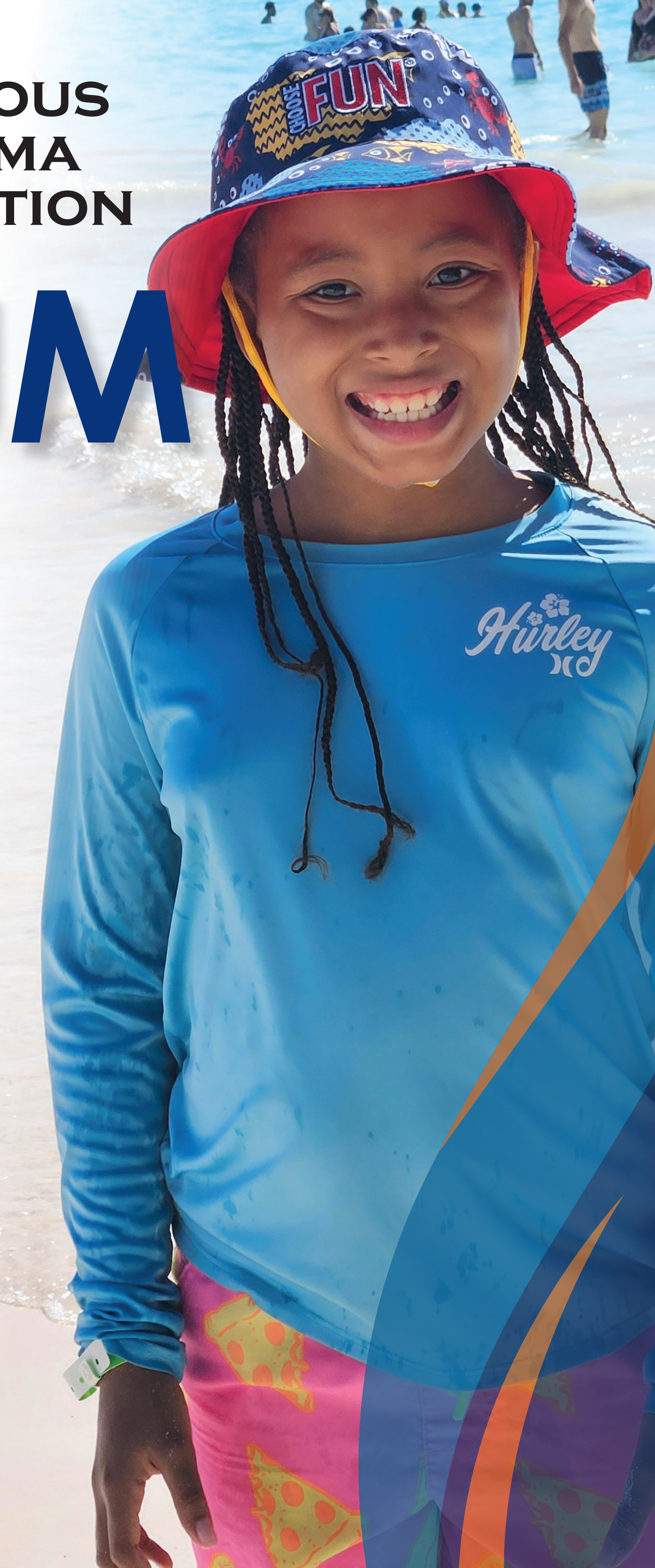
CUTANEOUS
LYMPHOMA
FOUNDATION

FORUM



2025 • Issue 2
www.clfoundation.org

FROM THE BOARD PRESIDENT AND CHIEF EXECUTIVE OFFICER

David Elefant, Board President; Susan Thornton, CEO

"Sun is shining. Weather is sweet. Make you wanna move your dancing feet." – Bob Marley

We hope your summer has been full of easy days and magical nights with family and friends. Perhaps a little bit of dancing under the stars too.

Welcome to the summer issue of the Forum—your go-to newsletter for finding information, inspiration, and the heartfelt voices of our fantastic community.

This edition is packed with updates and insights on a wide range of topics. Inside are highlights from recent medical meetings, reflections on new treatment guidelines for pediatric patients, and a beautiful story from a mom caring for her daughter with MF, and more. No matter where you are in your journey, we hope something here helps you feel more informed, connected, and empowered.

Check out Jim's recap of his experience on Capitol Hill representing the CL community as part of the Coalition of Skin Diseases Day and veteran clinician Suzanne MacRae's handy tips for accessing home light boxes. And oh, what a wonderful Annual Patient Conference we hosted in April in Philadelphia. Many have said it was the best one ever!

In June, the Foundation welcomed three new members to its Board of Directors. Each is a patient who brings their unique perspective and wisdom to help guide and direct the organization's strategic direction. Welcome, Kelly, Maddy, and Robert!

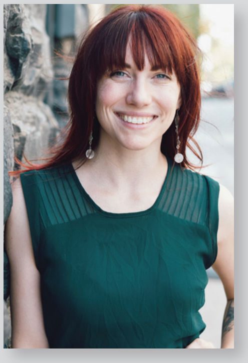
From the Board...continued on page 10

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.

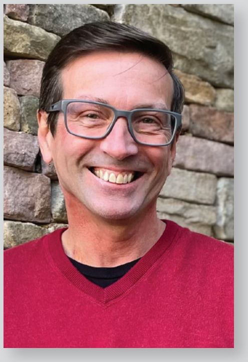
BOARD OF DIRECTORS NEWS

The Cutaneous Lymphoma Foundation welcomes three new members to our Board of Directors: Madeleine Curry, Robert Hulse and Kelly Paul.



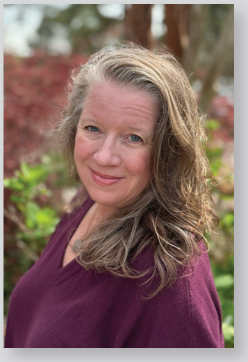
Madeline Curry

Madeleine (Maddy) Curry joins the board with a depth of nonprofit experience. Having been diagnosed at an early age, Maddy hopes to help expand the Foundation's support and resources for young adults and their unique concerns when navigating cutaneous T-cell lymphoma. Maddy and her family live in Canada.



