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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.

Which Type of Doctor Should I See and When?



Laura McGirt, MD

Carolinas Medical Center/Levine Cancer Institute  
Charlotte, NC

Being diagnosed with cutaneous lymphoma can be a difficult time. Significant anxiety can develop in having a new diagnosis of not only a cancer, but also one that is very rare, and of which many people are not aware. Additionally, as cutaneous lymphoma is a cancer of white blood cells within the skin, it can be even more confusing trying to figure out which physician (dermatologists, hematologist, oncologist) to work with.

After you are diagnosed with cutaneous lymphoma, with skin biopsy or blood work, I recommend (if possible) seeing a specialist within the field at least once. Most of the specialist locations are available on the Cutaneous Lymphoma Foundation website. You will likely undergo a workup to fully stage your disease - physical exam, blood work, and possibly imaging (CT scan, etc...). This will help your physician better develop a treatment plan for you.

If your disease has been diagnosed only within the skin, it is reasonable to seek out a dermatologist. You will likely need skin-directed therapy and this is generally accomplished through topical creams and gels as well as phototherapy, which is most often found in dermatology offices. Alternatively, if your disease has been identified in the blood or lymph nodes, you may want to consider seeing a hematologist or oncologist, in addition to a dermatologist. Your treatment will likely consist of both skin-directed as well as systemic therapy (pills, shots, infusions).

As some hematologists specialize in non-malignant blood conditions, and conversely some oncologists do not routinely treat blood-based malignancy, it can be helpful for you to inquire about the conditions treated by your physician prior to your visit. Additionally, there are dermatologists who may not be comfortable treating cutaneous lymphoma. Again, it will be of benefit to reach out to the clinic to ensure he or she will be able to appropriately care for you.

Oftentimes dermatologists and hematologists/oncologists work closely together to care for their cutaneous lymphoma patients, especially at the treatment centers specified on the Foundation's website. When a patient has more advanced disease, with both skin and systemic involvement, this is my preferred approach. I share the care of these patients with my fellow hematology/oncology physicians. Through their varied perspective and experience, I feel that dermatologists and hematologists/oncologists can work together to better

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**From the Chief Executive Officer**



**Susan Thornton**

It's Summer!

If you live in the northern hemisphere, summer is in full swing. Days are longer, warmer and many of us take time to relax on vacation. I hope you are taking the chance to slow down, enjoy time with family and friends and maybe a good book.

It's the time of year when the team here at the Cutaneous Lymphoma Foundation (CLF) also takes a little breather. As many of you know, the Annual 2-Day Patient Conference just finished up the last weekend of June. This year, we had close to 100 people registered. Many new faces and many folks returned again this year. It's always wonderful to see our friends each year. Special thanks to Charmagne Farrar for helping us out with registration this year. We really appreciated the extra assistance! If you were unable to join us, the presentations will be up on the website. Check them out. While being there in person, in my humble opinion, is special, you can still learn from watching the presentation videos. Take a little time to watch them if you can. This year's presenters and topics were fabulous.

Make sure to mark your calendars for the 2018 program that will be held in the Washington, DC area. 2018 will be the 20th anniversary of the CLF and we will be celebrating! If you can, this will be the 2-Day to attend. We are working on a few special things for that event you won't want to miss.

I love this month's articles. Looking through the eyes of those who love us, support us and many times provide non-clinical care for us as patients, sheds light on the impact this disease has on them too. For me, without the support of my family and friends as I've gone through this journey, I know I would be lost. As Sue Slaviero mentions in her article, my mom has been my care partner for over 26 years now. I am grateful for her capacity to listen, provide a shoulder for me to cry on when I needed it and for giving me hope that I could deal with this disease when I wasn't sure I could. To all the amazing care partners who give so much of themselves to us as patients, I honor you and thank you.

Enjoy the articles in this issue. Take some time for

*From the CEO...continued on page 7*

**From the President**



**Joe Eischens**

June 23, 2003 is a date I will always remember. That is the date I heard my doctor say, "you have cancer." After my wife and I picked ourselves off the floor and shared a quiet cry, we steered ourselves for the inevitable journey we have been on for the

last 14 years. Both being schooled in research techniques in our respective professions, we did exactly what my doctor told us not to do – we went to the internet to find out as much as we could about mycosis fungoides. Much of what we discovered was bad, and was not really applicable to my situation. I was diagnosed at Stage 1A or 1B and everything we were looking at was later stage articles and photos. So, we did not have a clear direction of where to go and what to do.

