



LIVING WITH CUTANEOUS LYMPHOMA

How do I live with a rare type of cancer that most people have never heard of, including many physicians? How do I plan my life when there are so many unknowns about my disease, how do I best treat it, and what might my future hold? Do I have a future?

Nearly all of my cancer patients have these kinds of questions when they are first diagnosed. My patients with cutaneous lymphoma often have a more difficult time finding an answer to these questions because cutaneous lymphoma is a rare cancer with widely differing prognoses. There are some types of cutaneous lymphoma that are easy to manage and may never cause any serious problems, and other types of cutaneous lymphoma that become life threatening. Because it is a rare disease, there is no readily available shared experience with others.

Very few people “know” how to live with cutaneous lymphoma when they are first diagnosed; you have to learn to live with cutaneous lymphoma.

Educate yourself about your disease. The Cutaneous Lymphoma Foundation has specific information for most of the various types of cutaneous lymphoma available online and in printed booklets. Ask your physician questions and don't settle for general non-specific answers. Attend education forums to learn more about your disease and to meet others who have cutaneous lymphoma. Go to or, if needed, organize



local get-togethers with other cutaneous lymphoma patients. The collective wisdom of others with this disease is vast and there may be someone out there who has figured out how to manage a particular symptom you are dealing with. It is not easy living with a disease that others have not heard of or understand; use what you know to help and educate others.

Living with cutaneous lymphoma also means being your own advocate. Sometimes you have to push to get the most appropriate treatment or to be able to see the most appropriate

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CUTANEOUS LYMPHOMA FOUNDATION

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

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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.

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 Cutaneous Lymphoma Foundation Community!

I hope this newsletter finds you in good health and enjoying the summer months. If you are able to get outside and enjoy some of the health benefits of the sun (with sunscreen of course) I hope you will take advantage of this seasonal offering!

This summer edition of the Forum is full of information on patient-centered care. We strive to provide you with real-life, useful information that will assist you on your journey with cutaneous lymphoma as well as remind you that you are never alone on this journey. There is a whole community of people living with this disease, including myself. We are all ready, willing and able to support one another and to learn so much through the expertise of our medical professionals. There is great insight and a soothing power to sharing each other's personal experiences.

In this edition you will enjoy a special and insightful piece on living with cancer – helping us all to find ways to truly LIVE with this disease. Remember, cancer does not define who we are or who we can be. The CLF is here to help you find ways to live with the medical uncertainties and emotional swirling that this disease has upon your life.

Our regular Skincare Corner also focuses on a delicate topic – dealing with cutaneous lymphoma impacting sensitive areas of the body. We are unable to dictate or predict where our disease will manifest itself; cutaneous lymphoma makes *From the Board President...continued on page 10*

FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton

A significant year. The CLF is celebrating its 20th anniversary this year. That's a big deal. We received our official nonprofit 501(c)(3) designation in December of 1998. When you take time to reflect on where we began 20 years ago, we have come a long way in a relatively short period of time.

Judy Jones began running the CLF from her home with support from Dr. Stuart Lessin and Judith Shea, a caregiver. Judy, along with help from her daughter Amanda and her daughter's best friend Holly, created the framework for patient education and empowerment we use today. Holly is still with us as our Chief Operations & Finance Officer. I'm grateful to Judy for her passion, her persistence and her immense fortitude for carrying us through the first 13 years and to everyone who supported the CLF along the way. It's been an amazing journey and a milestone worth celebrating.

I'm also reflecting on the last 20 years. Looking back on my life, 1998 was a significant year for me too. As many of you know, I was diagnosed with mycosis fungoides in 1991 and had very slowly progressive disease. By the summer of 1998, I was traveling an hour

each way to receive targeted electron beam radiation treatments. My disease had progressed into tumors, plaques and patches that were unresponsive to the treatments available at the time. Three months of radiation in preparation for what I thought was the first step in my journey to a stem cell transplant. If you have heard my story, you know that by the end of my radiation treatments in early September, my disease was under control and the transplant was not required. I am grateful for that positive outcome.

