



UNDERSTANDING THE DIAGNOSIS PROCESS: PART 1- BIOPSIES

If you have cutaneous lymphoma, you may have lived with the disease for a long time before receiving a definitive diagnosis. “Why did it take so long?” is a common question. The rarity of the disease even within the medical community, combined with how long it takes for the condition to fully evolve, how similar it may appear to more benign diseases (like eczema), and the lack of a specific medical test to detect early disease, all make cutaneous lymphoma very difficult to diagnose. So then, how IS the disease diagnosed?

Recognizing cutaneous lymphoma is a team effort, with pathology playing an important role. Dermatologists and/or oncologists work with pathologists to conclude whether what is visually seen on the skin, combined with what is seen under the microscope, point to cutaneous lymphoma. Over the next few issues of the Forum, we will look closer at the diagnostic process. However, it is important to keep in mind, the final diagnosis of cutaneous lymphoma requires the team to combine the clinical characteristics with the pathology (“clinicopathologic correlation”) and other tests, and cannot be made solely by a pathology report alone.



How Does Pathology Work?

Pathology involves a series of tests completed both visually and through technology to help determine diagnosis. A pathologist is trained to know what healthy, free-from-disease tissue, blood, or lymph nodes should look like under a microscope. The job is a process of identifying and characterizing what is “seen” through the microscope to determine what is abnormal.

First Step: The Biopsy

The first step in the diagnostic process is the biopsy. The physician, usually a dermatologist, determines that a lesion or rash should be biopsied and takes a sample to be analyzed by a pathologist.

General principles for taking a biopsy include:

- Select the most representative lesion or worse lesion
- Select a lesion that hasn’t been undergoing treatment (no topical steroids for a couple of weeks)

Diagnosis...continued on page 8

2019 Issue 3

From the President and the Chief Executive Officer 3

Taking the Cutaneous Lymphoma Voice to Washington, DC 4

Survey Update: Cannabis Use Among Patients 5

Virtual Cycling Event Update..... 5

My Journey with Cutaneous Lymphoma 6

2020-2023 Strategic Plan..... 9

Skincare Corner Q&A..... 10

Clinical Trial Update: SOLAR..... 10

Upcoming Events..... 11

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

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

The newsletter of the Cutaneous Lymphoma Foundation
ALL RIGHTS RESERVED

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: Deb Van Zegeren

Disclaimer

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

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



BOARD OF DIRECTORS

OFFICERS

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

DIRECTORS

Joe Eischens, Esq.	Director
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 (Co-Chair)	Thomas Jefferson University
Christine Eischen, PhD (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	Sidney Kimmel Cancer Center
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
Thomas Kupper, MD	Dana-Farber/Brigham and Women's Cancer Center
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
Tasha Williams	Development Director
Hilary Romkey	Program Manager
Debra Van Zegeren	Information Technology Manager
Susette Arnot	Administrative Assistant

FROM THE BOARD PRESIDENT

Laurel Carlson

Seasons Greetings to our friends in the cutaneous lymphoma community!

BOARD OF DIRECTORS NEWS

As of the November 2019 Board of Directors meeting, Laurel Carlson will serve as the new Board President, David Elefant as the new Vice-President, Jeff Ward as Treasurer, and Marianne Tawa, RN, MSN, ANP, as Secretary. Joe Eischens Esq., Lauren Pinter-Brown, MD, Steven Horwitz, MD, Youn Kim, MD, Michael Young, and Susan Thornton complete the current and full Board of Directors.

A brief biography of each Board member is available on our website: www.clfoundation.org/board-of-directors

Learn about our 2020-2023 Strategic Plan on page 9.

Many years ago I met Judy Jones when she was busily working to establish this foundation. Unfortunately, at that time, I was very busy with family and work and unable to help her. However, in 2011, I was able to join the Cutaneous Lymphoma Foundation's Board of Directors, and at our most recent meeting I was elected to the office of president. I could never have imagined that, when I first met Judy Jones, one day I would find myself working with this amazing organization that is committed to helping everyone affected by MY disease.

In addition to my new role with the Cutaneous Lymphoma Foundation, I also recently retired from my teaching career. My husband retired as well, and now our to-do list includes: relaxing, traveling, spending more time with family, reconnecting with friends, and ridding

our house of things that "do not bring us joy". To reduce the amount of "stuff" in our home, we are not only trying to dispose of items, but also trying to limit the acquisition of new things. During this month and next, we will be celebrating both of our birthdays and Christmas, which means that there will be multiple opportunities for gift-giving. And although we repeatedly request "no gifts please," our family members feel an obligation to give us something.

From the President...continued on page 7



"I could never have imagined that, when I first met Judy, one day I would find myself working with this amazing organization..."