Robert Hulse

Robert Hulse brings decades of work in nonprofit and volunteer organizations and an eclectic educational background in pharmacy, theology, and education to the task of helping the CL Foundation reach even greater heights of service to patients, physicians, and researchers across the globe. Robert and his family live in Georgia.



Kelly Paul

With a background in digital marketing, Kelly Paul brings both professional expertise and lived experience to her role on the CL Foundation Board of Directors. As a board member, Kelly is dedicated to advancing the Foundation's mission, amplifying patient voices, and ensuring that no one feels alone in their journey with cutaneous lymphoma. Kelly resides in North Carolina.

To learn more about our new and existing board members, visit www.clfoundation.org/board-of-directors

STORY OF HOPE: A MOTHER'S STORY OF CUTANEOUS LYMPHOMA

Shared by Jenny M.

Ava's cutaneous lymphoma journey began early. Born at just 31 weeks and weighing a mere three pounds, she was a fighter from day one. When she was six months old, we started noticing that her skin was very dry and she was always itchy. She started having hypopigmented spots, a discoloration of her skin, all over her legs and face that would become more prominent after sun exposure. She sometimes would also have marks like hives all over her body. Ava's pre-K friends would ask why her skin looked like it did. Family and friends suggested she had vitiligo.

Too young to understand what was going on, Ava always seemed desperate and frustrated, scratching her legs until they bled, trying to feel better. As her mom, I felt powerless and brokenhearted not knowing what was wrong with my baby or how to make her feel better. Dealing with my own cancer diagnosis, and now Ava's diagnosis, I was confused and overwhelmed as to how everything was going to play out.

DERMATOLOGY ODYSSEY

That's when we started our dermatology odyssey. We first saw an allergist because I thought Ava's itchiness and hives were allergies. We also started seeing a dermatologist who diagnosed atopic dermatitis, a common form of eczema, and prescribed steroid ointments. We changed to unscented laundry detergents, creams, shampoos and conditioners. However, Ava's skin did not improve as we were hoping. It just got a little better, but never really cleared up.

A second dermatologist referred us to our third, an adult dermatology practice at one of the local hospitals. They started her on a monthly injection for eczema, but three months passed and her skin was not improving. That's when the dermatologist decided to finally do a biopsy of two different areas on her leg. This was in August of 2022, when Ava was six years old, turning seven.

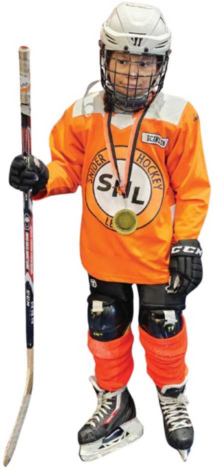
We waited close to two months for her results to come back. When the call finally came, I was told Ava had mycosis fungoides (MF) and that she needed to get off the eczema injections. I was really confused. I never heard of this condition. To me it sounded like a fungus infection.

By doing my own research online, I found out that mycosis fungoides is a type of skin lymphoma. I was really scared. I didn't know what to expect. As a cancer patient myself, this was a hard pill to swallow. We started seeing a pediatric oncologist and a pediatric dermatologist at Children's Hospital of Philadelphia.

Ava's treatments have varied. She does have eczema on some parts of her body, as well as MF. We use a variety of ointments: triamcinolone, mometasone, hydrocortisone, and cetirizine to help with her itchiness. We also use healing ointments to keep her skin moisturized. This is very important. But I think the treatment that has turned everything around has been light therapy. Ava currently has had UVB phototherapy twice a week for almost a year. Her skin looks amazing. From time to time she will have flare ups, but we know how to treat it now.

THE CHALLENGES

It can be challenging for Ava to keep up with her school assignments so as not to fall behind while juggling treatments twice a week during school hours. The teachers, nurses and the principal have been wonderful. They are very supportive of Ava's education and very accommodating to her needs. Twice a week she goes for her UVB light treatments in the morning and then off to school. She sees her oncologist every 6 months and her pediatric dermatologist every 6 months.



Keeping all of our appointments and treatments organized so we both get the care we need with no overlapping is challenging. Fortunately, my 20-year-old daughter is my "right hand," helping with medication applications and taking Ava to appointments when I'm unavailable because of my own cancer treatments. I am fortunate to have the support of my whole family, including my mom, sisters, and my daughters. What has been more challenging for

Story of Hope...continued on page 11

SETTING A NEW STANDARD: INTERNATIONAL CONSENSUS GUIDELINES FOR PEDIATRIC MYCOSIS FUNGOIDES

Cutaneous lymphomas are quite rare, and for many years, according to dermatologist Prof. Emmilia Hodak, Rabin Medical Center, guidelines developed for adults to diagnose, stage and treat mycosis fungoides were followed with some adjustments for pediatric patients.[1] More recently, cutaneous lymphoma research and clinical practice has shown that children differ from adults both clinically and histologically.

These differences led Prof. Hodak and fellow dermatologist, Prof. Chalid Assaf, from the Skin Cancer Center Krefeld, to spend three and half years developing a set of clinical practices, known as pediatric guidelines, for diagnosing, staging and treating children and young adolescents who have mycosis fungoides. They worked in collaboration with the three largest societies for cutaneous lymphoma, the International Society for Cutaneous Lymphomas (ISCL), European Organisation for Research and Treatment of Cancer-Cutaneous Lymphoma Tumor Group (EORTC-CLTG), and United States Cutaneous Lymphoma Consortium (USCLC) to produce the guidelines.