From the CEO...continued on page 10



"...cancer does not define who we are or who we can be..."
 Joe Eischens



"The future looks bright."
 Susan Thornton

OUR JOURNEY WITH CUTANEOUS LYMPHOMA: BECOMING EMPOWERED

Shared by Lisa K., Caregiver

When Mike was first diagnosed with cutaneous T-cell lymphoma, more specifically, Sézary syndrome, he was just 41 years old. He was an otherwise healthy guy, who loved to play racquetball, watch football, spend time with family and friends. He never complained. He could tough out just about anything, and believe me, he did. He had no idea how to be a patient.



“Mike...had no idea how to be a patient...”

he did not speak up for himself and insist on seeing the doctor, the rash got so bad that he ended up in a sauna suit for six weeks.

Patients are often out there on their own, floundering through the healthcare system, trying to figure out diseases, treatments and medications that are getting more complex by the day. I consider Mike and me to be pretty smart and savvy. But this experience was truly overwhelming and frightening. At times there seemed to be an unreasonable amount of expectations placed on the patient to keep track of everything.

During the transplant process, we saw a different doctor every four weeks. While we appreciated the benefit of multiple opinions, again, there was a lot of burden on Mike as the patient and me as the caregiver to keep track of what was happening.

Some days, there was nothing I could do except run up and down the stairs. Which I did...repeatedly. And be hyper-vigilant about what was happening so I could be a good advocate for Mike. He was such a trooper through the whole ordeal. I didn't want him to have to suffer one minute more than necessary. There were several times when I felt like if I hadn't been paying attention, things would have gotten missed. There were clearly times when I had to push for what Mike needed because his needs were getting lost in the shuffle of all the various members of the team. Each focused on their specific part of the process and not specifically on the patient's experience.

Shared Advice from Experience

If I could share two pieces of advice with anyone going through this ordeal, first, I would encourage patients and their caregivers to ask a lot of questions and take a lot of notes. **You are driving your care.**

You need to fully understand what the process is, what the timing is, what symptoms to expect, what doctors to see, and what to do if you have issues.

“You are driving your care.”

Secondly, it wasn't in Mike's nature to complain. So as a result he may have suffered more than he needed to. If you are a patient, be sure to let your team know what is happening with you. **You are not complaining, you are giving the doctors the information they need to help you.**

Caregivers, ask questions. Ask how today's symptoms are different than yesterday's. Ask how long they have been going on. Help your loved one learn to talk about their illness...and take lots of notes.

Cancer, especially Sézary syndrome like Mike had, is rare and unpredictable. It's not that the doctors are not super smart or the nurses are not working as hard as they can. It's just that when you have a rare disease, the patient and caregiver bring a unique perspective based on what they are experiencing and it's important that they feel empowered to participate in the process.



CLINICAL TRIAL UPDATE: FLASH STUDY

The FLASH (Fluorescent Light Activated Synthetic Hypericin) clinical study in early stage (Stage IA, IB, and IIA) mycosis fungoides patients continues to actively enroll patients at about 30 clinical centers throughout the US. The clinical study is assessing the benefit of using SGX301 (synthetic hypericin) in treating mycosis fungoides lesions.

The trial consists of three cycles of treatment in which ointment is applied to the treated lesions at home with the lesion treated the next day in the clinic with fluorescent light treatment for several minutes. In each cycle, treatments are administered twice a week for six weeks.

During the initial cycle (Cycle 1), three lesions are treated either with the experimental drug or an inactive ointment with 2:1 odds that a participant will receive the SGX301; however, neither the participant nor health

care team will know to which group participant is assigned. In Cycle 2 all participants will treat the same three lesions with SGX301. The final cycle (Cycle 3) is optional and treats all of the participant's lesions with SGX301.