Laurel Carlson

FROM THE CHIEF EXECUTIVE OFFICER

Susan Thornton



"This is the most unique and giving community of individuals that I have come across."

Susan Thornton

Happy Holidays!

It's that time of the year when the weather is brisk, maybe a little bit of snow, and the kids are going a little bonkers. It's the time of sparkling lights and for giving thanks for all that we have.

For me, this time of the year provides an opportunity to take a breath and look back at the year that has just flown by. If your life is like mine, time seems to be going faster and faster. This year was no exception. Our programs touched people across the world, including a special patient Q&A program that we co-hosted with a wonderful group of physicians in Athens, Greece. I'm always amazed when I hear similar stories of the long and frustrating time to diagnosis, the impact of the emotional roller coaster felt by so many, and similar feelings of isolation. What that tells

me is that we have more work to do to connect our patient and family community. We are all in this together and together we can help each other. That's the mission!

From the CEO...continued on page 7

TAKING THE CUTANEOUS LYMPHOMA VOICE TO WASHINGTON, DC

Summary from the American Academy of Dermatology Advocacy (AADA) Legislative Conference

In early September, the cutaneous lymphoma community patient voice was heard loudly in Washington, DC, as part of a joint effort between the American Academy of Dermatology and members of the Coalition of Skin Diseases. The AADA brought 203 people (clinicians, patients, and patient organizations) to Washington, DC, to raise awareness

tive strategies. Remaining vigilant as the Administration has started taking up some of the limiting strategies of private payers such as prior authorization and reducing payments when E/M services are reported with procedures.

Skin Cancer Prevention, Access to Sunscreen and Indoor Tanning: Advocating at the federal and state levels to educate policymakers about skin cancer prevention and detection, and to promote increased regulation of indoor tanning. Working to bridge the interests of sunscreen manufacturers and federal regulators to ensure fair consideration of new sunscreen ingredients based on scientific evidence and demonstration of patient/consumer safety.

As members of the Coalition of Skin Diseases, two days were spent preparing how to effectively communicate and deliver the messages. Then dermatologists were paired with patients or patient organizations to attend individual meetings. On day three, your stories, and others like yours, were shared in 235 scheduled meetings across both the Senate and House representatives from 35 states. Through a combination of stories, impact statements, and data sharing, representatives were provided a robust picture of the severity that these issues carry for both those providing service and for those people living with the added stress. Thank you for trusting us with your voices and knowing we will continue to fight so that all people affected by cutaneous lymphoma get the best care possible. 🌸



Foundation staff members, Holly Priebe and Deb Van Zegeren, joined other Michigan delegates to meet with Senator Gary Peters (back row, third from the right) to discuss key issues related to health care.

around key issues faced by people who are affected by skin diseases. The Academy selected the items below as the three top initiatives to bring to your representatives;

Pharmaceutical Access and Affordability: Working in collaboration with all stakeholders to minimize and/or eliminate barriers that patients face in accessing needed medications, including modifications to step therapy and prior authorization policies, as well as efforts to address rising drug prices and drug shortages. Also includes supporting efforts to improve price transparency and to advocate for policies that will encourage competition to lower the cost of medications and improve access to treatment for patients.

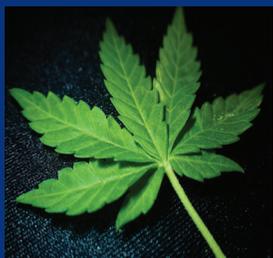
Medicare Physician Payment Policy: Advocating for fair reimbursement under the current fee-for-service program; working across dermatology and within the House of Medicine to preserve the 10- and 90-day global period payments for medical procedures, and in recognition of the challenges implicit with that effort, also working on alterna-



Deb and Holly also had the opportunity to meet with Michigan Representative Andy Levin's Legislative Director, Catherine Rowland.

SURVEY UPDATE | Cannabis use among patients with cutaneous lymphoma

Itch is a common and often debilitating symptom of skin lymphoma that may not respond to standard treatments, such as antihistamines or topical steroids. There is limited evidence that cannabis (marijuana) may have anti-itch properties. Despite an increased availability of cannabis for commercial or medical use, most of the available data on cannabis for cancer-related symptoms is from non-scientific sources (friends, social media, and blogs). Few studies have evaluated the use of cannabis among patients with cutaneous lymphoma.



We surveyed patients with cutaneous lymphoma on their use and opinions of cannabis as an anti-itch treatment. Approximately 75% of survey respondents had early-stage mycosis fungoides, and most used moisturizers and topical steroids for anti-itch treatment. About half of all patients reported having used cannabis at some point, and 40%

are currently using cannabis. In states where cannabis is legalized, these numbers were even higher. Half of patients who used cannabis did so to alleviate anxiety, pain, and stress, while 25% reported using cannabis to treat itch.