HOW ARE GUIDELINES CREATED

The process for creating the pediatric guidelines included several steps, starting with their interdisciplinary colleagues, including dermatologists/pediatrics, hematologists and pathologists from around the world responding to questionnaires asking about their experience caring for young patients. The questionnaire asked about the population of the children who have mycosis fungoides, the typical clinical and histological presentations, how often they saw early and advanced stages, and their treatment plans. Expert feedback on the data collected was provided through face-to-face discussions, online meetings, and a hybrid meeting at the 2021 EORTC meeting. Further rounds of questionnaires were used until Profs. Assaf and Hodak were able to define the clear criteria for the diagnosis, including the clinical and histological presentations, and what is needed for staging and treatment.

In 2024, the pediatric guidelines were presented at the World Congress of Cutaneous Lymphomas held in Pasadena, California. As of June 2025, the ISCL, EORTC and USCLC officially recommended the clinical use of the Pediatric Guidelines for Mycosis Fungoides.

IMPORTANT FINDINGS

In our recent interview with Prof. Assaf about the pediatric guidelines for the Coffee & Community podcast, he shared some of the important findings the process revealed. Perhaps the most important is that children with mycosis fungoides (MF) usually have a very good prognosis and they usually stay in the early stage lifelong.

- The clinical features of mycosis fungoides in children are often quite different from what is seen in adults. In fact, children often present with hypopigmented (uncolored) lesions. It looks like vitiligo or a fungal disease and is often mistaken for one of those rather than mycosis fungoides. Hypopigmented mycosis fungoides is the most common subtype or form of cutaneous lymphoma in children and is less commonly seen in adults.
- Mycosis fungoides in children is more common among those with darker pigmented skin. The data showed an overt geographic distribution of mycosis fungoides in the pediatric population – it is more common in children originally from the Middle East, Asia, and South America (and in Africa it is assumed, although data was unavailable) than in European countries.
- Intensive staging analyses, like CT/PET-CT scans that involve radiation exposure, are usually not needed. The same is true for lymph node biopsies. Lymph node involvement is very rare. There is no need to be invasive or to “harm” children with diagnostic procedures that are more appropriate for adults. The children don't benefit from it.

TREATING CHILDREN WITH MF

When treating children with mycosis fungoides, Prof. Assaf shared that, similar to staging methods, aggressive treatment is rarely necessary.

With children, **active** watch and waiting is frequently the first course of action. For example, if the child has an enlarged lymph node, the clinician needs to check if there are other reasons why the lymph node is enlarged. They may have a bacterial or a viral infection. The nodes are checked for inflammation markers. The clinician may do an ultrasound of the lymph node. If there is a bacterial infection, antibiotics are given. After two to four weeks another clinical investigation and ultrasound is repeated to check if it’s back to normal.

> "What they have to know, especially the parents, is to not be afraid...these children can be treated, that there are a lot of treatment possibilities and the disease itself has a very good prognosis." ~ Prof. Chalid Assaf

Usually children have patches and plaques, very rarely tumors,

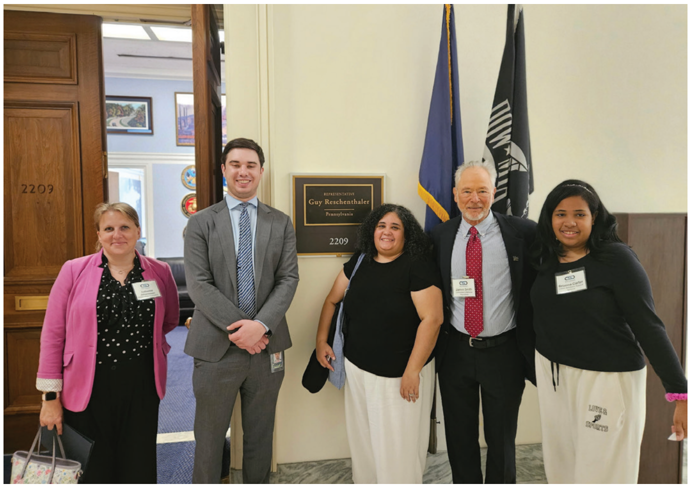
Setting a New Standard...continued on page 14

A DAY ON THE HILL WITH CSD

Shared by James S. - Patient Advocate

On May 19, a number of organizations having to do with skin diseases met under the auspices of the Coalition of Skin Diseases (CSD) in Washington, D.C., to advocate for legislation designed to help patients, the medical community, the government, and caregivers achieve new cures and treatment, continued research, and better access to information for all. The objective was to come up with a consistent message regarding the proposed legislation and share first-hand stories of those affected by skin disease and how the legislation would improve the lives of those involved.

There were 83 participants representing 13 organizations, including three (two staff, one patient - me) from the Cutaneous Lymphoma Foundation. Included in the types of medical conditions represented were fairly common types, such as psoriasis and eczema, as well as rarer conditions such as cutaneous T-cell lymphoma and lichen sclerosus.



After a day of preparation, the advocates met with their respective congressional representatives on Tuesday, May 21. Their objective was to create awareness of the impact of the diseases, the current situation they are faced with, and to seek support to give their representatives an understanding of how the legislation could make a positive difference.

The legislative asks had to do with several issues affecting patients and the medical community:

- FDA-approved treatment availability
- research to understand causes and develop cures and treatments
- creating awareness, especially among medical professionals and the population at large so that accurate, timely, authoritative and curated information is easily available
- medication costs and other barriers to access of accurate diagnosis and treatments of the conditions
- current laws that allow pharmacy benefit managers (PBM) to operate without transparency in ways that make prescription costs higher and the margins for pharmacies lower (and sometimes negative) while enriching the PBM at the expense of patients that rely on medications for their well-being
- current practices by medical insurers that often require patients to accept non-prescribed, but lower priced, medication in circumvention of the prescription of the medical provider, often to the detriment of the patient

> **" The most important voices are those of the patients."**

As a patient of a rare disease, all of the above have affected me personally. With a dearth of reliable information, I was initially at a loss on how to cope with my condition. Fortunately, I found the Cutaneous Lymphoma Foundation and was able to navigate my journey with much more confidence. They had information related to how the disease progressed and was presented, treatment options, locations of specialists, and experiences that were shared among fellow patients.