To date, it is worth noting that the majority of the patients in the study have opted in to the 3rd cycle. The results of the trial will be reviewed by a group of experts in October of this year who will determine how many more participants, if any, should be included in the trial. It is expected that the final participants will be enrolled in the trial no later than the early part of next year with the initial results of the trial publicly announced by June of next year.

To learn more about this clinical trial, search for “SGX301” under “Other Terms” at ClinicalTrials.gov.

LEARN...CONNECT...CELEBRATE!

Highlights from the 2018 2-Day Patient Conference



This year's annual 2-Day Patient Educational Conference in Bethesda, MD, was a dynamic, informative, successful event! With our highest patient and family/friends attendance in the last five years, we had over 95 in-person attendees and 50 virtual guests joining us on our live stream to come together to learn, network, and share a very special two days together.

Our main goal with these programs is to educate the cutaneous lymphoma community about the disease and provide patients and their families with a sense of confidence through awareness and education. We are thrilled to report that based on the information provided at the meeting, 90% of attendees left

feeling confident describing cutaneous lymphoma to others. By providing guests with the most up-to-date information as well as access to well-regarded physicians, this annual conference is unparalleled in its ability to immerse patients and their families in a fast-paced, yet understandable educational environment.

This year we were joined by many esteemed medical professionals who provided updates on research, FDA approvals, treatments, navigating insurance and finances, and other disease-specific information.

In addition to important clinical presentations, we were also able to



provide a hands-on workshop facilitated by London-native, Jenni Burrows. As this is not a one-size-fits-all kind of disease, we recognize the importance of providing a creative outlet for folks to express themselves and unwind after a busy two days of information that can often be overwhelming.

The 2-Day is a wonderful balance of clinical and quality of life information. We hope to see you at next year's 2-Day in sunny California!

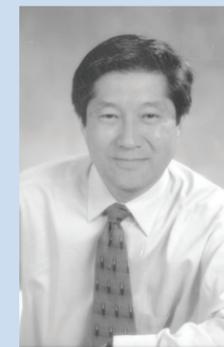


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physician. Consider participating in clinical trials; we learn more about cutaneous lymphoma and how new treatments become available through them. Ask for help. Receiving help does not foster dependency but rather allows you to be more successful in managing your own disease.

unknown can help reduce that stress and fear. Talk with your family and friends so that they can help support you. Have a plan for the "worst case" scenario and hope to never have to use it.

One of my patients was diagnosed with lymphoma at a relatively early age. It was treated into remission and there was hope that her lymphoma would not reoccur. After years of monitoring, it returned with only a limited amount of disease. She was treated again and it went back into remission. Over the next several years, she was constantly worried about her disease returning and how that might interfere with her life and future. She saw a colleague of mine who advised her that life is more than surviving your cancer. Cutaneous lymphoma can compromise the quality and sometimes the length of life. Life, however, is more than surviving your cancer. Live yours.



**"Life...is more than surviving your cancer. Live yours."
Dr. Craig Okada**

Living with cutaneous lymphoma involves learning to live with some degree of uncertainty; the unknown can be stressful and, frankly, scary. Being prepared for the

**Craig Okada, MD, PhD
Associate Professor
Hematology and Medical Oncology
Knight Cancer Institute
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SKINCARE CORNER Q&A

How do you advise patients to tend to such sensitive areas with mucosal involvement (such as oral and vaginal/perianal areas)?

First, this a great question because many patients forget or feel too embarrassed to ask their physicians about these areas. Perhaps their providers may not look in these areas especially if the patient is not completely undressed for their exam. I stress to all of my patients getting in a gown undressed is always in their best interest. You wouldn't want your cardiologist to examine only part of your heart so why would let a dermatologist only see a portion of your skin!

The approach to treating these sensitive areas is certainly not a "one size fits all" approach. Your dermatologist and oncologist must work together to find the best combination of therapies to address your disease including these more sensitive areas. It may be as simple as increasing the dose or frequency of your systemic therapy (your internal medications via pills or intravenous infusion) to better treat these more resistant areas.

