Since the development of the “scientific method,” people have been engaged in research in efforts to answer questions, solve problems, and add to our overall knowledge. Nowhere is this more evident than in the medical field, and in the study of cutaneous lymphoma. Ongoing research efforts in cutaneous lymphoma focus on two broad areas highlighted below where significant advancements have improved treatments and outcomes of patients.

**Pre-clinical/Basic science:** This is the broadest of the research categories. Pre-clinical/basic science data is constantly being generated by molecular biologists, cancer biologists, biochemists, pharmacologists, among others. Demonstrating how proteins and molecules interact with one another within a single cell, how cells interact with their surroundings, and how cancer cells are different from normal cells are some of the ways we can better understand disease and through that knowledge, develop potential therapeutics. It is also in this setting where we test potential new drugs outside of the human to first assess efficacy and potential side effects.

In cutaneous lymphoma there is a stream of data being published that provides new insights into its development. For example, investigations into the role of small RNA molecules (microRNA) showed that altering microRNA levels within cells affects the growth of cutaneous lymphoma. Additionally, research on epigenetic modifiers (regulators of gene levels) has shown changes in several of these proteins. Furthermore, with the advent of high-throughput genomic sequencing, multiple scientists have used this technology to better understand the possible genetic anomalies in cutaneous lymphoma. Sequencing of the entire genome within cutaneous lymphoma has generated large amounts of data and has allowed researchers to focus their efforts on specifically altered molecular pathways. Currently, researchers are focusing on growth...continued on page 5
**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:**
Hello and Happy Spring! I hope this New Year is treating all of you well and finding you in good health. Hopefully you are enjoying the season and looking forward to warmer weather and sunshine.

We hope you have received your copy of the annual Research Report and are as excited as we are about the impact you, along with the Cutaneous Lymphoma Foundation, have made in moving the needle on research. The publication highlighted the research efforts made by our CLARIONS and Young Investigator award grant recipients as well as, discussed the planning for the new research roadmap. As always we are thankful to our researchers in this industry who work tirelessly to provide new and effective treatments for this disease. I for one am eternally grateful to these folks who are leading the charge to develop new treatments and hopefully one day, a cure. I am equally as grateful to you, our generous donors, for enabling us to be part of the incredible work being done in cutaneous lymphoma.

Continuing our research focus, this edition of the Forum newsletter will also center on research in cutaneous lymphoma. In this edition, you will have the opportunity to read about the different types of research as it relates to cutaneous lymphoma shared by two of our Research Advisory Council members, Drs. Laura McGirt and Christine Eischen. This edition also features a personal story from Meredith Haab, the daughter of a patient, who is the brains behind our Skincare Corner. The Skincare Corner has brought insightful, everyday information regarding skincare to our newsletter, we are so grateful for Meredith’s dedication and are pleased to share her story.

While winter blustered along, the Cutaneous Lymphoma Foundation was actively out and about attending several scientific meetings, hosting our new Facebook Live interview series, launching the spring educational program events beginning with our Ask the Experts Live in Seattle on March 23, participating in Rare Disease Week and patient focused meetings hosted by the FDA. A special shout out to JP who represented us on visits to legislators and other events throughout Rare Disease Week. Thank you for representing all of us so well.

This issue each year focuses on research. Last fall saw the approval of brentuximab vedotin (Adceris®), an exciting new treatment targeting CD30+ proteins on cancerous cells. The way this drug works is innovative and different. It uses a method for encapsulating the drug in an antibody so the cancer cell thinks it’s okay to allow it to enter. Once inside the cell, the drug is released and kills the cell. Think of it like a trojan horse. Another new drug targeting a different marker on cancer cells, mogamulizimab, completed its Phase III clinical trial and the data has been submitted to the FDA for review and hopefully approval. Stay tuned. We anticipate news about this new treatment in a few months. Thanks to everyone who participated in these important clinical trials. Clinical trials can’t

FROM THE PRESIDENT
Joe Eischens, Esq.

Hello and Happy Spring! I hope this New Year is treating all of you well and finding you in good health. Hopefully you are enjoying the season and looking forward to warmer weather and sunshine.

FROM THE CHIEF EXECUTIVE OFFICER
Susan Thornton

Welcome to Spring!

For those of us who live in the Northern Hemisphere, spring’s arrival is more than welcome. If your winter was anything like mine, well, I’m happy it’s over.