Fortunately, my doctor did. He sent me to a wonderful team of practitioners who were educated and experienced in treating this rare, orphan disease. The team individualized my treatment plan and sent me on a lifelong journey of learning to cope, and persistence in treatment, that I remain on to this day. I know now I will likely not die from this disease, and I learned that I can live my life to its fullest as long as I stay diligent in my treatment regimen.

I started with three years of PUVA treatments that cleared up my skin remarkably well. This was done in conjunction with the use of various creams and gels, including nitrogen mustard (which was most unpleasant and was halted rather quickly – but it worked for me). After three years of thrice weekly PUVA treatments and daily, greasy applications of various gels and creams, I thought I was free and clear of this unwelcome life partner called mycosis fungoides. But, as with many facets of life, my unwanted friend reared its ugly head again, in earnest, about three years later. That's when I discovered the Cutaneous Lymphoma Foundation!

Through the resources available at the Foundation, and the medical partnerships it has established, I was again paired with an outstanding team of practitioners who helped develop my individualized approach to attacking this disease, and to maintaining my very active lifestyle. I stood in the UVB lightbox at my doctor's office for over 500 sessions before having the good

*From the President...continued on page 7*

**Forum**

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**What Is Cutaneous Lymphoma?**

Cutaneous lymphomas are cancers of lymphocytes (white blood cells) that primarily involve the skin. Classification is based on lymphocyte type: B-lymphocytes (B-cell) or T-lymphocytes (T-cell). Cutaneous T-cell lymphoma (CTCL) is the most common type of cutaneous lymphoma that typically presents with red, scaly patches or thickened plaques of skin that often mimic eczema or chronic dermatitis. Progression from limited skin involvement is variable and may be accompanied by tumor formation, ulceration and exfoliation, complicated by itching and infections. Advanced stages are defined by involvement of lymph nodes, peripheral blood, and internal organs.

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











## My Journey with Cutaneous Lymphoma



**Susan Slaviero**  
Lambertville, MI

My journey with cutaneous lymphoma began as a mystery when my symptoms initially presented. In the Spring of 2009, I developed a rash around my neck and upper chest area. It was reddish and itchy. I tried to ignore it, but my Mom noticed it during a

visit home (I lived in Chicago and she lived in Michigan). My Mom suggested that I see a dermatologist, but I thought she was overreacting to what I believed was an allergic breakout. I switched shampoo, laundry detergent, and tried numerous over-the-counter remedies rather than see a dermatologist - which seems ridiculous in hindsight.

**“... I developed a rash ... It was reddish and itchy.”**

By mid-August, I couldn't sleep because my skin was itching so badly. I would use a hairbrush to scratch my back. Finally, during another night of insomnia and itching, I saw a TV commercial for a cancer treatment center that featured a man describing a symptom of his lymphoma as “horrendous itching.” Alarm bells went off; that was it!!! Around the same time, I noted two lumps on the back of my neck. They were roughly the size of rounded quarters and it was as if they had grown overnight. My doctor wrote an order for a CT scan to investigate the lumps on my neck. The other skin issues were left unaddressed.

I consulted “Dr. Google” and became convinced that I had some type of lymphoma. Since I worked at a medical center, I was fortunate to have access to managers who helped expedite the CT scan. The radiologist who read my scan reported that there was no apparent reason to believe I had lymphoma, though the scan confirmed the existence of two “masses” on my neck. While somewhat relieved, I had reached my wit's end with the itching and next contacted dermatology. The dermatologist examined my red arms, back, and torso, which would appear - to the untrained eye - to be a sunburn. The kind, experienced dermatologist calmly told me, “Your body is trying to tell you something, and it is very good that you are here.” Skin biopsies were taken.