The approach to treating these sensitive areas is certainly not a "one size fits all" approach.

While oral bexarotene (Targretin®) is often an effective systemic therapy, topical bexarotene gel can find an effective and perhaps niche role in treating more sensitive and photoprotected areas. In my opinion this is where this medication finds its most useful role as other skin directed therapies are typically more effective, but more difficult to use in the anogenital region.

Topical nitrogen mustard mechlorethamine (Valchlor®) must be used carefully in these areas as severe irritation may occur. However, this product may be used in these areas with less frequency or in conjunction with topical steroids to address the subsequent skin irritation.

Excimer laser may be implemented in treating harder to reach areas that might otherwise respond to phototherapy. Excimer lasers (such as XTRAC®) administer ultraviolet B radiation in a more confined and controlled area with a potentially higher UV radiation dose.

Lastly, your radiation oncologist may be able to offer a safe and effective radiation option. Traditional radiation therapy carries the risk of significant morbidity and potential complications when applied to the oral mucosa and genital region. Complications such as poor wound healing, scarring/fibrosis, sexual dysfunction, and infertility have all occurred. Newer radiation therapy technologies, such as intensity-modulated radiation therapy (IMRT), have improved treatment outcomes while decreasing complications. If medical therapy has failed to benefit you it is worth asking your providers if radiation could be an effective and safe option for you.

There are many issues to consider when addressing cutaneous lymphoma involvement of the oral and anogenital regions. Unfortunately, there is no single agreed upon method or simple approach to treating every patient. As an informed patient, be sure to let your physicians know you have concerns and potentially lymphoma involvement in these sensitive areas so together you can work together to find a regimen that best fits your needs.

**Charles E. Mount III, MD, FAAD
Vice Chair, Division of Dermatology
Allegheny General Hospital/
Allegheny Health Network
Pittsburgh, PA**



While isolated lesions of mycosis fungoides on oral and/or genital skin is rare, it is not uncommon to develop patches, plaques, or tumors in the genital region in Stage 1B – IV disease. Lesions occurring on the lips, oral cavity, genitals, perineum and rectum involve mucosal skin, which is different than keratinized or hair-bearing skin. Mucosal sites are sensitive and lesions in these areas are associated with increased discomfort, both physical and psychological. Mucosal lesions must be identified by patients and physicians as they require additional attention and therapeutic planning. Many standard skin directed therapies such as topical steroids and phototherapy must be used with extreme caution on mucosal sites, and topical nitrogen mustard must be avoided altogether on the mucosa. Alternatively, topical therapies such as imiquimod have been used with some success, specifically on genital skin. In summary, each patient's treatment plan should be ideally designed to address all areas of MF involvement and providers want and need to know if your disease affects sensitive mucosal sites.

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imiquimod have been used with some success, specifically on genital skin. In summary, each patient's treatment plan should be ideally designed to address all areas of MF involvement and providers want and need to know if your disease affects sensitive mucosal sites.

**Jennifer Alston DeSimone, MD, FAAD
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From the Board President...

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us truly vulnerable – physically and emotionally. Being open with your doctor and seeking the medical attention needed is not always easy, but is necessary. We hope that the Skincare Corner continues to provide useful information on sensitive topics and empowers you to seek the support you may need. Please understand that there is no shame in getting help and relief.

We are proud to bring you continued support and knowledge through the Forum newsletter and the other myriad educational opportunities available to you. As always, our goal is to reach all those affected by cutaneous lymphoma. And, we would love to hear from you! We are always open to your ideas and suggested program topics you may be interested to learn more about. Please contact Hilary Romkey, program manager, should you wish to learn more about a specific topic or share your own personal story. You can email Hilary at Hilary@clfoundation.org.

We thank you for reading and hope to see you at one of our live events soon!