“We are thankful to our researchers...who work tirelessly to provide new and effective treatments for this disease.”
Joe Eischens

“Clinical trials can’t happen without you”
Susan Thornton

“...we are thankful to our researchers...who work tirelessly to provide new and effective treatments for this disease.”
Joe Eischens

From the President...continued on page 10

From the CEO...continued on page 10
The annual 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 through:

- Clinical Presentations
- Panel Discussions
- Expert Quality of Life Presenters
- Breakout Sessions
- And much more...

“Very positive experience! It is nice to connect with other patients and to hear from the experts.”

Plan to join us for our...

**CELEBRATION OF LIFE COCKTAIL RECEPTION**

**Saturday, June 23, 2018**

We hope you will plan to join us to unwind from the day and network with others.
pathways, such as the JAK/STAT and NF-κB pathways that were discovered to be genetically altered and remain constantly active, causing cutaneous lymphoma cells to grow uncontrollably. This discovery opens up new possibilities to target these pathways therapeutically.

Clinical research/Clinical trials: As compared to the pre-clinical/basic science research, human subjects/patients are involved in clinical research that also includes clinical trials.

Given the rarity of cutaneous lymphoma, clinical research for this disease is frequently comprised of case reports of a single or few patients and their treatment course and outcome or reports of a group of subjects evaluated retrospectively through use of the medical chart. Retrospective reviews have been performed on larger populations of patients and have reported on factors associated with the development of and prognosis within cutaneous lymphoma, as well as the prevalence of disease within specific areas of the world. Case reports and case series have also been useful in bringing to light the less frequently encountered subtypes of cutaneous lymphoma.

Clinical trials are the gold standard for evaluating potential new or modified (alternate dosing or combination) treatments for disease. There are a variety of strategies that can be used within clinical trials, including the use of multiple treatment groups (some with placebo), “blinding” (either one or both the subject and investigator are unaware of which treatment group a subject is in), and “randomization” (a random assigning of subjects to treatment groups). These clinical trials are essential to start the process of critically evaluating a medication within a specific disease. When new medications are first being evaluated in humans, Phase I clinical trials are run, which involve a small number of patients and work to develop appropriate dosing for the medication. Phase II clinical trials enroll a larger number of participants and their main effort is to identify the effectiveness of the treatment, and to evaluate for side effects. Phase III trials (sometimes run concurrently with Phase II) also address efficacy and side effect profile as well as comparing it to previously available therapy or placebo. Through this process, the ultimate goal is to have effective and safe therapeutics approved for use through the Food and Drug Administration. Once clinical approval is gained, post-marketing evaluation continues and data is collected from patients using the medication to get a better sense of tolerability when used across the population.

There are many opportunities for clinical trials within cutaneous lymphoma. Over the last decade alone medications including histone deacetylase inhibitors, chemokine receptor antibody, and reformulated topical gel therapy have been approved for use in cutaneous T-cell lymphoma. Additionally, there are multiple ongoing clinical trials throughout the world for patients with cutaneous lymphoma, which can be found on clinicaltrials.gov.

Throughout the years we have benefited greatly from the efforts of scientists, and research continues to be a vital part of our cutaneous lymphoma community. It is through this collective work that we will continue to make strides in the fight against cutaneous lymphoma.

Authors:
Laura Y. McGirt, MD
Director of Dermatologic Oncology
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Christine M. Eischen, PhD
Professor and Vice Chair
Department of Cancer Biology
Thomas Jefferson University Hospital
My Mom, Gabrielle deHart Schwarz Haab, had cutaneous T-cell lymphoma (CTCL), mycosis fungoides. She’d been going to her dermatologist and internist for years and was told she had psoriasis or hives. It was only when an ulcerative lesion developed on her leg that she was sent to an oncologist – she was diagnosed with late stage 4 CTCL. What the heck was this? We’d heard of breast cancer but not CTCL. Despite our fear, we were reassured that if you had to have a cancer, this one was manageable like diabetes.

Mom started treatments but unfortunately went through them pretty quickly. While the treatments sort of worked, the cancer was aggressive. In 2011, Mom went into the hospital in early December and we were given a last best option: to try a drug that was in clinical trial. We were all in shock wondering how we had gotten to this point and yet we were so thankful for the research and new medicines being developed. The medicine worked a miracle and bought us some time. Mom was able to celebrate Christmas in the hospital with Dad and our whole family. She was happy and able to open gifts and even worried that she didn’t have anything for us (Mom loved being Santa Claus). But that year, my family got THE best gift we’ll ever receive – we got Mom.

