

THE INFLUENCE OF EMOTIONAL SUPPORT ON CUTANEOUS LYMPHOMAS-RELATED STRESS

As a rare disease, cutaneous lymphoma can often be isolating and can leave patients feeling like they are the only one suffering from this disease. Patients can be left deeply stressed from their diagnosis and seeking a sense of understanding from others going through a similar journey. Human nature drives our need to connect and relate to others through networking and sharing mutual experiences; patients may find a sense of emotional healing and gain valuable support. While there aren't many disease-specific studies, stress relief may also be a cathartic side effect of emotional connection.

Studies from the United Kingdom indicate that cutaneous T-cell lymphomas (CTCLs) impact patients' quality of life including employment, leisure activities and relationships. Patients with CTCLs are frequently concerned about delays in diagnosis, disease progression, disease being serious, and worried about dying. Depression and anxiety are common, especially in patients with advanced disease stages. Family members that are caregivers also experience multiple demands from the disease and their specific needs remain to be investigated. (Beynon 2014, 2015, Selman 2014)

One study that interviewed 19 subjects with CTCLs, (Benynon 2015) found that despite the symptom burden and disease impact on patients' quality of life, participants described effective coping strategies such as drawing on social support, maintaining normal lives and becoming well informed about CTCLs. Another study described that patients participating in an online support group felt supported and better informed about new and current treatments.



For illustrative purposes only.

(Lamberg L. 1997). While there is a need to further investigate the role of emotional support in cutaneous lymphomas, these small studies suggest that emotional support can lead to stress relief.

"I believe that the importance of emotional support through peer understanding is immeasurable and something that we as medical providers, cannot offer within the walls of our offices. As a medical provider, I encourage my patients to take advantage of opportunities that allow them to connect with others to bring mutual support. Networking groups, patient support groups, social

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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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Disclaimer

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

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



FROM THE BOARD PRESIDENT

Joe Eischens, Esq.

Greetings from the Cutaneous Lymphoma Foundation!

I hope this spring season finds you well and that the groundhog was right this year; I for one am ready to see the end of this snowy season!

We have reorganized the themes of our Forum newsletter, so that this edition will focus on patient-centered care and our summer edition will be centered on research. We hope each edition brings you new information pertinent to your life and experiences.

We are very excited that two patients who attended our 2-Day Patient Educational Conference in 2018 are contributing to this edition. Jenni, one of our 2018 speakers, as well as Paula, a patient herself, connected in Bethesda at the 2-Day and have put together a special piece highlighting the way they met at the conference and the friendship they have maintained since then. We truly hope this will inspire you to attend a future conference and emphasize the amazing connections that are made through these incredible events. Speaking of our 2-Day Patient Educational Conference, inside this edition you will find information for the conference this year in Manhattan Beach, California. If you are local, we hope you will join us, and if not, we encourage you to consider making the trip!

Our feature article focuses on the impact of stress on emotional health and one medical professional's advice on combating stress



“So often we overlook the power of...support from others who can better understand what we are going through.”

Joe Eischens

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FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton

Winter finally seems to have lost its grip on all of us in the Northern Hemisphere. For that I am grateful! Summer is on its way and along with the first bursts of new life around us, we too look forward to a full season of offering inspiration and hope.

As Joe mentioned in his article, we've shifted the focus of our Forum newsletter this year to begin with topics around the non-clinical areas of living with cutaneous lymphoma. For many of us, we have managed to figure out how to cope with this unwelcome, long-term companion as the years have gone by. For those of you who may be newly diagnosed, this can seem like a huge leap as you grapple with digesting everything that comes with getting this diagnosis.



“...Finding other (patients) through the CLF in 2008 was a huge relief...”

Susan Thornton

Personally, meeting other people has been one of the most inspiring ways that I have found to help me in my own journey. Talking with others who have been down the road before me and sharing my experience with people who understand and appreciate the challenges, has made a big difference. If you talk with my family, in particular my Mom, they will tell you that it has been a challenging journey for them too. When I was originally diagnosed in 1991, there was no internet, no online listserv, no Cutaneous Lymphoma Foundation (CLF). I was given a scientific

paper that I couldn't begin to understand and told not to worry as this was a “good” cancer to have. While my story is certainly outside of the “typical” early stage patient's experience, finding other people through the CLF in 2008 was a huge relief for me. Finally there were others who truly understood. A huge weight was lifted off of me and my family members who also struggled trying to find the best way to support me through everything.

From the CEO...continued on page 9

Our Journey with Cutaneous Lymphoma

Shared by Jenni B. and Paula K.

