⁵

Physical Activity

I want to pivot to another topic: physical activity; notice I didn't mention exercise. I wrote an article for a nursing journal about NEAT which stands for non-exercise activity thermogenesis. NEAT is the number of calories you burn daily doing things other than sleeping, eating, or exercising.^{7,9} Basically, it means any form of movement is good and considered as an activity.

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As a society, we have been indoctrinated to sitting. Right now, you might be sitting somewhere reading this article. Yes, sitting for brief periods can help us recover from stress or recuperating from exercise. But, nowadays, our lifestyles make us sit much more than we move around. Our bodies were not designed for such a sedentary lifestyle. Inside us are 360 joints and 700 skeletal muscles that enable us to move in an easy, fluid motion.¹⁰ A common way of sitting is with a curved back and slumped shoulders which places uneven pressure on your spine. Over time, this causes wear and tear on your spinal column and puts strain on muscles that serve to accommodate your back's position. This also decreases the air space in your lungs, requiring more effort to breathe.

Believe it or not, the dangers of sitting too much are very real. Sedentary behavior is closely related to premature death, preventable disease, and healthcare costs. A decreased level of physical activity, largely due to prolonged sitting and increased screen time, with an increase in food intake has also contributed to rising rates of obesity. We sit in our cars, at our desks, at the doctor's office, in classrooms and, if you think about it, we probably spend most of our day sitting.⁸

Any type of physical activity such as yard work, fidgeting (moving while standing), cleaning the house, or using some type of a standing desk while working on your computer can help mitigate stress on the body and keep your body in motion. Standing for at least 2 hours a day can reduce all-cause mortality up to 10%. If you're working from home, take a break to walk the dog or take out the trash. Or maybe set a timer for yourself to get up at least every hour if you are sitting.⁹

The process of change is not easy. For many of us, lifestyle change will require some time. Most importantly, you need to find your why in wanting to make a change to stay on this health trajectory. Lastly, you can eat all the kale you want but if you dismiss other aspects of your mental health, such as sleep and stress management, you may not succeed in healthy lifestyle changes. Remember, overall health is more important than what you eat!

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The Cutaneous Lymphoma Foundation recommends always consulting with your health care provider before making any changes to your lifestyle behaviors that may impact your health.

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2022 CATALYST RESEARCH GRANT AWARDEES ANNOUNCED

The Cutaneous Lymphoma Catalyst Research Grant was initially launched in 2019 as a bridge funding mechanism to existing research projects. Since 2019 this grant has been expanded to also support cutting edge pilot projects as well as quality of life research. This year we had an incredible response of 22 applications from researchers around the world. While we wish we could support them all, and hopefully someday can, this year we are pleased to announce this year's awardees are:

Cosmin Tegla, MD, from the NYU Grossman School of Medicine for his pilot project entitled *Repurposing atovaquone, an FDA-approved antimicrobial, for the treatment of cutaneous T-cell lymphoma.*

Neha Akkad, MD and Co-Primary Investigator, **Neha Mehta-Shah, MD** from Barnes Jewish Hospital for their Quality of Life pilot project entitled *Quality of Life in Patient with Cutaneous T-Cell Lymphoma: Validation of a Novel Quality of Life Instrument.*

To learn more about either of these projects, please visit our website (<https://bit.ly/3jglEib>) to see a short explanation provided by each of the researchers regarding their work.

Thank you to our Scientific Review Committee for your time, dedication and expertise to the Foundation and the scientific review process. Without you, we would be unable to provide these important research grant opportunities.

And to you, our donors, without your support and dedication to the mission of the Foundation, there would be no grants to support this much needed research. Thank you for believing in the mission and for being partners in our vision of a life free of cutaneous lymphomas.

THANK YOU to our Scientific Review Committee for their dedication & commitment

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Sidney Kimmel Cancer Center

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social work in your community. Usually then what I recommend is that people use any number of organizations such as CancerCare, Cancer Support Community, the Leukemia & Lymphoma Society and, of course, the Cutaneous Lymphoma Foundation. These organizations can help, at the very least, guide people and can often help locate resources in a patient's local community.

Going back to your original point, because many people with early-stage cutaneous lymphoma do not necessarily recognize that they can access services for patients with a cancer diagnosis, they don't look or ask for it. I'd love to see that change.

Susan:

Where do you start as even a newly diagnosed patient or a family member or somebody that's trying to support someone who's diagnosed? What do you do first? What would some of your thoughts be?

Leora:

For medical care, find specialists who have self-identified and been verified as people who specialize and treat significant numbers of patients with these diagnoses. And as you know, for those having trouble finding a specialist, the Cutaneous Lymphoma Foundation has a lot of helpful information ready and available.

