



INSIDE THIS ISSUE

From the President 2

From the Chief Executive Officer 3

My Experience with Cutaneous Lymphoma..... 4

Farewell to Mike Silver 5

Skincare Corner..... 6

Upcoming Events..... 7

Your Support 8

Cutaneous Lymphoma Foundation
 PO Box 374
 Birmingham, MI 48012-0374
 telephone: (248) 644-9014
 fax: (248) 644-9014
 email: info@clfoundation.org
 www.clfoundation.org

Forum is published by the
 Cutaneous Lymphoma Foundation.
 Editor: Hilary Romkey
 Layout & Design: Bridget Safadi

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.

Being an Advocate



Aaron Mangold, MD, FAAD

Mayo Clinic
Scottsdale, AZ

Cutaneous lymphoma is a rare diagnosis, and as such, necessitates being an advocate at the individual and the group level. As it pertains to your own healthcare, remember to ask important questions of your physician including: "How often do you see this disease?", "How certain are you of the diagnosis?", "Where can I go to seek a second opinion?", and "What are my treatment options?" You should feel comfortable with your physician's level of experience as well as their willingness to seek help of his or her colleagues. The cutaneous lymphoma world is relatively small and through patient organizations, such as the Cutaneous Lymphoma Foundation, and collaborative physician working groups, such as the United States Cutaneous Lymphoma Consortium, International Society for Cutaneous Lymphomas and others, we all work closely to provide high-quality care for patients. Both you and your physician should use these resources to identify the best place for consultation as well as care. There is no single formula for the management of rare and complex diseases. Depending upon your situation and geographic location, you may receive care at a single, multidisciplinary clinic or at your local dermatology or oncology office, with intermittent consultation at a comprehensive clinic. The most important factor is that you feel comfortable and satisfied with your care.

As a patient, the rarity of cutaneous lymphoma provides a unique opportunity to raise awareness and to provide support. As I always tell my patients, "You will quickly become the expert." Your emotional experience in being diagnosed, navigating the healthcare system, and undergoing treatment and follow up is unique. As a physician, I can provide a facsimile of your experience to a newly diagnosed cutaneous lymphoma patient; however, this is rarely as satisfying as actually meeting someone who has gone through the process. As a patient advocate, you are the most powerful voice.

As a patient, the rarity of cutaneous lymphoma provides a unique opportunity to raise awareness and to provide support.

In today's political climate, advocacy has many new connotations. As the director of the Mayo Clinic Multidisciplinary Cutaneous Lymphoma Clinic in Scottsdale, Arizona and the acting president of the Arizona Dermatology and Dermatologic Surgery Society, a group focused on state policy, patient well-being, and physician's practice, I have a unique view on advocacy.

Be an Advocate...continued on page 5

Forum

The newsletter of the Cutaneous Lymphoma Foundation
ALL RIGHTS RESERVED

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

BOARD OF DIRECTORS

OFFICERS

Joe Eischens, Esq.	President
Marianne Tawa, RN, MSN, ANP	Vice President
Jeff Ward	Treasurer
Laurel Carlson	Secretary

DIRECTORS

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

RESEARCH ADVISORY COUNCIL

Pierluigi Porcu, MD (Chair)	Thomas Jefferson University
Christine Eischen, MD (Co Chair)	Thomas Jefferson University
Jaehyuk Choi, MD, PhD	Northwestern University
Alejandro Gru, MD	University of Virginia
Bradley Haverkos, MD, MPH	University of Colorado
Steven Jones, MD	Patient
Michael Khodadoust, MD, PhD	Stanford University
Stuart Lessin, MD	KGL Skin Study Center
Laura McGirt, MD	University of North Carolina
Anjali Mishra, PhD	Ohio State University
Alison Moskowitz, MD	Memorial Sloan Kettering Cancer Center
Christopher Shipp	Patient

MEDICAL ADVISORY COUNCIL

Ellen Kim, Chair, MD (Chair)	University of Pennsylvania
Wei Ai, MD	University of California San Francisco
Kim Bohjanen, MD	University of Minnesota
Francine Foss, MD	Yale University
Richard Hoppe, MD	Stanford Cancer Center
Erick Lansigan, MD	Dartmouth-Hitchcock Medical Center
Cecilia Larocca, MD	Dana-Farber/Brigham and Women's Cancer Center
Leora Lowenthal, LICSW, OSW-C, MPA	Beth Israel Deaconess Medical Center
Sue McCann, MSN, RN, DNC	University of Pittsburgh
Amy Musiek, MD	Washington University School of Medicine
Steve Rosen, MD, FACP	City of Hope
Debjani Sahni, MD	Boston University
Michi Shinohara, MD	University of Washington
Jasmine Zain, MD	City of Hope