For many diseases, this is not available. In addition, many diseases have little awareness among the medical community and are lacking FDA-approved treatment. With 84 million Americans suffering from a skin disease, and 1 in 10 Americans with a rare disease, most people either have or know of someone in this situation. I am fortunate with my situation, but many of my fellow patients are not, and for this reason it's important to be able to advocate on their behalf.

Day on the Hill with CSD...continued on page 11

CAN YOU AFFORD TO NOT HAVE A HOME PHOTOTHERAPY DEVICE?

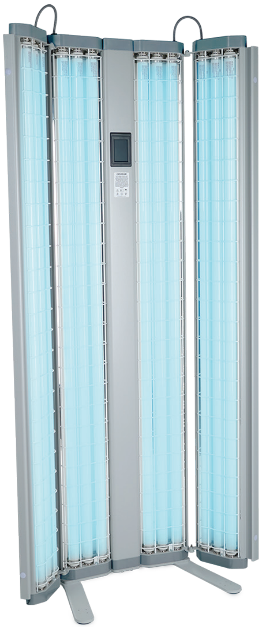
A discussion of the advantages and challenges of acquiring a personal unit

Suzanne MacRae, RN, BA, BS, MPH
Dana Farber Cancer Institute - Department of Cutaneous Lymphoma

In the previous installment of the CL Foundation Forum newsletter, Sue McCann, MSN, RN, DNC, explained the nature of home phototherapy as a treatment option for cutaneous lymphoma and laid out the pros and cons of using a home phototherapy device. Home light therapy has been in use in various forms since 1979. Its effectiveness has been proven for both psoriasis and cutaneous lymphoma, and yet here we are still discussing why and how insurance should cover this treatment 46 years later. While frustration with health insurance companies is at an all time high and coverage for medically necessary treatment is no longer assured, there are approaches which we can take together to grapple with both the process and the cost.

Why do I want a home device?

The dermatologist who manages your cutaneous lymphoma may prescribe either PUVA (psoralen and ultraviolet A) or NBUVB (narrowband ultraviolet B) phototherapy if they believe your cutaneous lymphoma will respond to this type of treatment. (As UVA light is rarely prescribed for home treatment, we will focus on NBUVB.) The dermatologist and their team may provide treatment in their office or a referral to a dermatologist's office closer to your home who offers in-office phototherapy. NBUVB treatment in an office setting is usually prescribed 3x a week for at least 12 weeks before tapering the frequency of treatment is considered.



If office phototherapy treatment is effective for your cutaneous lymphoma, you are a reliable and compliant participant in your care, would likely benefit from this treatment for many years, but find the financial and travel burden too cumbersome, the dermatologist may recommend ordering a home NBUVB device. A home device changes the treatment site from the doctor's office to your home and permits you to treat in the comfort of your home at your convenience. If your dermatologist does not discuss the option, it is appropriate to bring the idea up to your dermatologist or provider to pursue together.

Pathway to ownership:

If you both agree that home treatment is appropriate, the doctor's office will submit an order on your behalf to a company which manufactures home phototherapy machines. There are currently four companies, with the largest being Phothera. The NBUVB device requires a prescription from a provider to start the process. The prescription must verify that the device is medically necessary for some or all of the following reasons in order to meet insurance policy requirements: the device must be FDA approved, prescribed by a dermatologist for a serious skin condition requiring long term therapy, NBUVB has been used and proved effective, the recipient is able to use the home unit responsibly and capable of using it, and you are unable to travel to NBUVB in the office OR it has been determine that home therapy is most cost effective.

Procurement of a home device, from paperwork/prescription submission to approval and then delivery, takes an average of six weeks. Although you may conduct research and contact the companies on your own, the process is faster when done in collaboration with your medical team. During this process, Phothera (for example) provides status updates through their order portal or one can also call the sales department. The process is protracted due the many steps involved: processing of application by the company, submission of predetermination review by the insurance provider, and back and forth. The companies have experience with the process and access to insurance companies that the consumer does not, so allowing them to guide the process is beneficial. Once a coverage determination is finally made, the device manufacturer will reach out to you, the patient, to discuss how much your insurance will cover and what other options may be available to afford the device.

"Insurance does the strangest things"

Depending on your insurance coverage, this is where the process becomes tricky. One study showed that 76% of patients obtained home units through insurance approval but percent of coverage varies. A home phototherapy device is considered DME, or durable medical equipment which is the same category as a home hospital bed or commode. While a patient understands DME devices are necessary, to insurance they are thought to be optional and coverage may be partial, if anything.

Many insurance companies look to Medicare coverage policies for guidance and may or may not cover a home unit for the indication of cutaneous lymphoma.

Medicare: Medicare approves home phototherapy devices for the diagnosis of psoriasis but not cutaneous lymphoma, despite the risk for developing cutaneous lymphoma increased with age and many older Americans have Medicare B as primary coverage (that will cover office treatments).

Medicare Advantage plans: Coverage varies from plan to plan but some do stipulate coverage for cutaneous lymphoma.

Private 3rd party payers (United, Blue Cross, etc.): Coverage of a home phototherapy device varies on the plan.

Veterans Administration (VA): VA will provide a home device. However, patients must have VA insurance and devices must be ordered by a VA provider.

State-based insurance (ACA, Medicaid, etc.): Coverage of DME varies from plan to plan and state to state, but many do!

One of the more frustrating observations made during this process is how much more cost effective, for both the patient and insurer, a home device can be versus office-based treatment, and yet insurance does not see it the same way. Phototherapy is quick, non-invasive and painless, but it is not cheap.