For emotional and practical support, I would similarly suggest connecting with a patient community that is already in some way familiar or living with the diagnosis. Particularly, for those who are diagnosed or who love someone who's been diagnosed with a rare disease, they likely haven't, in their day-to-day lives, already met others with the same diagnosis. It can be so wonderful and valuable to find other people who may share some of your experiences and to realize that you have a community.

If you are a loved one trying to assist, it's always hard to know how to be helpful and there's certainly no one answer. For most people, even if we're grateful to have help offered to us, we really don't want to be in a position where we need help and we may not have a clear sense of what kind of help we will want or need. I often work with people and their families or friends to have open conversations about this. Again, there is no one answer but getting communication going helps.

Susan:

What can you share in your experience of speaking with others on coping mechanisms? What kinds of things can people think about to cope?

Leora:

I think something important to acknowledge is that we're talking about a diagnosis that is considered incurable and is essentially a chronic illness. That means you will have to learn to cope with it over the course of many years and what you are coping with, along with your skills, may change over time.

I'd also say that there are scales of what we're talking about with coping. There's the day-to-day "How do you cope with stress?" and then there's "How do you cope with something like depression or anxiety?" When do you know that you need professional help or help from someone else and allow yourself to ask for that? I think that's a really important part of the



conversation with one's healthcare providers in general, and that if you're having trouble coping, you should be letting your doctors know. If you don't feel comfortable talking about it with your cutaneous lymphoma specialist, talk about it with your primary care physician (PCP). If you're not comfortable talking about it with your PCP, maybe get a doctor who you're comfortable talking about it with because your emotional well-being and mental health is so important and so intricately connected to everything else. I hope very much that people make this just a part of the conversation of how they are approaching what we want to see as a lifelong diagnosis, meaning something that you will live with and hopefully live with very well

Susan:

With the inherent challenges of our health care systems, what recommendations would you have regarding affordable medications?

HELP ENSURE THE FUTURE OF THE CUTANEOUS LYMPHOMA FOUNDATION: CHARITABLE BEQUESTS

There are so many ways you can support the Cutaneous Lymphoma Foundation by:



Your estate planning: Make a gift to the Cutaneous Lymphoma Foundation through your Will or Revocable Trust, or by designating the Cutaneous Lymphoma Foundation as a beneficiary of a life insurance policy or retirement account. The Cutaneous Lymphoma Foundation can be named to receive all or a portion of the gift. For those over 70 ½, a Qualified Charitable Distribution (QCD), where you can make a charitable donation from your IRA to a charity and the QCD can be counted towards satisfying your required minimum distribution, may be an excellent option.



Employer Matching Gifts: Many employers will match charitable contributions made by their employees. Check with your HR department to see if your company sponsors such a program...you may be surprised to learn that your company has such opportunities.

DAF

Donor Advised Fund: A Donor Advised Fund (DAF) has been compared to a charitable savings account. When funds are contributed to a DAF, which can be set up at most brokerage firms, you get an immediate tax deduction (up to certain limits), those funds are invested for tax free growth, and the funds will be distributed to charities you designate.



Direct Gifts of Cash to the Cutaneous Lymphoma Foundation: Direct gifts of cash qualify for a charitable deduction, subject to certain limits depending on whether or not you itemize.



Gifts of Appreciated Assets: An example is stock, where you will receive a charitable deduction for the full fair market value of the donated stock and avoid payment of any capital gains tax if you have owned it for at least one year.

Leora:

If you're at a cancer center, there's almost always a social worker, community resource specialist or a financial aid specialist you can talk to, hopefully all three. My basic advice is to find the people, either at your treatment center, pharmacy or one of the organizations I listed earlier, who will know what patient assistance programs exist and how to help you navigate.

Leora Lowenthal, LICSW, OSW-C, MPA, FAOSW
Sr. Clinical Social Worker
Dept of Psychosocial Oncology and Palliative Care
Dana-Farber Cancer Institute

Join Community Connections

Make sure to check out the Cutaneous Lymphoma Community Connections, a place where you can interact with others facing the same or similar experiences as you. In order to provide privacy and encourage open communication with each other, Community Connections is open exclusively to patients and their loved ones.

To learn more, visit
www.clfoundation.org/connections

Frequently Asked Questions

The following questions and responses are from an "Answers from the Experts: Open Q&A" event with Drs. Larisa Geskin and Joan Guitart.

Is there a reason why a systemic treatment medication is preferred over localized topical treatment?