MEDICAL ADVISORY COUNCIL EMERITUS ADVISORS

Madeleine Duvic, MD	University of Texas MD Anderson
Lars French, MD	University Hospital Zurich
Robert Knobler, MD	Medical University of Vienna
Liliane LaRoche, MD	Hospital Avicenna
David Ramsay, MD	New York University School of Medicine
Alain Rook, MD	University of Pennsylvania
Martin Weinstock, MD, PhD	Brown University
Sean Whittaker, MRCP	Guy's and St. Thomas' Hospital

STAFF

Holly Priebe	Chief Operating and Financial Officer
Hilary Romkey	Program Manager
Deb Van Zegeren	Information Technology Manager

From the President



Joe Eischens

Holiday Greetings Patients, Caregivers and Friends!

I hope that this note finds you in good spirits and reflecting positively upon the year. During this holiday season, we at the Foundation are grateful more than ever for your support!

This edition of the Forum Newsletter is focused around "Awareness and Engagement." Within this edition, you will find information on being your own patient advocate. Finding ways to help direct your care can be crucial in your treatment and day-to-day living; we hope you will find this information empowering and applicable in your own life. Within these pages, one of our own experts discusses the difficult yet critical topic of skincare in sensitive areas. Our goal is to provide you with supplementary information to help better your daily lives by discussing at-home skincare tips and inspiring you to live your best life. As always, our real-life patient experience also serves as an AWARENESS aspect of this edition. Read about Joe Peck's personal journey with cutaneous lymphoma and feel connected to others who are on a similar journey with you.

As always, we hope that these articles and personal stories will continue to motivate you and to help inspire you to help fulfill our mission of funding and supporting research, and to continue to provide the educational and inspirational resources that are made possible through the Foundation. Without the support of our doctors, researchers, Board of Directors, staff, community and YOU, our supporters, none of this would be made possible.

You may have recently received this year's Annual report and read about yet another successful year here at the Foundation. In 2017, we were able to host 9 live programs including Patient Educational Forums and Answers from the Experts LIVE! In addition, our live streaming was able to reach four different countries providing the most up-to-date information to folks around the world. While our quest to find a cure is supported by our corporate partners, we need your support.

From the President...continued on page 5

From the Chief Executive Officer



Susan Thornton

Happy Holiday Greetings!

In all the hustle and bustle of the holiday season, I try to set aside quiet time and reflect on the past year. There is so much I am personally grateful for this year.

One of the privileges I have had is the opportunity to attend and listen to the many scientific and clinical presentations delivered at medical meetings throughout the year. While at times very scientific and complex, the general conclusion I have come to is this: there is hope for our collective future in understanding and treating cutaneous lymphoma. The more we learn about the way this disease functions, the better and more targeted the treatments can be. With so many clinical trials underway and new treatments being approved, I see a time in the not too distant future where each person's disease is diagnosed properly and treated in a way that works best for them. While we have a long-term vision to find a "cure", in the meantime, I am excited to see the progress being made to bring better treatments to all of us now to help manage the disease in new ways that allows us to live life fully on our terms.

Exciting as the promise of clinical trials and new therapies are, just as important is making sure everyone has access to these new treatments. Being our own best advocates with our healthcare team and within our country's healthcare systems is important too. As Dr. Mangold discusses in his article, the patient's voice, our voice, is a critical component in raising awareness to policy makers and regulators about the impact of living with this rare, chronic disease. While not everyone has a desire to actively participate as a patient advocate in Washington, DC or at the local level, let us know how your life has been impacted so your experience and voice can be included in our active efforts with policy makers and regulatory authorities around the world. Know that the CLF is taking your challenges, stories and personal experiences with us when we meet with representatives from these important groups. Your voice makes a difference.

From the CEO...continued on page 5

 Find us on
Facebook

Check out the latest news and information from the Cutaneous Lymphoma Foundation by liking us on Facebook!