- In-office treatments may cost $175 to insurance plus an average $40 out-of-pocket (OOP) patient copay.
- OOP copay for 3x a week treatment: $40 a visit x 3 x a week = $120 a week x 12 weeks (at least initially) = $1440 over 3 months
- Office costs: roughly $175 per treatment x 3= $525 x 12 weeks = $6300
- A home therapy machine averages $5000 out of pocket x 1.

When feasible, treatment should be started in an office setting, but once NBUVB proves to be effective, home based treatment is often the more cost efficient approach, especially since effective NBUVB treatment often requires more than 3 months and phototherapy cycles may be repeated over years to manage disease flares and maintain the benefit of other treatments, as well as be used in conjunction with other treatments.

Home based treatment results not only in decreased financial burden via less time away from work, reduction in lost wages, decreased transportation costs (parking, wear and tear on a car, gas), but provides other advantages such as decreased stress, improved quality of life, more schedule flexibility, improved sleep, and improves treatment compliance and improved disease outcomes – all of which can improve health and thereby reduce insurance costs.

Why am I preaching to the choir?

'Common sense need not apply' is a familiar refrain when jumping the frustrating insurance hurdles of prior authorizations, letters of medical necessity, and denials of care without material explanation. But upfront expenditures of both time and money should be kept in perspective with the greater goal of disease remission. Insurance and healthcare is a business, and while personal for you, don't take the denial personally, press on, and be your own best advocate. Below are some options and resources to continue to explore if the coverage you received isn't what you need.

- Work with your team and fight any denial if the treatment is medically necessary. Writing and submitting descriptive letters of medical necessity take time, but sometimes submitting them with a one-inch-thick packet of supportive records and literature can change minds.
- Explore the in-house payment plans offered by the manufacturers to make a high initial cost more affordable.
- Contribute to a health savings plan to offset future out-of-pocket costs.
- Transfer of Ownership - If someone no longer needs their home device, you can acquire it through donation or purchase. Then contact the company who manufactured it and they can transfer ownership to you. This allows your doctor to work with a company to create unique settings to treat you. You may find devices on eBay or similar sites or through patient forums, etc. Be aware, you may need to purchase new bulbs and be sure it is a NBUVB device and not another type of light device. It is also a good idea to involve your provider to be sure your purchase is appropriate for you.
- Go Fund Me - Worth a try!
- Purchase a smaller less expensive device if your doctor agrees it is appropriate. This may take more of your time to treat all the areas needed, but if money and not time is the concern, this is an option.
- Grants and Foundations - Explore any grants to offset out-of-pocket costs cutaneous lymphoma through the Leukemia & Lymphoma Society (LLS), Patient Access Network (PAN Foundation), Lymphoma Research Foundation (LRF), and many more.

Phototherapy...continued on page 8

Phototherapy…*continued from pg 7*

- Explore and recommend patient/provider partnerships. A hospital in New York bought home therapy devices and were able to provide them for patients. Perhaps this novel approach to cost sharing will encourage similar initiatives.
- Learn to Lobby - Let your state and federal representatives know you are not happy with Medicare and Medicaid coverage policies related to cutaneous lymphoma and that cancer treatment deserves to receive parity with psoriasis, or however you want to phrase it… just make a call!
- Check with your physician to see if the specifications of this used unit will meet your treatment needs and ensure that your physician will order and monitor the phototherapy treatments in the same way they would if you obtained the unit directly from the manufacturer.
- Your dermatology office will still need to load a set of treatments on the unit at periodic intervals and instruct you on initial time settings and interval increases in time.

If you are interested in exploring the possibility of a home phototherapy unit, please discuss the option with your doctor prior to making any decisions. The following is a list of companies we are currently aware of that offer home equipment. It is provided for informational purposes only and does not represent a recommendation or endorsement by the Cutaneous Lymphoma Foundation.

Phothera (Daavlin and NatBio Merger)
https://www.phothera.com/

SolRx Systems (United States/Canada)
https://solarcsystems.com/

Ultralite
https://ultralitesystems.com/

UVBioTek
https://uvbiotek.com/

Affording treatment is a collaborative endeavor, and by supporting each other through sharing information and knowledge learned through our health care challenges, I hope we will make access easier in the future.

References

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Would you like to connect with others who share your cutaneous lymphoma experience?

Connecting online through one of the CL Foundation's networking groups is a great way to meet others affected by cutaneous lymphoma. Whether you have the disease or a loved one who does, these online groups offer an opportunity to share and learn from each other's stories and experiences.

To learn more about our Online Networking Group meetings held monthly on Zoom, visit: clfoundation.org/patient-networking-groups

To learn more about our Networking Group on Facebook, see Groups on: Facebook.com/clfoundation

USCLC DEVOTES SESSION TO CTCL IN DIVERSE SKIN COMPLEXIONS

The USCLC (United States Cutaneous Lymphoma Consortium) Annual Workshop 2025 was held in Orlando, Florida, on March 6, 2025. It is a scientific gathering dedicated to clinical updates and insights about cutaneous lymphomas. This year, clinicians presented on topics related to cutaneous lymphomas in special populations.

The second session, CTCL in Diverse Skin Complexions, focused on clinical findings, epidemiological data, and social factors that collectively called attention to the disparities experienced by individuals of color living with CTCL. Topics covered included racial differences in disease incidence and outcomes, additional quality of life barriers, and recommendations for improving representation in clinical trials. This important session highlighted the urgent need for more inclusive research, better training on diagnosis in skin of color, structural healthcare reform, and deeper exploration of biological and environmental contributors.

Common themes from the session included:

- CTCL presents earlier, at higher stages, and with poorer survival rates in African American patients, particularly in younger females, based on a study with patients who had mycosis fungoides and Sézary syndrome.Quality of life is lower with the influence of socioeconomic status, insurance coverage, and environmental exposure on disease severity.
- Delays in diagnosis and treatment are more common in Black patients, contributing to outcome differences.
- A need to shift from race-based to race-conscious approaches in clinical research and care delivery, in addition to the underrepresentation of racial minorities in CTCL clinical studies and trials.