Two weeks later, I was informed that I had a rare type of cancer - cutaneous T-cell lymphoma (CTCL) - and was scheduled to see the Medical Director of Dermatology, as

well as a doctor specializing in CTCL. I had an inkling that it could be serious, so I called my family and closest friends. My Mom packed her bags and drove from Michigan to Chicago. (She stayed with me for years and was a rock of support.) During my next appointment, several rounds of blood work were run and I was promptly scheduled for surgery to determine whether the cancer had spread to my lymph nodes.

While staging of my diagnosis was pending, the tops of both of my hands developed a pattern of growth that was foreign to me and could not be hidden from others in the workplace. I later learned that they were “plaques.” Many people at work were compassionate, but the business reality was that I retained responsibility for a heavy workload while dealing with matters related to CTCL.

By mid-September 2009, I had my diagnosis: cutaneous T-cell lymphoma, Sézary syndrome, Stage IVA. The cancer had indeed spread to my lymph nodes. My case was referred to oncology and a treatment plan was developed.

I learned that Sézary syndrome is an extremely rare type of cancer, even within the CTCL world. Blood tests revealed a significant number of “Sézary cells” - cloned, aggressive cancerous cells - in my bloodstream. I understood it to be the CTCL version of leukemia.

In the early weeks of my diagnosis, I received light therapy several times a week, which was like standing in a tanning booth with goggles on - though I emerged red, not tanned. I sought additional medical opinions and continued to report to work as able.

For many patients with Sézary syndrome, the treatment of photopheresis is generally prescribed. In this treatment, blood is extracted through an IV in the arm, is exposed to UV light to treat cancer cells, and is then returned to the body. This treatment was recommended by two of the three opinions I had sought. Based on the advanced stage of my disease, the oncology group I selected did not recommend photopheresis. Instead, I was prescribed continued light therapy, along with interferon shots to self-administer three times a week.

Mercifully, I was also prescribed hydroxyzine to help relieve itching. Immediately, I became a weekly patient at the CTCL clinic and a regular in oncology blood draw; it was all surreal. By October 2009, I was too ill to work.

**“My Mom ... was a rock of support..”**

**“... my diagnosis: cutaneous T-cell lymphoma, Sézary syndrome, Stage IVA.”**

tainted and therefore recalled. Interferon was discontinued from my treatment plan.

As a “what do we have to lose” next step, I ultimately tried photopheresis - also ineffective, as my team initially determined. Close to the end of treatment options at that time, I was advised that a bone marrow transplant/stem cell transplant (BMT/SCT) was necessary to save my life. No one in my family was a potential donor, so the Be The Match Registry was contacted to find an anonymous donor, an unrelated “allogeneic” donor. In the meantime, I was prescribed Campath® (altemtuzumab), a drug that was injected into my arm daily - by my Mom. Campath® brought me to a temporary remission while we awaited availability of a donor.

While awaiting transplant, my Mom, Brother and I attended a workshop in Chicago sponsored by the Cutaneous Lymphoma Foundation. Many medical experts gave presentations, and Susan Thornton shared her journey with the disease. She injected humor and shared that her Mom - much like mine - had attended virtually every appointment with her. I was new to the disease and was comforted by the receipt of an informational binder, as well as the opportunity to meet Susan and others afflicted with various stages of the disease. It helped to know I was not alone in this journey.

As my oncology team predicted, Campath® was only a temporary remedy and Sézary cells aggressively began to re-invade my bloodstream. I developed plaques under both of my armpits. They seemed to “bloom” as swollen layers of skin - uncomfortable and unsightly. The disease also attacked my inner thighs. These changes reminded me of Susan Thornton's comment at the Foundation's event - that the disease had no respect for the body.

My transplant was scheduled for May 12, 2010, and I checked into the hospital on May 5, 2010 for a series of intensive chemotherapy treatments. My basic understanding was that the chemo would kill the “good” and “bad” cells, and I would receive my donor's cells to grow a new immune system to fight the Sézary cells. I will not elaborate on the transplant process, as I hope that most of you

The lumps on my neck grew and interferon shots were increased. However, a batch of interferon I received from my pharmacy was

reading this will not reach that point of treatment. I will say, however, that having a BMT/SCT is not an overnight cure.