EVERY DAY INFORMATION NEEDED
Within a week, Mom went from the hospital to skilled nursing care in a continuing care community with fewer developing skin lesions and ulcerations. And in a few more weeks, Mom came home and we were together for another 4 months. During Mom’s time at continuing care and at home, my family and I realized we needed every day information for CTCL skin care that wasn’t readily available to “lay people.” Very little seemed written for me, the caregiver, in step wise instructions that I could follow in a difficult time. For example, I constantly worried and wondered:

*What do we do to get stuck bandages off lesions without causing too much pain? Could Mom be given pain meds before or during bandage changing?*

As it turned out, the answer was yes. Mom was able to receive pain meds before and during bandage changes to decrease her discomfort and anxiety. Doctors and wound care nurses told us to use Vaseline®, apply it liberally around the bandage, and then apply warm compresses to loosen the bandages. This definitely helped but still, I often couldn’t get the bandages off with any ease. This was my nightmare: I was causing Mom pain by being her caregiver and changing her bandages! By this time, it took a nurse and myself or my sister-in-law hours to remove, clean, and redress the ulcers and lesions. Hard times…

IF I COULDN’T GOOGLE IT...WRITE IT
And yet…(big sigh)…and yet…out of adversity came inspiration. Mom and I had a moment of grace that we recognized and clung to: I’ll never forget the moment. It came to me, seemingly out of the blue: I needed skin care guidance written for the caregiver about everyday living situations – in lay language – and I needed it now. If I couldn’t google it – Mom told me to write it. So, Mom and I started our research as a team. We would discuss and document each step we took doing skin care so that others would have stepwise directions to follow. Mom gave me permission to photograph her skin care to have visual pictures too. No one would have to figure everything out anew each time – always reinventing the wheel – alone.

Mom and I had a purpose bigger than ourselves and it felt good, even a little hopeful. Mom and I were a team. And then we ran into a problem very quickly – how to get our information out there for others to see and use? What type of legal or medical issues were involved? Was this something I could just blog about or did I need more professional support since I’m not a medical professional? What to do, what to do? After all our progress – everything came to a sudden stand still and was put on hold. And even worse, Mom was starting to get more ulcerative lesions again.

REACHING OTHER CAREGIVERS
One day my school’s dear librarian, Marti T., sent me to a site she found: the Cutaneous Lymphoma Foundation’s (CLF) website. My brothers and I were immediately drawn in and read everything on the website…but still, no practical instructions on how to help care for loved ones with CTCL. Hmmm. I had an idea….I called Susan

“Caregiving was a hardship and a gift that has never left me...”
Meredith Haab

Meredith Haab, Ed.D.
Thornton, the CEO of the CLF. I asked if by any chance she’d meet me for lunch – I had an idea to run past her. She immediately said yes and I asked: Can you help me reach other caregivers? We caregivers learn by necessity, on the job, and often alone. Could she help me start talking and sharing skincare techniques from professionals, caregivers, and patients? Susan again and always immediately said yes, yes, yes – and that’s how the Skincare Corner in the CLF newsletter was born! I ask two or three medical professionals a skin care question per newsletter (questions crafted by a board of medical professionals that Susan brought together for this purpose as well as to further develop a skincare institute in my Mom’s name: The CLF-GSH Skincare Institute) and then we publish their explanations/answers for everyone to see.

In keeping with Mom’s and my vision, I’d like to share with you how we learned to remove her most stubborn bandages expanding on the professional guidance we’d received. This worked for us but you should consult with your physician before trying anything new. You can find the step-by-step recommendations on the CLF website at www.clfoundation.org/lesion-care.

LOOKING BACK
Looking back, nothing was perfect. Mom and I learned through trial and error each step of the way. I did the best I could. I regret the times I wasn’t patient or gentle enough. I regret the times I did what had to be done when Mom really didn’t want anything done except to be left alone and have me sit down and just be with her. But I understand that doing something – anything - was the only way I could cope and feel I was helping my Mom in a situation that was beyond difficult.