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. ☺

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



My Experience (so far) with Cutaneous Lymphoma



Joe Peck
Arlington, VA

My story, such as it is, is a tad different from many I've heard in the DC area CLF Networking Group. Travel back with me to January of 2016 when I first noticed two odd-looking bumps

on my scalp. Could they have been pimples or dermatitis? Yes, perhaps. When they began spreading though, I consulted my doctor. Two doctors and two misdiagnoses later, I respectfully insisted on a biopsy. What the dermatologist called a skin infection was taking over my scalp and quickly heading for my eyebrows. Two weeks later (late April)

I got the word: Primary Cutaneous Anaplastic Large Cell Lymphoma (pcALCL). I was immediately referred to an oncologist with an appointment that very day and a "good luck" from the dermatologist.

"... I first noticed two odd-looking bumps on my scalp."

I went in a matter of days from the oncologist to a radiation oncologist where, luckily, I was able to quickly begin radiation treatment for the lesions on my scalp. The electron beam radiation worked wonders. Although my

head did look like a tomato by the end, there was only moderate discomfort, a little tiredness and clear skin. Once my scalp had been zapped (July), I was told by the oncologist to report back in six months for follow-up. Things were looking up ... until in November when I started to experience sciatica. Why am I telling you about sciatica? Well, it turned out that between my diagnostic PET scan in April and November 2016, the pcALCL had gone metastatic to my bone, including my spine. Unfortunately it took until April of 2017 and many scans and tests to get that worked out. Ultimately a bone biopsy confirmed my



predicament, and scans showed it was everywhere in my skeleton. Unfortunately, that isn't an exaggeration.

As I write this, I have completed a five-month course of high dose chemo (CHOEP) and have been told I have had complete metabolic response (also known as remission). Thank goodness for that! The chemo was certainly not fun, but it was not as bad as advertised. There were side effects to deal with - constipation, weariness, light neuropathy, some swelling, and indigestion in my case - but nothing unbearable. I still am working through some lingering side effects two months after the fact. Even so, I had been in tremendous pain from the bone lesions just before the chemo began, but the pain disappeared with only one round of treatment.

"... I have had complete metabolic response to the treatment..."

As a result of my struggle with this disease, I'm learning to live every moment "in the moment." In other words, I'm trying to remember that each moment is a gift and to experience it with that in mind. All through this journey I have been fortunate enough to have the patient and loving support of my partner, Patrick, as well as the comfort of being able to compare notes with my friends in a great support group like the CLF Networking Group. It's incredibly encouraging to know you're not alone! CLF has also been a very good source of information about this rare disease with which even some of my doctors weren't familiar. Some of those doctors have, of course, been traded in for new, more informed ones. But, even the informed folks tell me that the course my disease has taken is rare even within this rare diagnosis.

"I'm learning to live every moment 'in the moment'."

On a lighter note, after the initial diagnosis of the lesions on my scalp, my urologist (with whom I had a check-up appointment and whose area of practice is somewhat farther "south" anatomically) asked to see the area! At least that's one doctor who has a little more familiarity with cutaneous lymphoma. ☺

Be an Advocate...continued from page 1

Policymakers do not relate to physicians telling stories about their patients with rare, difficult to pronounce diseases. They relate to people. Your physical presence on Capitol Hill in Washington, DC, or at your local or state governing body, changes the dynamic of the conversation and focuses on people. While it is easy to deconstruct and disregard a policy or bill, it is difficult to do the same for a voting constituent who is significantly impacted by such a policy or bill. There are great resources on how to get involved including the Cutaneous Lymphoma Foundation, the American Academy of Dermatology Association, and the Rare Disease Legislative Advocates. I encourage you to get out, be active, and make a change.

"When the whole world is silent, even one voice becomes powerful."

- Malala Yousafzai, Nobel Laureate, Peace 2014 ☺

Some important questions to ask your physician:

- How often do you see this disease?
- How certain are you of the diagnosis?
- What is the name of my disease (variant)?
- What is my stage of disease?
- What are my treatment options?

Farewell to Mike Silver

It is with gratitude that the Cutaneous Lymphoma Foundation says goodbye to Mike Silver as he steps down from his position on the Board of Directors. Mike resides in Toronto, ON and has been a valued member of our Board since 2013. We wish Mike all the best in his future endeavors! ☺



From the President...continued from page 2

During this season of giving, please consider making a donation to the Foundation. Our staff would love to assist you with discovering the most effective and beneficial method to give, either through personal donations, wills/trust designations, memorials, or any other avenue that makes the most sense for you and your family. Now more than ever, we need YOUR engagement to continue providing education and support to folks like yourself and the entire cutaneous lymphoma community.