My life leading up to CTCL diagnosis and throughout treatment has been a physical and emotional rollercoaster. I've had many complications from the transplant and high doses of steroids that were prescribed. Fast-forward - I have now survived over eight years post-CTCL diagnosis and seven years post-transplant. I can't emphasize enough the importance of the incredible support I received from my family and friends. I received phone calls, books, videos, cards, letters, pictures drawn by children, prayers, food, flowers, clothing, balloons - from those close to me, from people I barely knew, as well as people I did not anticipate reaching out to me. All of it helped.

If you know someone touched by any illness, please know that all gestures matter - even a smile in a waiting room. This support in no way minimizes the critical expertise of the compassionate medical professionals who oversaw my care at all levels. I will never forget them.

I have come to realize that survivorship is not an end, but remains a continual challenge - as life in general. I have had periods of relative normalcy and the enjoyment of social activities, in between episodes of frustrating setbacks.

There are scars that are apparent, but other scars that no one sees - or at least that I try to hide. I am grateful for the gift of a

**“... all gestures matter - even a smile in a waiting room.”**

second chance at life, while sometimes struggling with how to use my gift. One of the most difficult challenges for me has been the inability to return to work. Last year, I moved from Chicago to be closer to family in Michigan. I live near my Mom and see her often. I keep in close touch with my friends, spend quality time with family, and have a two-year-old dog - Coco. I'm taking piano lessons, collaborating with independent composers to write songs, and trying to live each day without obsessing about tomorrow - not always easy for me.

I hope that sharing my story will help people to perhaps recognize warning signs earlier than I did. Remember to reach out to resources, such as the Cutaneous Lymphoma Foundation and other support groups, and to be grateful for life. We can take nothing for granted. The cliché of a “new normal” continues to be an evolving reality, yet also a life worth exploring and living. ☺

## Caregiving in Cutaneous Lymphoma: A Pilot Study to Explore the Concepts

**Sue McCann, MSN, RN, DNC**

University of Pittsburgh Medical Center  
Pittsburgh, PA

**Oleg Akilov, MD, PhD**

University of Pittsburgh  
Pittsburgh, PA

Assisting in the care of a person diagnosed with a chronic illness presents many challenges. It is increasingly required in today's health care system where rising health care costs put more and more responsibility on the family to provide care for loved ones. Caregiving can impact a family's quality of life, both financially and physically, increasing the risk for fatigue, stress, anxiety, depression, insomnia, and physical illness<sup>1</sup>. Caregiving demands often conflict with other family and work responsibilities, resulting in lost work time and income, decreased productivity, and exponentially increased stress.

As a nurse, I have had the extreme privilege of caring for patients with cutaneous lymphoma over the past 30 years. During this time, sitting alongside my patients and hearing their stories, struggles, victories, and worries, I have also learned much from the caregivers who share in this experience. These caregivers are the evidence that the disease doesn't just affect the patient, it affects the entire family. I have personally witnessed the difficulty experienced by some caregivers who were wearing out



right before my eyes as they cared for an ill loved one with multiple skin care and treatment needs that also required many trips to physician offices and treatment centers. It became evident that the experiences of the caregiver and their ability to keep pace with care demands impacted outcomes for the patient.

As the caregiver started to wear out, or even became ill themselves, the care of the patient at home became compromised. This scenario begged the questions:

1. Are we, as health care providers, doing enough to support the caregiver, given that their success (or lack of it) could ultimately influence successful outcomes for the patient?

2. Were the stressors experienced by caregivers of cutaneous lymphoma patients, especially related to skin symptoms, unique to this group of caregivers?
3. How does disease burden of the patient impact the caregiver?
4. Do caregivers feel that the health care provider is doing enough to address their needs?



Based upon these questions, and experience at the University of Pittsburgh Medical Center (UPMC), we decided to do a pilot study to look at the characteristics of the caregiver group (demographics), the caregiver burden and quality of life impact experienced by caregivers of patients with cutaneous lymphoma. We were particularly interested to know if caregiver burden differed depending on the severity of the loved one's disease.