A wonderful 'side effect!'

Anyone reading this is probably very much aware of the many issues that have to be dealt with when diagnosed with cutaneous lymphoma. But in all the reading I have done, I have never come across 'a wonderful friendship' listed as one of the possible side effects. Maybe it should be!

Last June I attended the Cutaneous Lymphoma Foundation's Annual 2-Day Patient Educational Conference in Bethesda, Maryland, which was outstanding, informative and supportive. The first morning, I was enjoying a delicious breakfast when a colorfully dressed woman with a bright smile on her face and a bunch of curls atop her head sat down and introduced herself, her British accent immediately noticeable. She was Jenni, an artist, and the keynote speaker.

The connection between us was evident and went beyond that we are both patients. Amazingly, I was going to be vacationing in Brighton, England, a short drive from where Jenni lives, in just a few weeks' time.

A few emails later, Jenni and I spent a delightful day together in the gorgeous South Downs in rural East Sussex. In the tiny, old village of Rodmell, we had lunch at an authentic English



pub; the fish and chips were great. We then visited a 17th-century cottage known as Monk's House where Virginia Woolf lived for many years. That's us in front of it in the picture!

After spending a perfect day in the English countryside, after many laughs along with serious conversation we said our goodbyes with the two very English expressions "bye for

now" and "lots of love." But not before thinking about getting together either in Jenni's home in Cornwall or my home in northern California, whichever can happen first!

The other side of the pond!

As I was driving over the South Downs to meet Paula, a wonderfully energetic and upbeat lady whom I met at the Cutaneous Lymphoma Foundation's Conference in Washington in June, the words on the CLF website from the president Joe Eischens, 'this disease doesn't have to define you' kept repeating in my head.

"...A wonderful friendship...(is) one of the possible sides effects."

Over the last three years, I have tried not to let it define me and have wanted to work through the diagnosis in my own personal way. In some aspects, my life has become richer, I don't sweat the small stuff as much, and most significantly, I have met an incredible array of people from my medical team to the CLF team and other patients both here in the UK and in America.

I recall with great fondness how welcoming and encouraging everyone was, always willing to share ideas and help wherever possible throughout my stay in Washington.

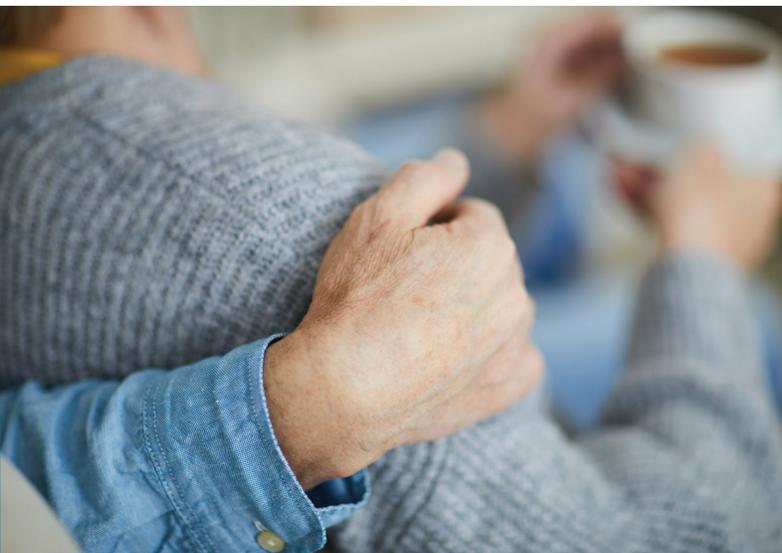
Spending time with Paula was one of those days when I just look back and smile. Paula made me laugh so much I nearly had to pull over! We were able to travel through the beautiful countryside, eat delicious food, and see exquisite flora and foliage.

We could freely talk about our diagnosis without having to provide answers, just share experiences, Paula has made a huge impact on my life, reminding me life is for living, laughing and loving!

Like Joe, Paula also reminded me that this disease doesn't have to define us and I realize how much I have to be thankful for. It's not always easy and there are grey days as well as blue skies.

I must not forget there are those unexpected delights in life that you do not imagine right around the corner. For me, making a new, special friendship with Paula is another richness to add to the list! 🌸

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outside of a doctor's office and to help find ways to facilitate these patient meetings.”

- Hilary Romkey

Encouraging patients to network and share with each other, can be greatly beneficial in numerous ways, but most importantly, we believe it can have a positive impact on a patient's emotional health. We urge anyone affected by cutaneous lymphoma or any chronic disease, to seek understanding, support, and take advantage of any community or peer encouragement available. Through mutual support, we can hopefully encourage positivity and continued emotional healing.