Dr. Shamir Geller from Memorial Sloan Kettering Cancer Center presented findings showing African American patients are diagnosed with mycosis fungoides (MF) and Sézary syndrome (SS) nearly nine years younger than white patients, and often at a higher stage of disease. While reviewing data without considering disparities related to income and insurance status, significant gaps in survival persist. Some ideas as to why this gap can still exist were environmental reasons, molecular pathways, genetic/epigenetic, difficulty in diagnosis, access to health services, and different responses to treatment, such as phototherapy and extracorporeal photopheresis. Female Black patients under the age of 40 were identified as being particularly vulnerable, with worse outcomes and quality of life, including more severe itch and a higher risk of infection. Data from the SEER and National Cancer Database confirmed these patterns, but limitations in retrospective analysis prompted calls for more center-specific data and better inclusion in prospective studies. A systematic review of 45 published CTCL studies highlighted a major gap in clinical research with only 37% including race-based or race-adjusted subanalyses.

Dr. Pam Allen from Winship Cancer Institute of Emory University emphasized the importance of understanding race as a social and political construct – or shared idea – rather than only a biological one. She discussed the clustering of CTCL cases in environmentally polluted areas, such as in Georgia, and urged researchers to consider social determinants of health when designing studies. She called for a shift toward race-conscious medicine and stressed the need for inclusive trial design, training of diverse patient experts, and equitable access to care.

Three case studies were also presented by medical students. Caroline Chen discussed the disparities in narrowband UVB phototherapy outcomes for mycosis fungoides patients across Fitzpatrick skin types. achary Thomas presented on the skin microbiome differences between Black and White patients with cutaneous T-cell lymphoma. Lastly, Sara Khoshniyati explored the interplay of race and the history of atopic dermatitis in cutaneous T-cell lymphoma outcomes.

Overall, the session underscored the significant disparities faced by individuals of color living with CTCL, highlighting key clinical, epidemiological, and social factors. Discussions revealed racial differences in disease incidence and outcomes, additional quality of life challenges, and underrepresentation in clinical trials. The session emphasized the urgent need for inclusive research, improved diagnostic training for diverse skin tones, structural reforms in healthcare, and further investigation into biological and environmental influences.

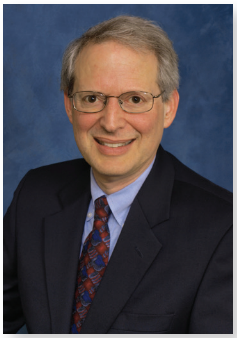
From the Board...*continued from pg 2*

We know that living with a rare disease can feel lonely at times. But remember, we're building this community together, where your voice matters and support is never more than an email or phone call away.

A huge thank you to everyone who contributed to this issue and all of you for being part of our wonderful community.

Don't forget to join us in September for the CL Challenge, where we'll raise our voices together to invest in the mission for a brighter future for everyone impacted by cutaneous lymphoma.

Until next time - take care and take a moment to do a little dance.



David

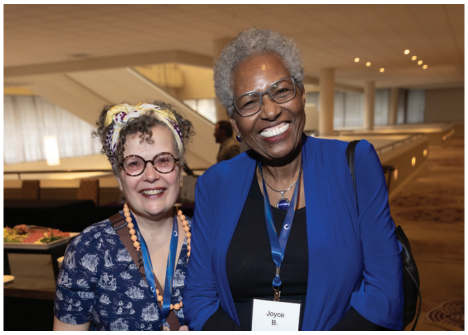
David Elefant
Board President

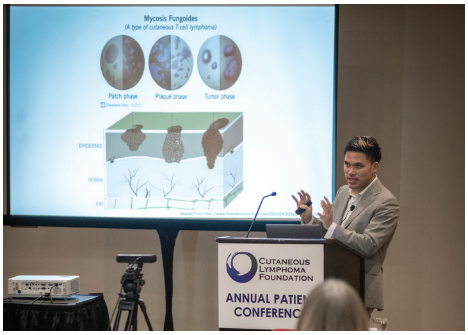
Susan

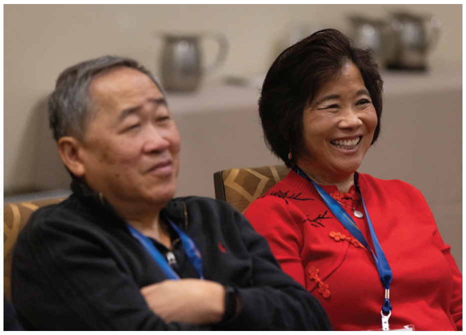
Susan Thornton
CEO

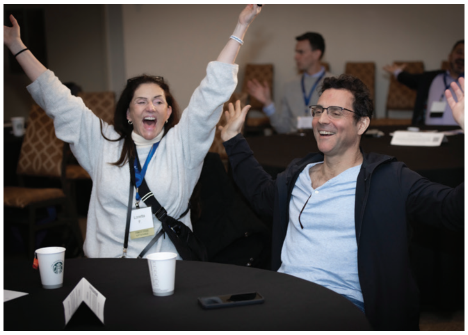
2025 Annual Patient Conference

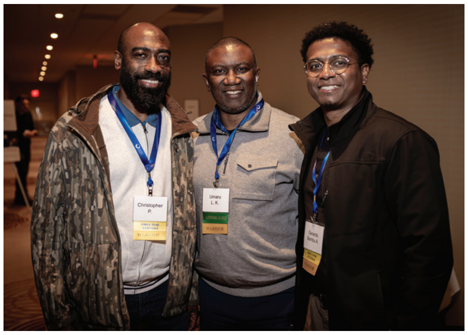
Our thanks to everyone who helped make the 2025 conference such a success!