Patients who used cannabis reported that it reduced their itch and improved their symptoms overall. Additionally, patients

demonstrated a strong interest in learning about cannabis as a possible treatment for skin lymphoma, and the vast majority indicated a willingness to discuss cannabis with a physician, particularly their cutaneous lymphoma doctor. Several cited the fact that cannabis is a natural alternative as the primary appeal.

Cannabis use among the general population is high (approximately 13%). We found that cannabis use is even higher among cutaneous lymphoma patients (40%). Those who have used cannabis to treat symptoms report improvement; the role of cannabis as an anti-itch therapy deserves further evaluation. We encourage patients who are using or interested in using cannabis to engage in conversation with their provider team about the risks and benefits of this therapy.

Thank you to all the patients who generously provided their input into our initial survey.

Michi Shinohara, MD
Seattle Cancer Care Alliance Dermatology
University of Washington

Olivia R. Ware, BA
Howard University College of Medicine

Tyler D. Coolman, MPH
Kirksville College of Osteopathic Medicine
A.T. Still University

THANKS FOR JOINING US

On September 13-22, the Cutaneous Lymphoma Foundation hosted its inaugural World Lymphoma Awareness Day Virtual Cycle Event. This special event was created to inspire and give hope to those living with cutaneous lymphoma as they continue on their unique journey. Cyclists were encouraged to share highlights from their ride via photos, mementos, and personal stories. Each participant received a certificate as a token of appreciation for their efforts.

There were over 80 people who participated in the event as a cyclist, fundraiser, and/or donor. Over \$12,000 was raised and will be used to support research, advocacy, and programmatic efforts globally.

We could not have done it without you – thanks! See you next year!



MY JOURNEY WITH CUTANEOUS LYMPHOMA

Shared by Mary M.

My personal journey with cutaneous T-cell lymphoma began over 15 years ago, when I developed rashes that would not resolve with topical corticosteroids. During those years, I visited eight different dermatologists, leaving with diagnoses of eczema, psoriasis, chronic dermatitis, anxiety, and even “poor body hygiene,” which was most unsettling.

By 2016, my skin issues were intensifying. I developed uncontrollable full body itching and was taking medication daily. Several areas became raised and red, with occasional recurring infections requiring oral and topical antibiotics. However, the lesions never fully resolved and the intense itching continued to plague me. It was clear to me that my symptoms were not normal, despite adequate treatment.

I spent the following two years traveling between 40 and 200 miles throughout rural Montana visiting multiple dermatologists and getting eight biopsies. I prayed that someone could help me. I eventually had 14 areas of raised plaques and patches. The itching continued to torment me. I was desperate for answers.



My eighth dermatologist was proactive enough to consult a dermatopathologist who personally directed another biopsy. In the fall of 2016, I received THE phone call. She kindly prefaced the conversation with “don’t worry ... but we found some unusual T-cell development in your last biopsy.” She gently explained that I had a rare form of cancer, a lymphoma called CTCL, cutaneous T-cell lymphoma, which is treatable but not curable. Of course, all I heard was “lymphoma” and googled “CTCL” ad nauseam. I then drove another 280

miles for staging blood work, to rule out a more severe form of CTCL. I waited 30 very long days for the results of that testing.

**“I know that I am
not on
this journey
alone.”**

Mary



During that month, I truthfully began planning for my demise. I even made special monogrammed blankets for my grandchildren to remember me by each holiday season. I was certain that was my last Christmas with my family.

After a full month of waiting, I was informed that I did NOT have the most aggressive form of CTCL. What a huge relief!

I was referred to a specialist in Seattle, Washington, for confirmation of diagnosis and was staged at CTCL-MF 1B. Plans for continuous corticosteroids with possible NB-UVB light box therapy at home. I was given the booklet that I consider my “bible” published by the Cutaneous Lymphoma Foundation. Through this network and their many publications, I felt like I finally had a handle on my situation. I returned home with hope and a lifted spirit.

The topical steroids were messy, so I devised clothing that could be worn under regular garments to protect my body from any chafing or irritation. I stopped wearing slacks completely, and skirts became my new friend. I had minimal improvement from the topical therapy; therefore, I began the NB-UVB light box. With apprehension, I stepped into “the box” for the first time, which has proved to be my savior! I enjoyed a significant reduction in symptoms after just 6-8 treatments. After three months of light box, I was in a remission. I experience flare ups about once a year and return to the light box for treatment.

I realize that my story of CTCL-MF is not unique in that most of us have had a very delayed diagnosis with multiple