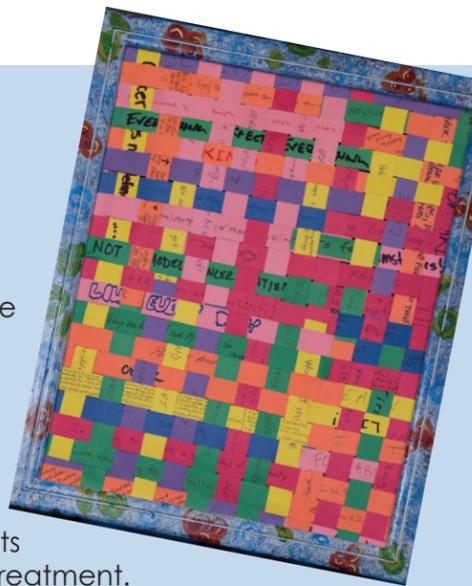
From the CEO..continued from page 3

I celebrated my 40th birthday with a huge party and a different outlook on life. I will be spending my 20 year anniversary and 60th birthday this September reflecting on how fortunate I am. It's been an incredible 20 years. I'm grateful for the progress that has been made in treating this disease and the clinical trials that are now happening. I continue to be inspired by the dedication of the international group of clinicians and researchers who are working hard and diligently to find new ways to treat and manage this crazy disease. As I still need to treat my disease, knowing what is on the horizon gives me hope that in the near future we will have more options in the treatment toolbox and have a better understanding of how best to treat each individual's disease with better outcomes. The future looks bright.

As we celebrate our 20th anniversary, I invite you to join us. We will be launching a fun 20-20-20 fundraising

COMMUNITY

When life is touched by cutaneous lymphoma, it can be lonely. Very few people have ever heard of the disease, and even many in the medical profession are unfamiliar with its diagnosis and treatment.



As a part of the 2-Day Conference, attendees wrote their thoughts about living with cutaneous lymphoma on colored strips of paper. Workshop leader and artist, Jenni Burrows, wove the strips into a work of art symbolizing that, gathered, these shared experiences can create a beautiful community.

The finished piece hangs in the Cutaneous Lymphoma Foundation office as a tribute to the community CLF has helped to create and faithfully continues to serve.

campaign to help sustain the organization, grow and expand our programs and reach more people. We can't do that without your support. My dream and vision is that we close our doors one day because cutaneous lymphoma is treatable, curable, maybe even preventable and the CLF is no longer needed. Until then, I will do everything in my power to ensure that we are here to support all of you and your loved ones no matter where you live in the world.

I wish you a very happy, fun summer. Look for our announcements. Join us in the 20-20-20 celebration. Be a part of our future.

Enjoy this issue of the Forum.



CUTANEOUS LYMPHOMA PATIENT EDUCATIONAL OPPORTUNITIES

UPCOMING 2018 EVENTS*

OCTOBER 6, 2018: RALEIGH, NC
Cutaneous Lymphoma Foundation
Patient Educational Forum

OCTOBER 24, 2018: NEW YORK, NY
Cutaneous Lymphoma Foundation
Answers from the Experts

NOVEMBER 3, 2018: SAN FRANCISCO, CA
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.*



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 about the different types of cutaneous lymphoma, treatments, or 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!

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-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



CUTANEOUS LYMPHOMA FOUNDATION
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TIME SENSITIVE MATERIALS ENCLOSED

HELP CLF RAISE \$43,000

Pledge to be a 20-20-20 Fundraising Partner

20 Pledge to be a 20-20-20 partner and make a \$20 donation to the Cutaneous Lymphoma Foundation.

20 Personalize your fundraising site with a photo and a few sentences about your connection to CLF. Send your link to 20 of your friends & family.

20 Ask your friends & family to support the life-changing work of the Cutaneous Lymphoma Foundation by making a \$20 donation.

Visit clfoundation.org/20-20-20 or contact pr@clfoundation.org to pledge.

All proceeds benefit the services CLF provides the cutaneous lymphoma community, free-of-charge.