Geskin: One of the reasons we need to use systemic medications for lymphomatoid papulosis (LyP) is because you never know where your next spot is going to appear. Lymphomatoid papulosis is a very diverse group of conditions in which some patients develop just one or two spots over months, and some people have hundreds of spots. The more spots you have, the more you benefit from systemic therapy. If you have just a couple of spots, sometimes we do use topical steroids. When a spot of LyP is coming, you can start applying the steroid even before it erupts and it may stop it in its tracks.

How effective is surgery to move lesions of primary cutaneous anaplastic large cell lymphoma (PCALCL)? How deep should they go? Does it remove muscle or lymph nodes?

Geskin: Surgery is one of the ways primary cutaneous and anaplastic large cell lymphoma can be treated. It's usually a localized disease and it usually comes in a single spot. When it's just a single tumor, it can be excised and does not have to go into the muscle. The lymph nodes do not need to be removed. In fact, we don't even have to do surgery because sometimes radiation therapy works just as well. It may be able to irradiate the tumor and it just melts away. Some patients prefer surgery because it's a single procedure and it's quite effective. It may be removed completely; however, because it's a lymphoma (i.e., not a specific kind of skin cancer, but rather a malignancy of white blood cells), sometimes we do see recurrences after surgeries.

With patients being treated with mogamulizumab, how long have you seen consistent efficacy or effectiveness?

Geskin: In pivotal clinical studies, the response rate to mogamulizumab lasted for a couple of months, but this is over hundreds and hundreds of patients. Some patients had a very short lasting response, but many patients had long-term responses. My experience is that some patients benefit long term but, unfortunately, we cannot tell who will and for how

long each patient is going to benefit from a particular drug. Only a trial and error type of situation will show us how well some patients may respond to certain drugs.

When is the best time to start treating mycosis fungoides patients systemically?

Guitart: This is the type of question that if you ask a dermatologist or an oncologist, you'll get a different answer. My approach after 30 years of seeing patients with CTCL is that I like to stay on skin-directed therapies for as long as possible. Over time with the skin-directed therapies, if we cannot control the disease or if there are signs of progression, then I like to combine the skin-directed therapies, like phototherapy, with retinoids, like bexarotene or interferon. We try to limit the use of systemic chemotherapy until there is advanced disease or if there is nodal involvement or large lesions that don't respond to radiation. We know that chemotherapy tends to only give us short responses. As long as you can preserve the immune system, just attacking directly the skin with radiation, with phototherapy, with topical steroids, the better you're going to be then switching to chemotherapy, which, as I was saying, the results don't tend to be very long lasting.

Can primary cutaneous anaplastic large cell lymphoma (PCALCL) move into the lymph nodes? And if so, is it common for the disease to spread quickly throughout the entire lymphatic system?

Geskin: Primary cutaneous anaplastic large cell lymphoma, by and large, is more of a localized disease. For many patients, it's unusual for PCALCL to move to the lymph nodes. In fact, when something like that happens, I'm wondering if it wasn't systemic lymphoma to begin with. In some of these cases, though, it may extend to the lymph node and cause a real nodal disease, but usually the PCALCL has a favorable prognosis and a vast majority of patients with this condition do quite well.

Guitart: PCALCL is a rare lymphoma that's in the spectrum of lymphomatoid papulosis. When lymphomatoid papulosis becomes like a large tumor lesion, we call it anaplastic large cell lymphoma. This can go to the lymph nodes, but that's extremely rare. Maybe less than 10%. Less than 5% of the patients with PCALCL will have nodal involvement. The nodal involvement can be a single node that is treatable with radiation or excision, or you can have extensive

involvement. In my experience, patients with anaplastic large cell lymphoma, less than 5% require systemic therapies. It does happen, but it's extremely rare.

What is the consensus on maintenance narrow-band UVB for early stages or only treatment of lesions when they appear?

Guitart: There is no consensus on maintenance therapy, but as a matter of fact, there's a lot of controversy. I think we all agree that UVB works very well for patients with patch or plaque stage mycosis fungoides. Once you get a good result, I think everybody pretty much agrees that you need to consolidate the good results by prolonging the therapy at least another three to six months. When to stop the treatment is controversial. In my practice, I like to decrease the frequency of treatments. In Chicago, which obviously has a long winter, I stopped the treatment of UVB in the summer months once the patients have achieved a good response, but there is no consensus. I believe that decreasing the frequency of UVB treatments, maintaining the good response is an indication that the patient is doing very well. I do like to slowly decrease the frequency. But again, not everybody is of the same school of thought.