Take care. ☺



From the CEO...continued from page 3

As I reflect on 2017 and look ahead to 2018, I am thankful to each and every one of you for being part of our community. Perhaps you joined us at a program, engaged with us through email, talked with us on a call, provided financial support or participated in our mission in some way. It is an honor and a pleasure to serve you and connect with you.

To our dedicated volunteer Board of Directors who give so much of their time and talent, our wonderful medical and research advisors who also volunteer their expertise and guidance, the fabulous networking group leaders who have stepped up to bring people together locally - we thank you! I also want to thank the tireless staff of the CLF who make all of this happen. You may not have the chance to meet them, but Holly, Deb and Hilary work hard throughout the year and make the mission a reality.

As we look forward to an exciting, fast-paced year ahead and celebrate the 20th year of the CLF, know that the future looks bright for all of us. We are glad you are a part of our community and hope to see you along the way in 2018!

Happy, Healthy Holidays Everyone! ☺



SKINCARE CORNER Q&A

How should a patient or caregiver take care of lesions in mucosal areas such as oral/vaginal/perianal areas?

Taking care of skin lesions in or on the mucosal surfaces can be difficult, and different than on other areas of the skin. They are areas that may be overlooked by physicians, so the first thing I would recommend to patients is that if they have lesions in mucosal areas, they bring them up specifically to their physicians so they can be sure they are addressed.

The second general principle is that people should be cautious about what over the counter products they use in the mucosal areas. Many topical products can cause irritation, especially when used on already irritated or inflamed skin. For example, dermatologists typically recommend avoiding the use of toilet wipes, because they can contain fragrance and preservatives that can cause allergic reactions. Similarly, some types of toothpaste can be painful to use when there is inflammation in the mouth.

I would recommend that patients check with their providers about all topicals they are using, but generally the “blandest”, the better. For the genitals and perianal area, I often recommend using only water to wash if the skin is broken. Topical steroids can be used in the mouth and genitals/perianal area, but patients should always check with their provider about whether they can use a particular steroid in that area, because some areas (like the groin folds) are more prone to the side effects of steroids.

Drainage in the groin or perianal area from open skin or ulcers can cause a secondary irritant rash, similar to diaper rash. Try to be extremely gentle with the skin; blot dry gently and don't rub. Using a hair-dryer set on cool can help dry the skin and reduce inflammation. If that's not helpful, ask your doctor if it's appropriate to use an over the counter drying agent, like Burrow's Compress or Domeboro Solution.

Using dressings in the groin/perianal area can be difficult as well, because the skin can be very sensitive to adhesives. Bring this up with your physician, as there are some types of dressings that are easier to use.

Michi Shinohara, MD
Associate Professor
University of Washington
Dermatology and Dermatopathology

Cutaneous Lymphoma Patient Educational Opportunities

The Cutaneous Lymphoma Foundation offers free Patient Educational Forums 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.
- Q&A sessions - probably the most popular portion of the day. Have questions about the different types of cutaneous lymphoma, treatments, or daily living? The Q & A sessions provide you an opportunity to ask in a relaxed and friendly environment.
- Meet and network with other individuals affected by cutaneous lymphoma. Being diagnosed with or caring for an individual with a rare disease can be lonely. 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 an event soon!

Patient Networking Groups

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

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

CLR-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

Upcoming 2018 Events*



April 14, 2018: Detroit, MI
Cutaneous Lymphoma Foundation
Patient Educational Forum



April 28, 2018: Denver, CO
Cutaneous Lymphoma Foundation
Patient Educational Forum

Save the Date

Please plan to join us for our next 2-Day Patient
Education Conference

Saturday June 23 and Sunday 24, 2018
Bethesda, MD

For more information and to register for these 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
extends its thanks to the following generous
supporters of our events:





CUTANEOUS LYMPHOMA FOUNDATION

PO Box 374
Birmingham, MI 48012

TIME SENSITIVE MATERIALS ENCLOSED

Thank you for helping us make a difference at the Cutaneous Lymphoma Foundation!

Your support allows us to provide quality information through our Online Learning Center and free publications.

Your support allows us to support research initiatives and bring cutaneous lymphoma experts to our live events.

Your support provides assistance in finding beneficial care and treatment options in response to your phone calls and e-mails.

Your support has a tremendous impact on our ability to make a difference in the lives of those affected by cutaneous lymphoma.

Please continue to support the Cutaneous Lymphoma Foundation by using the enclosed envelope or online at www.clfoundation.org/giving-online.