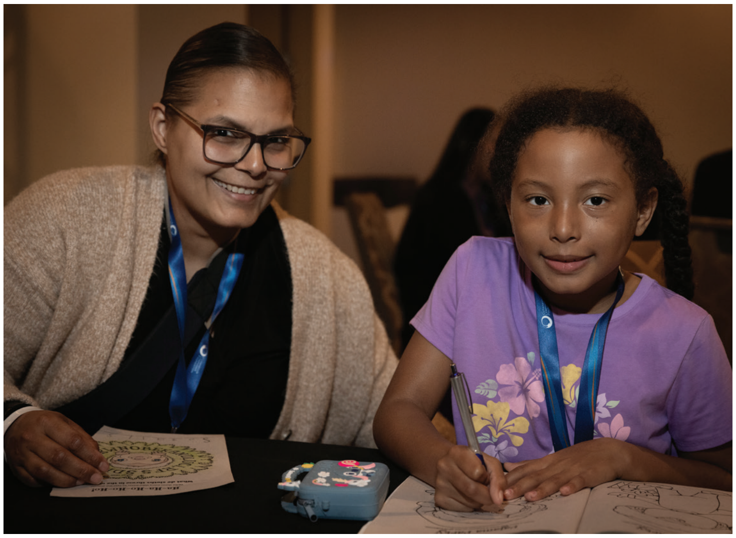




Story of Hope...*continued from pg 3*

Ava is that she is a really active and sporty little girl. She has always been interested in sports. We tried soccer and basketball, but with her condition, sun exposure makes her itch. One day, we found the perfect sport for her ice hockey. It's indoors and cool enough that when she skates, even if she sweats, it doesn't bother her like the other sports have. She is also doing Taekwondo and has earned her yellow belt.

Ava is a strong, determined, passionate, kind and loving little girl. I have seen her rise up and be brave about her condition. She is eager to learn more about MF and meet other kids her age who are also struggling with any type of cancer.



Jenny and Ava at the 2025 Annual Patient Conference

WORDS OF ADVICE

Looking back, I wish I would have been more aware that some skin conditions can mimic eczema, and it's important to consider alternative diagnoses. I also wish I would've asked for a biopsy sooner.

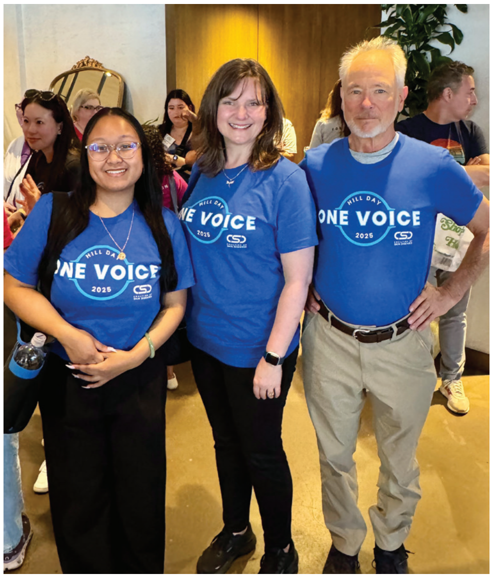
I would encourage every parent to be your child's best advocate. Ask as many questions as you need. Ask why this is not getting better. Are there any other treatments we can try? Push for more testing, maybe biopsy the areas sooner. If it doesn't feel right with one doctor, always ask for a referral or a second opinion. Do what feels right for you and your child.

Day on the Hill with CSD...*continued from pg 5*

Many of the issues that are barriers to effective diagnosis and treatment can be most effectively dealt with at the federal level. That's why it is so important to advocate for effective legislation to alleviate suffering. The cost of not having an accurate diagnosis in a timely manner often makes the cost of treatment, both in terms of the progression of the disease and the treatment regimen itself, much more expensive.

It all begins with research, which is funded in part by the federal government. The most important voices are those of the patients. That's why these opportunities with advocacy groups such as the Coalition of Skin Diseases and the Rare Disease Legislative Advocates are so important as they advocate directly to your congressional representatives.

You have an opportunity to tell your story, which is the most impactful message they can receive. Don't forget, they work for you, and you have to make your voice heard.



James joined CL Foundation staff members Elizabeth Accad (left) and Holly Priebe (center) for the CSD Hill event.

Frequently Asked Questions

How do we know whether it's MF, Sézary or something else? I've always been told CTCL, but nothing further, and I've had this since 2009?

Dr. Shamir Geller: CTCL is a group of entities, and some of these entities are very well described and some are a bit overlapping with other conditions, making it hard to make the diagnosis. Even in big referral centers like ours, it sometimes takes a while to clarify the diagnosis and we end up with terminology that is more broad, like cutaneous T-cell lymphoma.

Eventually, the diagnosis is based on the histological findings which are the biopsy results, some additional workup that is done on the biopsies, and the clinical appearance. Putting together all of these gives us the results - what it is exactly. Sometimes, patients get the diagnosis that is more broad and requires being consulted by a more experienced team. Sometimes, even the experienced team doesn't have enough to call it or to put it into the right “drawer,” and eventually we end up with a broader and more general terminology. Telling the exact subtypes is sometimes a matter that causes a lot of confusion even for us, so it's not an easy issue.

Dr. Paola Ghione: I completely agree, and I would say usually when patients go for a second opinion, besides for seeing a new doctor, etc., the second opinion is really the expert pathologist that sees cutaneous lymphoma all day, every day that could maybe recognize something a little more particular, and so this is really the additional value of maybe going to a bigger center for one visit so that you can have your material analyzed.

Shamir Geller, MD
Memorial Sloan Kettering Cancer Center
New York, New York

Paola Ghione, MD
Memorial Sloan Kettering Cancer Center
New York, New York

Questions and responses taken from the recording of our "Answers From the Experts: Q&A - April 2025." For the full-length recording, please visit: https://youtu.be/pqGE8q9FQ9E

Aside from monitoring stress and supporting the immune system, are there any other lifestyle recommendations you typically suggest to patients with MF, such as diet supplements or other supportive measures in addition to medical treatments?