Lucia Seminario-Vidal, MD, PhD
Co-Director

**Multidisciplinary Cutaneous Lymphoma Clinic Moffitt
Cancer Center**

Hilary Romkey
Program Manager
Cutaneous Lymphoma Foundation

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*events, and, local forums, are all avenues to bring patients and their families together with a common bond. I recently participated in an evening **Answers from the Experts...Live** program with the Cutaneous Lymphoma Foundation. The evening was not only informative for patients on a medical level, but there was also an amazing feeling of community in which patients were able to share their personal stories with each other and sought to continue networking outside of the Foundation program to offer each other support.”*

– Lucia Seminario-Vidal, MD, PhD

“As a participant in many patient educational forums, and patient support groups, I have witnessed the incredible impact that patient networking can have and believe that it is greatly beneficial for a patient's emotional health to be supported and understood by others. I am a strong advocate for patients, and I am constantly seeking ways in which they can connect

Having someone who understands how chronic cancer impacts your life is an important part of managing feelings associated with having a diagnosis of cutaneous lymphoma.

You can locate resources for finding emotional support on the Cutaneous Lymphoma Foundation's website at:

www.clfoundation.org/emotional_support

SKINCARE
CORNER
Q&A

What's the difference between exfoliative erythroderma and exudative erythroderma and how can a patient/caregiver best treat/deal with each?

Erythroderma is the term used to describe generalized skin redness. It can present with thickening of palms and soles, damage to the fingertips, breakage of nails, dry eyes, and even swelling of legs. In some diseases, such as Sézary syndrome (SS), erythroderma can be the first symptom. For other already diagnosed skin conditions, such as eczema, psoriasis or mycosis fungoides (MF), a flare of the disease can show up as erythroderma.

In addition to redness, erythroderma can be accompanied by weeping lesions (exudative erythroderma) or dry scales (exfoliative erythroderma). These presentations may suggest underlying diseases. For example, exudative erythroderma is commonly seen in blistering diseases and exfoliative erythroderma in psoriasiform diseases. These two subtypes can coexist in MF/SS.

The initial management of erythroderma is the same regardless of etiology:

- Baths with lukewarm water and wet dressings to weeping or crusted sites should be followed by application of bland emollients and low-potency topical corticosteroids. Higher potency topical corticosteroids are not recommended because of risk for systemic absorption secondary to the extensive body surface area and the enhanced cutaneous permeability. Skin irritants such as hydroxy acid moisturizers and tar should be avoided.
- Fissures on fingertips are usually painful and may affect your daily activities. Apply a topical corticosteroid and cover them with a thick moisturizer. Finger topper bandages are an option. A topical liquid skin adhesive that holds wound edges together might be prescribed by your doctor.
- Dressing changes can be painful and cause anxiety. Speak to your doctor to evaluate the pain. You might be a candidate for pain medications to decrease the discomfort during bandage changes.
- A thick moisturizer such as fragrance-free petroleum jelly applied on nails overnight may help prevent breakage.
- Eye dryness can improve with artificial tears. If it is constant, it needs to be evaluated by your ophthalmologist.
- Swelling of distal legs is a common complication of erythroderma. It could respond to leg elevation and local skin care.
- Secondary superficial skin infections are common in erythroderma. They may present with small areas of malodorous weeping or yellow-crusting lesions and can be treated with topical antibiotics, such as mupirocin.



Information researched and compiled by:
Meredith deH. Haab, Ed.D.

- Many MF/SS patients experience a clinical course characterized by waxing and waning of erythroderma, with flares occurring when the skin is heavily colonized with bacteria. These patients usually require hospitalization and therapy with wet wraps and intravenous antibiotics.
- Bleach baths decrease the number of bacteria in the skin, preventing superficial skin infections and flares. Use one half cup of regular strength bleach to a full tub of water two to three times a week. If baths are not an option, you could shower with an antibacterial wash that contains chlorhexidine gluconate.
- Speak to your physician about erythroderma. Severe erythroderma may require hospitalization for systemic complications (infection, fluid and electrolyte imbalances, thermoregulatory disturbance, cardiovascular and respiratory compromise).

Lucia Seminario-Vidal, MD, PhD

Assistant Professor

**Department of Dermatology and Cutaneous
Surgery**

University of South Florida; and

Co-Director

**Cutaneous Lymphoma Multidisciplinary Clinic
Moffitt Cancer Center**

Watch for an additional response to this question in the next issue of the Forum!