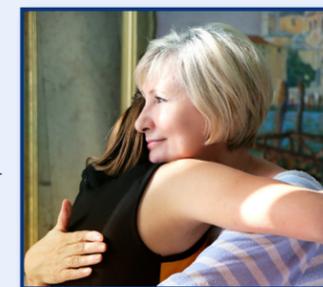
The decision to perform the study was influenced, in part, by the lack of research related to caregiver burden and quality of life impact on cutaneous lymphoma caregivers<sup>2</sup>. This study was conducted at UPMC by Sue McCann, MSN, RN, DNC; Jill Huwe, MSN, RN; Betsy Astley, BSN, RN; and Cindy Lipner, BSN, RN, all nurses caring for this group of patients, and Oleg Akilov, MD, PhD, the physician director of the cutaneous lymphoma program.

Forty-two caregivers participated in the study, which involved the completion of three anonymous questionnaires: Demographics of the caregiver, the Caregiver Quality of Life - Cancer, and the Zarit Burden Interview. These tools assessed 1) characteristics of the caregiver (age, gender, relationship to patient, and years caring for the patient, along with more in-depth information about the disease stage and its symptoms experienced by their loved one, 2) overall well-being, and 3) personal and role strain. While this was a very small sample of caregivers who were caring for a range of reported disease burden, there were trends in the analysis of data that indicated a relationship exists between the patient's disease severity and its impact on the quality of life experienced by the caregiver.

Plans for future research with a much larger sample size are underway, as it is an important area of study. It is necessary to more fully understand the quality of life impact on caregivers of patients with cutaneous lymphomas. From this knowledge, we hope to define how to better provide appropriate and relevant support to caregivers of cutaneous lymphoma patients, as it is vital to achieving successful outcomes for the patient. It is a win-win situation.

In the meantime, if you find yourself in a caregiving role and are feeling its potentially difficult and challenging effects, there are some things you can do to lessen some of the stress or strain you may be sensing.

- Take time out of every day to do something good for you. Try to put recreation and exercise in your daily schedule and prioritize it. Taking a walk, doing yoga, and meditation/visualization are great stress busters.
- Find an empathetic ear in a friend or relative, spiritual advisor, support group, or trusted health care provider.
- Get back to, or develop, a hobby that helps to relieve stress.
- Keep a close watch on your own physical and mental health status; don't let feelings of sadness, important appointments or physician recommendations go by the wayside.
- Make sure you are eating properly: avoid skipping meals or consuming non-nutritious foods routinely
- Don't be afraid to ask for or accept help. If someone offers help—TAKE IT! If you need help—ASK FOR IT!



### REFERENCES

1. Ohman, M. & Soderberg, S. (2004). *The experiences of close relatives living with a person with serious chronic illness. Qualitative Health Research, 396-410*
2. Beynon, T. R. (2014). *What are the supportive and palliative care needs of patients with cutaneous t-cell lymphoma and their caregivers? a systematic review of the evidence. British Journal of Dermatology, 599-608.*

## From the CEO...continued

yourself. Enjoy your family and friends. Read a good book or catch up on your favorite TV shows. It's summer. Time to take a break and take time for yourself.

Exciting things coming soon. Be on the lookout for our new website launch, along with a fun campaign that you can become involved with, which we will be launching in September. It only took one patient, one physician and one caregiver to get the CLF started - JustOne Makes a Difference!

Happy Summer!!!

*Susan*

## From the President...continued

fortune of obtaining my home light box - now I simply visit my basement 3 times a week! I also continue to use Targretin® and clobetasol and I am happy to report that all is well! Believe me, I know how fortunate I am and I thank God every day for my unbelievably supportive family and friends, for my outstanding medical team, and for the Cutaneous Lymphoma Foundation! Each has been, and will always be, my partner on this life long journey as a cancer survivor!

I am now very humbled to be writing to you as the President of the Cutaneous Lymphoma Foundation Board of Directors. I can say without hesitation that the Foundation Board and staff comprise the most incredible group of people I have ever had the privilege to work with and to call my friends. The Foundation literally changed my life! I urge each of you to experience the Foundation for yourselves, and to find out just how rich and fulfilling the resources we make available to you can be for you and your loved ones.

If, like me and many others, you find something useful and helpful, please let us know. And, please also consider a monetary "thank you" to the Foundation. Your support is so vital to our effort to one day eradicate this disease through our focus on research, and to our mission to provide the best resources and care possible to all of us who struggle with this disease.