Geskin: I completely agree, there is no consensus. In fact, there are several schools of thought on the subject of maintenance therapy with narrowband UVB. One of them is very strict proponents of maintenance and the other is opponents. And so depending on who you talk to, you can get two different answers. But the truth is, as Dr. Guitart said, there is really no data and we like to base our treatment recommendations based on data.

One thing I have to say, that during the COVID pandemic, we had discontinued narrowband UVB therapy for several patients who were coming to the office. These people, some of them got home units, but several of them stopped therapy and they did have relapses. This is something that we are publishing now. The International Society of Cutaneous Lymphomas is publishing a manuscript which describes the experience of treatment interruptions for patients with cutaneous lymphoma, whether they were on narrowband UVB or anything else. It looks like maintenance therapy is important. At least it seems from that observation that we made during the pandemic that interruption of therapy was leading to disease relapse.

Joan Guitart, MD
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Department of Dermatology
Professor of Dermatology (Dermatopathology) and Pathology
Northwestern University Feinberg School of Medicine

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Questions and responses taken from the recording of our "Answers From the Experts: Quarterly Q&A - April 2022" webinar. For the full-length recording, please visit: <https://youtu.be/LiPRZUUf8mQ>

DON'T MISS OUT...

To learn about upcoming events, visit www.clfoundation.org/upcoming-events or scan the QR-code below.



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



VIRTUAL PATIENT CONFERENCE RECAP

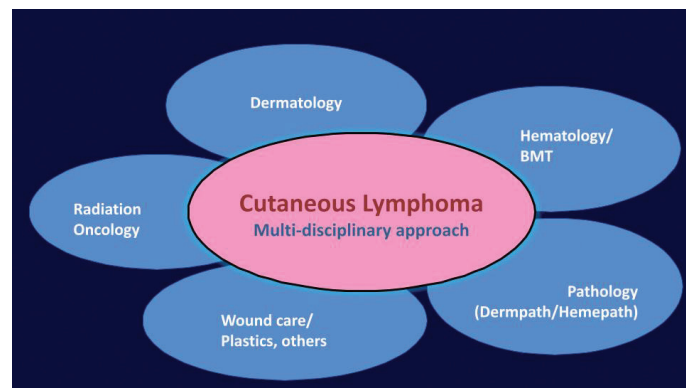
This year’s Virtual Patient Conference was a wonderful two days of learning and sharing. We had an amazing turnout with 148 attendees joining us to learn, ask questions, and share their experiences. Our two track program, introduced this year, offered something for both those who were newly diagnosed or have been living with the disease for longer. Initial feedback is that this format was a success and we will continue with it for future conferences.

In our programs, we strive to educate the cutaneous lymphoma community about the disease and offer patients a community where they, and their loved ones, can feel confident learning and sharing. We are pleased that our survey results showed over 97% of attendees reported learning at least one new thing about cutaneous lymphoma at the conference and would attend again.

While we all miss having the conference in person, we were still able to provide opportunities for attendees to network with each other. Over 60 people participated in our Friday night networking event and 89 attended the Saturday sessions. We are so happy attendees were able to share their personal stories and feel connected to others with this rare disease.

At the core of every Patient Conference are the cutaneous lymphoma experts who provide important clinical presentations. This year’s presentations included:

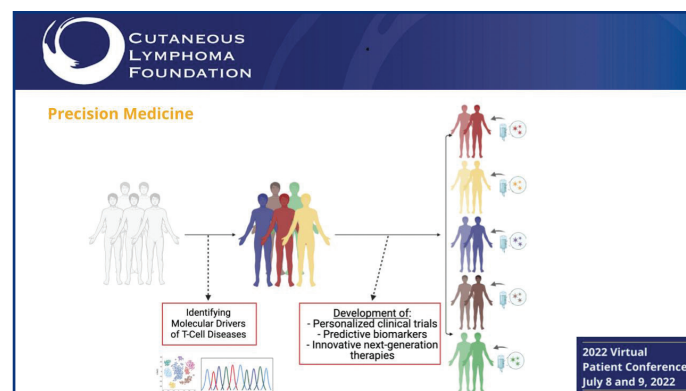
Dr. Basem William’s presentation on *Cutaneous Lymphoma 101* provided a thorough overview of a sometimes confusing disease and discussion on the importance of a multi-disciplinary approach.