Dr. Theresa Pacheco: This is always a question that we encounter with our patients. We counsel you to eat well, make sure you get enough sleep and then move your body - which is what any person with or without cancer can do.

Dr. Brad Haverkos: I don't think there's really good data to say that taking any given one supplement or doing anything specific is really going to change your outcome or how you're feeling. I know it's hard because I know patients want to have control and want to do something to make their disease better. There really isn't something you can do outside of probably what your doctors are recommending or the information you're getting from the Cutaneous Lymphoma Foundation to try to learn more about the disease and treatment options.

I think one of the recommendations that I sometimes will give is that I think patients should try to get out there and live their life - not only be healthy and take care of themselves medically, [in addition to] whatever the cutaneous T- cell lymphoma issues may be causing you. When I see people kind of forget about their disease is usually when I know things are heading in the right direction. We always try to tell people to live their life - I mean the whole reason to treat this disease is so that you can have a good quality of life. If you're hunkering down and not going out because you're concerned about infection or you are constantly worrying about the disease, I certainly understand, but it's important to try to get out there and go on vacations and do things. We're very willing, Dr. Pacheco and I, to try to cater to patients' lifestyles, like adjusting treatments so they can go on a vacation. You know those things are really important and I think that as a medical team working with patients we should help try to make those happen for you.

Theresa Pacheco, MD
UCHealth - Dermatology Clinic
Aurora, Colorado

Brad Haverkos, MD, MPH, MS
University of Colorado Cancer Center
Aurora, Colorado

Questions and responses taken from the recording of our "Answers From the Experts: Q&A - June 2025." For the full-length recording, please visit: https://youtu.be/DFiV8KHV-eM

I have mycosis fungoides which is often described as indolent. What should patients watch for to know when to bring concerns to their doctor?

Dr. Craig Okada: It is very patient specific. A lot of it depends on the burden of disease. A lot of it depends on the type of lesion you have. The main thing is we don't want to let the skin get beat up from the disease where you're getting ulcerations, you're getting cracks/fissures - so keeping it under control. And, you are probably aware, experience. Once you start getting to know your disease and how it behaves in different settings, you'll know if it is behaving differently than it has in the past. (Your clinician) needs to have to take a look at it to make sure it hasn't changed.

It is hard to give you a general how frequently you need to be seen, because it can vary quite a bit depending on both disease and your familiarity with it, and somewhat, what the physician's familiarity and comfort is. It is a rare disease and some of our patients are being seen by people who only have one or two patients with this disease, so they get a little nervous too.

Dr. Lindsay Ackerman: I would just very simply add that itch tends to be oftentimes a symptom that's associated with the recrudescence of disease. So, if you've had really very limited disease burden - it's been indolent, it's been under fairly good control - and all of a sudden you're having a diffuse itch that just doesn't make sense even before any skin lesions would arise, that is something I think that's worthy of bringing to the attention of your physician.

Dr. Craig Okada: Or if the rash looks different, I think it would be another (reason to tell your doctor).

Craig Okada, MD
OHSU Knight Cancer Institute
Portland, Oregon

Lindsay Ackerman, MD, FAAD
Medical Dermatology Specialists
Phoenix Arizona

Questions and responses taken from the recording of our "Answers From the Experts: Q&A - February 2025." For the full-length recording, please visit: https://youtu.be/2YEvnLgIIM8

YOUR LEGACY, THEIR FUTURE: MAKING A LASTING IMPACT

Including a charitable bequest to the Cutaneous Lymphoma Foundation in your estate planning is a wonderful way for you to benefit a mission that is important to you, and to leave a legacy.

Charitable bequests are very flexible. With a bequest to the Cutaneous Lymphoma Foundation, you can make a commitment without spending anything now or dipping into your current assets or current cash flow. Your bequest can be easily changed down the road if you wish to modify it.

A bequest included in your will or revocable trust is easy to set up with your attorney's assistance. Bequests usually are made in one of two ways… either a gift of a specific dollar amount (or a gift of a specific asset), or a percentage of your estate.

If you are considering making a planned gift and have not yet decided the form of your gift, please contact your estate planner. Or if you have already included the Foundation in your estate plans, please contact the office so our staff can thank you for your gift and keep you informed of our ongoing activities.

To learn more about bequests, please visit our website at **www.clfoundation.org/charitable-bequests**

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Setting a New Standard...*continued from pg 4*

so once clinicians decide to treat, skin-directed treatment is a treatment of choice. Treating with potent topical steroids and UVB phototherapy is the most frequent approach and generally very successful. Only for a small group of patients might a systemic treatment, like a retinoid, be added to the skin-directed treatment.

Prof. Assaf added that phototherapy, while effective, is not recommended as a maintenance treatment for children. Once the child is free of lesions, it is stopped and can be followed with a topical skin-directed treatment.

While children with mycosis fungoides usually stay in an early stage throughout their lifetime, relapse is common. If patches or plaques (less common) return, it is the same protocol for treatment, similar to children who have psoriasis or atopic dermatitis as a chronic disease.

Related to relapses, Prof. Assaf stressed that it is important to know when children have a relapse, it doesn't mean the disease is starting to get aggressive or that it is going to an advanced stage. It is still in the same early stage and can be treated with the same procedure as was used initially.

A WORK IN PROGRESS

The pediatric guidelines are a work in progress. To quote Prof. Assaf, "I think with this guideline, our primary attempt was to increase awareness that mycosis fungoides occurs also in children and is different compared to adults. We have to include it as a differential diagnosis. And with this awareness, we have already started further research programs." Areas of research include a better understanding of whether the occurrence in children is due to differences in the color of skin or if there are regional differences and/or environmental factors involved.

The Pediatric Guidelines for Mycosis Fungoides are currently available online ahead of printing and links are available on our website at www.clfoundation.org/pedguidelinesMF

You can hear the full interview with Prof. Chalid Assaf about the pediatric guidelines for mycosis fungoides by listening to our podcast interview on our Coffee & Community page: www.clfoundation.org/coffee-community

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