WET WRAP THERAPY INSTRUCTIONS FOR HOME

This treatment should be done twice daily.

1. The patient should take a lukewarm bath. If needed, use a mild soap-free cleanser such as Cetaphil Liquid Cleanser and rinse well. Avoid open areas.
2. Immediately after leaving the bath, the patient should be gently towed dry and medications should be applied as follows: Triamcinolone 0.025% cream should be applied from the neck down on all areas except skin folds, face, scalp, and ears; Hydrocortisone 2.5% cream should be applied to the face and skin folds.
3. Cover the entire skin area with a thick moisturizer such as Vaseline (Cetaphil Cream, Eucerin Cream or Aquaphor can also be used).
4. A warm wet layer is then applied over the treated skin. This is done most conveniently by moistening a pair of snug-fitting pajamas. The pajamas should be soaked in warm, clean water and wrung out, so that they are not dripping and worn such that there is contact between the moist garment and the treated skin.
5. Over the wet pajamas, a dry pair of pajamas or another soft garment should be worn. Cover with a warm blanket (toss in the dryer to warm it prior to beginning the bath).
6. The patient should remain like this for at least one hour, and two hours if possible.

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WELCOME TASHA WILLIAMS!



The Cutaneous Lymphoma Foundation welcomes new development director, Tasha Williams, to our team.

Tasha is a Detroit native and brings to the Foundation years of experience from both the nonprofit and higher education sector. She most recently was with the American Diabetes Association, where she served as manager of development as well as the community engagement manager.

"I am excited to engage all members of the community who are connected to this disease and desire to assist us in ensuring that each person gets the best care possible."

- Tasha Williams, Development Director

WE DEPEND ON YOU!

As a dedicated member of the CLF team, nothing means more to me than speaking with an individual who reflects back on being first diagnosed with cutaneous lymphoma. From not understanding what the terms meant, to not knowing how having the disease would impact their body, the one thing each story has in common is the Foundation and the level of comfort in knowing that there were resources available to support and assist in every way.

The significance of being able to speak with people who have traveled the same road, and receive insight on how to live with the disease continues to drive our work and what we do daily. Donations from our supporters play such an important role in the physical and emotional wellbeing of individuals living with the disease, day after day, week after week, month after month.

This is why your support is so essential. It allows us to offer services such as educational programming and tools to patients and caregivers at no charge.

We are depending on loyal friends like you to continue in the work of being a source of support. Thank you in advance for your generosity.

With Sincere Gratitude,

A handwritten signature in black ink that reads "Tasha".

Tasha Williams
Director of Development

Support the Cutaneous Lymphoma Foundation

Online: www.clfoundation.org/giving-online

Phone: 248.644.9014, ext. 1

Mail: P.O. Box 374 Birmingham, MI 48012

(A remittance envelope has been enclosed for your convenience)

In fiscal year 2018, the Cutaneous Lymphoma Foundation...



Introduced and hosted 9 Facebook Live events; a monthly livestreamed Q&A with cutaneous lymphoma clinicians and daily living experts.



Hosted 9 educational events, including our 2-Day Patient Conference and an "Answers from the Experts" event in Switzerland.



Distributed over 25,000 pieces of literature.

From the Board President..continued from page 3

while encouraging peer-to-peer support. So often we overlook the power of patient networking and support from others who can better understand what we are going through. By taking advantage of networking opportunities via patient educational programs, networking groups, patient support groups, or one-on-one support, we continue to support each other in

the cutaneous lymphoma community while also improving upon our own emotional health.

Please enjoy this edition and, as always, let us know how we can better continue to support you in your journey.



From the CEO..continued from page 3

It's with that in mind, this issue focuses on connecting, communicating and sharing our experience with others like us, whether they come from the patient perspective or from a family member or friend who cares about us. Having the opportunity to get to know both Paula and Jenni over the last few years brings joy to my heart. Learning about their story and how they have formed a lasting friendship shows me the power of connection. It's available to everyone and one of the hidden benefits of being a part of the cutaneous lymphoma community.

If I wasn't diagnosed with this disease, I certainly wouldn't be writing this letter to you or have had the beautiful experiences of getting to know many of you personally. That's the silver lining in it all. And, if we at the CLF can continue to bring you valuable information along with a personal connection that helps you in dealing with your particular journey, that's the goal. It was the vision of Judy Jones 20+ years ago when she began with one email out into the space of the internet and received the first response. With technology at our fingertips today, we now have the chance to bring you our in-person patient educational programs via livestream right into your home. Our Facebook Live interviews provide an opportunity for you to learn about a topic from an expert in the field each month and ask your questions. When you think about how far we've come, it is really amazing.