I look back with love and gratitude that I was so close to Mom toward the end of her life. I loved being so physically close to her and caring about her in ways words failed me. Caregiving was a hardship and a gift that has never left me six years later. I’ll speak for myself and Mom and say, we hope patients, caregivers, and loved ones can find practical everyday support and guidance in the Skincare Corner. Please know it’s written and put together with a great deal of love from all of us (the nurses and physicians, the staff at the CLF, me and Mom) to you.

"... out of adversity came inspiration."
**What are your general skin care recommendations for Erythroderma?**

Erythroderma is a medical term used to describe a skin condition when you have a red, scaly rash involving most of your skin. Usually at least 90% of the skin is involved. You may have severe itching and feel very cold when you have this rash. There can be several types of skin disease that cause this condition including cutaneous T-cell lymphoma and Sézary syndrome, but there are also diseases that are not related to lymphoma that cause this rash.

It is important to work with your doctor and they may prescribe oral and topical medications to help with this condition. You need to maintain your hydration and nutrition with this rash. A warm humid environment will usually also help. Your doctor may want you to use a “Sauna Suit” which is similar to a nylon jogging suit to create a warm humid environment for your skin. You may require oral antihistamines (like Benadryl/diphenhydramine) to help with the itch. Oatmeal baths sometimes also decrease the itch. Use a bland moisturizer like petroleum jelly or a petrolatum based ointment several times a day to help maintain your skin barrier function. Your doctor may want you to use topical steroid ointments as well.

Doctors may also want you to use “wet wraps” to help your rash. Watch for infection. If you get open sores or areas with weeping or yellow crusting, let your doctor know. Your doctor may want you to do diluted bleach baths to decrease the amount of bacteria on your skin. Eye care also is important. Your doctor may make recommendations to help protect your eyes and may refer you to an eye doctor. Erythroderma is a significant skin condition that greatly impacts your health and daily life.

Erythroderma is a term used to describe when most (>80%) or all of the skin becomes diffusely red and scaly. It can result from a number of skin conditions including cutaneous T-cell lymphoma (CTCL), in particular, Sézary syndrome and advanced cases of mycosis fungoides. Having erythroderma can be uncomfortable and patients can feel itching and burning of the skin and often shiver and feel cold. The skin feels dry and leathery, the nails often become brittle and thickened, and patients can lose their hair. Erythroderma can also cause irritation and excessive tearing of the eyes.

**Skin care recommendations for erythroderma**

Your dermatologist and/or oncologist will put you on systemic therapy for your erythroderma dependent on how advanced your disease is, what medications you have tried before, and what other medical conditions you have. In addition, there are many things you can do to your skin at home that can make you feel more comfortable and actually improve the erythroderma.
• It is important to be gentle on your red, sore and irritated skin. I recommend washing with lukewarm water, avoid using drying soaps to wash and instead use a gentle soap substitute like Cetaphil Body Wash or Cerave Cleanser. Taking bleach baths is very helpful. Not only does it soothe the skin, but it also helps to improve erythroderma by reducing bacteria in the skin. Use one half cup of regular strength bleach to a full tub of water every day or every other day. If the face and scalp are affected, you can submerge your head with your eyes closed under the water for a few seconds at a time.

• Erythroderma makes the skin dry and scaly so it is important to moisturize while the skin is damp after bathing and then several times a day. I recommend either regular petroleum jelly Vaseline or if this is too greasy, then a bland cream like Vanicream.

• Your doctor will often prescribe a mid-potency steroid ointment which can be applied all over your skin and will reduce the redness and itching. It is always best to rub ointments and creams into the skin in a downward motion and not against the hair to prevent folliculitis.

• If the skin feels very dry and itchy, wet pajamas can soothe the skin when applied on ointments overnight. This is done by wetting old close-fitting pajamas in lukewarm water and then, wringing them till damp and putting them on. Then put on dry pajamas over this before going to bed.

• For the hair, using coconut oil can help with dryness and scaling, and can be massaged into the scalp in addition to a topical steroid prescribed by your doctor. It works best if left on overnight with the scalp wrapped in a headscarf, then washed off in the morning with a gentle shampoo.

• Brittle, thickened nails should be trimmed as short as possible and Vaseline applied on them overnight to prevent chipping and breaking.

• Artificial tears can often be helpful for dry gritty eyes in erythroderma in conjunction with seeing your ophthalmologist.