In her presentation *Cutaneous Lymphoma Treatments - Early & Late Stage*, Dr. Niloufer Khan discussed how the disease is staged and general strategies for approaching treatments for both early and late stage disease. In addition to providing an overview of many treatment options, Dr. Khan shared these “take home” points related to treatment:

- Manage as a chronic disease
- Goal is often sustainable partial response rather than lasting complete response
- Optimize use of skin-directed therapies and supportive care
- Optimize/maximize use of single agent systemic therapies prior to combination chemotherapy
- Participation in clinical trials is encouraged
- Growing interest in incorporating biomarkers and precision medicine

For those who wanted a bit more of the science, Dr. Jaehyuk Choi’s *What’s New in Research* was exactly what they were looking for. Dr. Choi shared exciting information on precision medicine and on how it is being used to identify the molecular explanations for why lymphomas occur.



Continuing on the science theme, Dr. Steven Rosen presented on *A Scientific Approach to Understanding Cutaneous Lymphomas*. Dr. Rosen discussed dissecting the environment in which cancer lives. This can lead to a better understanding of why the environment harbors and sustains the growth of the cancer and how the immune system can be enhanced to kill it.

Annoyed by itch? In Dr. Steve Daveluy’s *Itch, Itch, Itch*, he presented on how itch works in the body and options for dealing with it, including the use of oral medications, phototherapy, topicals, wet wraps, gentle skin care and systemic steroids. If you struggle with itch, Dr. Daveluy’s presentation may offer possible solutions for relief.

Quality of life is another important topic to individuals living with cutaneous lymphoma. Dr. Trisha Scharff discussed quality of life from a scientific point of view in her *Quality of Life: The Long-Term Impact of Living with Cutaneous Lymphoma* presentation. She focused specifically on health-related quality of life (HRQL), defined as “...the value assigned to duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy.”

CUTANEOUS LYMPHOMA FOUNDATION

All-stage CTCL associated with more severe symptoms compared to vitiligo and non-melanoma skin cancer

Disease	Symptoms (Average)	Emotions (Average)	Functioning (Average)
All-stage CTCL	37.1	35.0	22.7
Vitiligo	13.9	35.9	16.7
Non-melanoma skin cancer	29	20	9
Without skin disease	14	9	4

One of the most popular sessions of every patient conference is the Open Q&A with our expert clinical panel. We were very happy to be joined by Dr. Lauren Pinter-Brown and Dr. Jina Chung to address your questions.

Another new addition to this year’s conference agenda was the Pharmaceutical Highlights Roundtable. Representatives from multiple pharmaceutical companies joined the roundtable to provide up-to-date information about their therapy and/or current clinical trials.

If you were unable to join us or would like to watch all or part of the clinical sessions again, they are now available to view and share as a playlist on our YouTube channel, CutaneousLymphomaFnd.

The 2-Day conference is where we can all come together for a balance of clinical information and camaraderie. We hope to see you at our next conference, whether it be in-person or virtual.

From the CEO...continued from pg 3

No matter what challenges we may face, we can make a difference as long as we can meet them together. We are stronger as a community of patients, care companions, clinicians, researchers, and biopharma companies. It takes all of us connecting, collaborating, and engaging to make a difference in finding new therapies, finding a new way to fight itch, or sharing tips to help you deal with the day-to-day emotional fears that many of us experience. It's more than a disease community. It's a family. We support each other, are there for each other, and cheer each other on. That's what makes this community so incredible.

Laurel shared in her column all the great programs and opportunities available to you. An exciting lineup for the fall season. And, the special sauce that makes it all worthwhile is YOU! You let us know what is most valuable to help you in your journey. You find us and ask us for support and guidance. You support us and invest in our programs so we can provide

more opportunities to more people. You give your time and compassion to fellow travelers to give them a hand up. That's what makes this a family.

Yes, all the essential pieces keep you abreast of what's happening in research, available clinical trials, engagement in active policy work, and resources that provide support. And yet, every individual inspires hope, whether you are a patient, care partner, CL Foundation staff, Board member, or volunteer.

That is why we are here - to inspire hope for every person impacted by cutaneous lymphoma. In the following pages, may you find inspiration and hope for your future. Avocado Time - you bring out the best in us, which is worth cherishing.

With hope,



CUTANEOUS LYMPHOMA FOUNDATION
PO BOX 374
BIRMINGHAM, MI 48012

TIME SENSITIVE MATERIALS ENCLOSED

Cutaneous Lymphoma Care-A-Thon September 10 - 18, 2022



Who: Anyone can participate!

What: Annual fundraising event - Care-A-Thon

When: September 10 - 18, 2022

Where: Wherever you are - this is a virtual fundraiser

Why: Make a difference in your life, and the life of others affected by cutaneous lymphomas! Another way to show you care.

In search of: Care-A-Thon event ambassadors and sponsors; people willing to lead the movement. Interested? Contact us today!

holly@clfoundation.org (248) 644-9014 ext 200

Don't forget - Mark your calendar!