I wish you all good health.

*Joe*

## Cutaneous Lymphoma Patient Educational Opportunities

The Cutaneous Lymphoma Foundation offers free Patient Educational Forums throughout North America providing an opportunity to:

- Receive the latest information about cutaneous lymphoma and learn about treatment options from experts in the field.
- Learn what's new in cutaneous lymphoma research and clinical trials.
- Q & A sessions - probably the most popular portion of the day. Have questions about the different types of cutaneous lymphoma, treatments, or daily living? The Q & A sessions provide you an opportunity to ask in a relaxed and friendly environment.
- Meet and network with other individuals affected by cutaneous lymphoma. Being diagnosed with or caring for an individual with a rare disease can be lonely. Meet others who know and understand what you are going through.
- Learn about available resources for treatment and support.

*We hope to see you at an event soon!*

### Patient Networking Groups

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

**CLF-DC**  
Fairfax, Virginia  
[www.clfoundation.org/CLF-DC](http://www.clfoundation.org/CLF-DC)

**CLR-LV**  
Las Vegas, Nevada  
[www.clfoundation.org/CLF-LV](http://www.clfoundation.org/CLF-LV)

**CLF-NYC**  
New York, New York  
[www.clfoundation.org/CLF-NYC](http://www.clfoundation.org/CLF-NYC)

**CLF-OR**  
Portland, Oregon  
[www.clfoundation.org/CLF-OR](http://www.clfoundation.org/CLF-OR)

**CLF-SLC**  
Salt Lake City, Utah  
[www.clfoundation.org/CLF-SLC](http://www.clfoundation.org/CLF-SLC)

### Upcoming 2017 Events\*



September 30: Portland, OR  
Cutaneous Lymphoma Foundation  
Patient Educational Forum



October 4: Pittsburgh, PA  
Cutaneous Lymphoma Foundation  
Answers from the Experts...Live!



October 15: London, England  
Cutaneous Lymphoma Foundation  
Answers from the Experts...Live!



November 11: Hackensack, NJ  
Cutaneous Lymphoma Foundation  
Patient Educational Forum

**For more information and to register for these events, visit [www.clfoundation.org](http://www.clfoundation.org) or call 248.644.9014, ext. 4.**

*\* Dates and venues are subject to change. Please check the website for detailed information.*

## Save the Date

Please plan to join us for our next 2-Day Patient Education Conference and 20th Anniversary Celebration

**Saturday June 23 and Sunday 24, 2018  
Washington, DC**

The Cutaneous Lymphoma Foundation extends its thanks to the following generous supporters of our events:



## Caregiving: A Personal Journey



**Trish and Jeff Ward**  
London, England

“You need to get that rash checked!” What started as a dime-sized red patch on Jeff’s cheek 16 years ago, has taken us on a long, baffling and itchy journey of discovery about cutaneous lymphoma.

Based in London, England, in time we would realise that my 49-year-old husband was atypical of someone living with cutaneous lymphoma; the ebb and flow of the condition, the shuttling between consultants (physicians) to get a definitive diagnosis, interspersed with well-meaning nagging friends and family to find out what caused the condition.

“He’s allergic, change detergent, Trish!” “We don’t mean to interfere, (oh yes?) but get Jeff to see this great Chinese Herbalist we know.” “Go to the Dead Sea and coat him in mud.” Nothing helped; he just got more patchy and itchy.

A referral to a dermatologist was set up. He wasn’t sure. Eczema or psoriasis? He took biopsies and prescribed powerful steroids. After an initial response, the patches returned and spread, while the itching and scratching became a vicious cycle. Jeff switched dermatologists. Curiously, Doctor No. 2 came up with a ‘possible’ diagnosis of mycosis fungoides and prescribed PUVA (ultraviolet A light with psoralen, a photosensitizing drug) three times a week. “Okay,” we thought, “it’s a fungal condition.” There was absolutely no mention of lymphoma. With a heavy workload, the commitment was too much and he didn’t proceed.