• Finally, make sure to take plenty of rest (as your skin is working overtime during erythroderma) and keep well hydrated with plenty of fluids (your skin loses water when it is red all over). Stay comfortable by wearing comfortable loose fitting cotton clothing.

Debjani Sahni, MD
Assistant Professor in Dermatology
Director, Cutaneous Oncology Program
Boston University School of Medicine
Boston Medical Center
From the President...

Speaking of dedication, we are so grateful to all of you who continue to support us and make our collateral materials and live programs possible. Without you, we would not be able to bring you the most up-to-date research and information, which is so crucial, especially with such a rare disease. Please consider a donation to the Foundation if you are able, so that we can continue to provide these services to our community.

We hope that you find this information impactful and continue to utilize our available resources and engage in this wonderful community we have made together.

From the CEO...

happen without you.

Several new drugs are in the wings, moving into Phase II or III clinical trials or just beginning the clinical trial process in early Phase I. The landscape of new, targeted treatments for all subtypes and stages of cutaneous lymphoma is robust. Of course, it takes years for treatments to go through the process and become available, but the future looks very bright.

In addition to new treatment therapies in the research pipeline, investigators around the world are working hard to learn more about how this disease functions. By understanding how these cells grow, evade the immune system and move throughout our bodies, researchers can understand what to target when treating someone’s specific disease. There is still a long way to go in this research, but great strides are being made that can hopefully be translated into new treatments or better ways to use current treatments to maximize beneficial outcomes.

It’s an exciting time in cutaneous lymphoma research.

NOW AVAILABLE WITH UPDATED AND NEW INFORMATION

“A Patient’s Guide to Understanding Cutaneous Lymphoma”

The guide has been updated with new information, including:

- Variant types, including folliculotropick mycosis fungoides, pediatric mycosis fungoides and CD30+ disorders;
- Treatments; and
- Fertility-related information

Order a FREE copy today!

Online: www.clfoundation.org/publication-ordering
By Email: info@clfoundation.org
By Phone: 248.644.9014, ext. 1

From the CEO...continued from page 3

As new developments are announced and clinical trials become available, stay informed by checking the CLF’s website, eNews and social media for updates. Working collaboratively with our amazing group of medical advisors, we do our best to keep you informed as research evolves.

Enjoy the content of this Forum and let us know how we can provide you with support as you travel along your journey. As we always say, its a marathon, not a sprint. The more knowledge you have, the better you are able to make decisions about your care and treatment that will work for you. We’re here to provide information online, in print, by phone or in person. While this isn’t the club you wanted to join, we are happy to have you as part of our community. You don’t have to walk the road alone - we are right there with you every step of the way.

Enjoy the beauty and energy of Spring. Hope abounds!
CUTANEOUS LYMPHOMA PATIENT EDUCATIONAL OPPORTUNITIES

UPCOMING 2018 EVENTS*

JUNE 23-24, 2018: BETHESDA, MD
Cutaneous Lymphoma Foundation
2-Day Patient Conference

SEPTEMBER, 2018: TBA, NC
Cutaneous Lymphoma Foundation
Patient Educational Forum

OCTOBER, 2018: KANSAS CITY, MO
Cutaneous Lymphoma Foundation
Answers from the Experts

NOVEMBER, 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.
- Q&A sessions - 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

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
SO, WHAT DOES THE CUTANEOUS LYMPHOMA FOUNDATION REALLY DO FOR ME?

Improving your quality of life and access to the right care is what drives us every day. This philosophy is what makes the CLF the leading patient advocacy organization in cutaneous lymphoma. Here are just a few highlights of our recent work on behalf of cutaneous lymphoma patients:

- Susan, our CEO, traveled to over 9 medical & scientific meetings last year and represented cutaneous lymphoma patients and their families in the boldest way possible—her personal voice.
- CLF hosted 9 patient education meetings in 2017 with over 345 patients in attendance. Most importantly, they were all FREE.
- We continued to share the most up-to-date, medically-vetted information about cutaneous lymphomas than any other patient advocacy group in the world for FREE.
- CLF furthered our partnerships with leading researchers and clinicians to advance treatments to help ease the burden for cutaneous lymphoma patients.

We know there are many worthy organizations to which you can belong and donate in the world today. The Cutaneous Lymphoma Foundation works hard to stand out above the rest by connecting patients, physicians and research towards a cure!