We would love to see you in person at one of our events, especially at the upcoming annual 2-Day Patient Conference. We have some surprises in the works that you won't want to miss and will only be available to those who join us in person.

If you can't make it to Manhattan Beach in June, we hope you will join us for one or more of our Facebook Live programs or at an upcoming program this fall.



As always, if there is anything we can do for you personally as you walk this path, don't hesitate to give us a call or drop us an email. While we don't have all the answers, we will do our best to provide you with as much guidance or information as we can to make your life better.

I'll leave you with this quote:

"The flower that blooms in adversity is the rarest and most beautiful of all."

— Walt Disney Company, Mulan

Know that each and everyone one of you are the rarest and most beautiful of all.

Enjoy your spring!





REGISTER TODAY!
2-DAY PATIENT CONFERENCE
MANHATTAN BEACH, CA
JUNE 22-23, 2019

Plan now to join the Cutaneous Lymphoma Foundation in Manhattan Beach, California, for our 7th Annual Patient Conference!

The 2-Day Patient Conference is an all-encompassing, weekend event open to anyone affected by cutaneous lymphoma. Regardless of where you are in your journey, the conference is an opportunity to network and learn more about living with cutaneous lymphoma.

GUEST CLINICIANS INCLUDE

- Brad Haverkos, MD, MPH, *University of Colorado School of Medicine*
- Craig Okada, MD, *OHSU Knight Cancer Institute*
- Lauren Pinter-Brown, MD, *Chao Family Comprehensive Cancer Center*
- Michi Shinohara, MD, *Seattle Cancer Care Alliance*
- Marianne Tawa, RN, MSN, ANP, *Dana Farber Cancer Center*

CONFERENCE LOCATION

Westdrift Manhattan Beach
1400 Parkview Ave
Manhattan Beach, CA 90266

For more information and to register, visit www.clfoundation.org/2DayManhattanBeach or call 248.644.9014, ext 1.

CUTANEOUS LYMPHOMA PATIENT EDUCATIONAL OPPORTUNITIES

UPCOMING 2019 EVENTS*

JUNE 22-23, 2019: 2-DAY PATIENT CONFERENCE - MANHATTAN BEACH, CA

Cutaneous Lymphoma Foundation
Details to come!

NOVEMBER 2: FRAMINGHAM, MA

Cutaneous Lymphoma Foundation
Patient Educational Forum

For more information and to register for CLF events, visit www.clfoundation.org or call 248.644.9014, ext. 4.

** Dates and venues are subject to change. Please check the website for detailed information.*



PATIENT NETWORKING GROUPS

The Cutaneous Lymphoma Foundation also offers patient networking groups in the following cities. Visit our website for more details on meeting times and locations.

CLF-BOS

Boston, Massachusetts
www.clfoundation.org/CLF-BOS

CLF-DC

Fairfax, Virginia
www.clfoundation.org/CLF-DC

CLF-LV

Las Vegas, Nevada
www.clfoundation.org/CLF-LV

CLF-NYC

New York, New York
www.clfoundation.org/CLF-NYC

CLF-OR

Portland, Oregon
www.clfoundation.org/CLF-OR

CLF-SLC

Salt Lake City, Utah
www.clfoundation.org/CLF-SLC

CLF-TPA - coming soon!
Tampa, Florida

The Cutaneous Lymphoma Foundation offers free educational programs throughout North America providing an opportunity to:

- Receive the latest information about cutaneous lymphoma and learn about treatment options from experts in the field.
- Learn what's new in cutaneous lymphoma research and clinical trials.
- Have questions answered about the different types of cutaneous lymphoma, treatments, and daily living. The Q & A sessions provide an opportunity to ask in a relaxed and friendly environment.
- Meet and network with other individuals affected by cutaneous lymphoma. Meet others who know and understand what you are going through.
- Learn about available resources for treatment and support.

We hope to see you at a program soon!



CUTANEOUS LYMPHOMA FOUNDATION
PO BOX 374
BIRMINGHAM, MI 48012

TIME SENSITIVE MATERIALS ENCLOSED

Do You Follow the Cutaneous Lymphoma Foundation on Facebook?

Then join us monthly for *Facebook Live* - our livestreamed educational events!

These social media events provide:

- Topic driven interviews with clinicians, researchers, and quality of life experts
- Live Question & Answer opportunities

www.facebook.com/clfoundation

Can't join us in person?

Facebook Live events are recorded and available for later viewing on CLF's YouTube channel:

CutaneousLymphomaFnd at www.youtube.com