Meanwhile, patches developed into plaques, the itching/scratching cycle got worse. Bedsheets were covered in dead skin and patches of blood each morning. Going away became complicated. Despite being no-nonsense and never vain about his appearance, Jeff looked miserable and frustrated, whilst I got increasingly anxious. Something had to explain what was going on.

An appointment with a third consultant, who got a friend’s raging psoriasis under control, was booked. Jeff didn’t have that funny fungal condition, he had eczema after all! A diagnosis at last! But, another year of biopsies and steroids still didn’t improve things. Small tumours were starting to form and Doctor No. 3 performed yet more tests, sending Jeff a note. “I want you to see a colleague specialising in rare skin conditions. It is very important you keep this

appointment.” ‘Very important?’ Alarm bells started jangling. After going on his own to see Doctor No. 4, Jeff phoned me. His opening words were “sit down.” My stomach lurched. It was mycosis fungoides – but also called cutaneous T-cell lymphoma. Cancer. The consult seemed encouraging – Jeff was staged at IB. He was informed that in most cases cutaneous lymphoma is a chronic condition; a nuisance that needs managing, but in most cases, it won’t kill you. Also noted were two crucial factors, it wasn’t infectious, and what had never had occurred to me before, it wasn’t genetic – our children were not at risk.

My automatic reaction was to go online. As everyone later tells you, not the greatest idea – worse case scenarios were also on display and I found myself in floods of tears. Having worked in the voluntary sector for most of my career, I scoured the internet for support forums, but nothing was available in the United Kingdom (UK).

However, an organisation called the ‘Cutaneous Lymphoma Foundation’ in the United States (US) flagged up, together with its founder - Judy Jones. I rang her and she was lovely and reassuring. “As you’re in the UK, get your husband to see an authority on cutaneous lymphoma, Professor Sean Whittaker.” “That’s who he’s seeing!” came my reply. A huge cloud lifted.

After seven years of searching, Jeff had finally reached the right place for help and since diagnosis in 2008, gone through a range of treatments; PUVA, Targretin®, and radiotherapy - including total skin electron beam radiation (TSEB), which he tolerated well, and remained clear for 30 months before relapse. He is monitored on a regular basis and although looks a bit patchy at times, the itching is minimal and he is fit and well.

Meanwhile, the Foundation newsletters were helpful and encouraging. Hearing about other people living with cutaneous lymphoma, particularly new research, and the Foundation’s lobbying on behalf of patients when they cannot get appropriate funding for treatment.

One edition had a ‘call to arms,’ looking for involvement on their Board from interested patients - particularly for finance. As we spend time on the East Coast, and Jeff’s work in that field takes him regularly to the US, I suggested he contact the office to see if he could help. He has been Treasurer for the Foundation for the past six years and I am proud of his involvement. I know it gives him added empowerment over a condition that for so long he had no control over, and that makes me feel more positive too.

*Caregiver Journey...continued on page 11*

# SKINCARE CORNER Q&A

***What do you recommend for scalp care and in particular, for pruritic (itchy), lesional skin?***

The scalp care in mycosis fungoides and Sézary syndrome differs based on whether there is pruritus (itching) without lesions or pruritic lesions. The care also differs if the lesions are patches/plaques, or if they are nodules.

For itching in general, the physician would likely try to determine if this is localized (in one area) or diffuse (multiple different areas of the body). If localized, we will attempt local anti-itch treatments, such as topical steroids. If diffuse, we will usually try systemic anti-itch agents, such as gabapentin.

However, if there are associated lesions as well, it is important to know that anti-itch agents such as gabapentin are temporary measures. The true treatment for this is the treatment of the condition itself --- the regimen your physician has determined is needed for your disease.

In patches and plaques, the associating flaking can contribute the itch. Your physician may suggest various shampoos such as T/Sal® or T/Gel® to help with that temporarily while your treatment is beginning. However, if there are areas that are ulcerated or open sores, they may suggest you meet with a wound care specialist for training on appropriate dressings until those areas resolve.

*Answer provided by:*  
 Farrah Abdulla, MD, FAAD  
 Director, Cutaneous Lymphoma  
 University of Chicago

For scalp care, I would recommend a gentle shampoo without fragrances, such as a baby shampoo to wash the scalp that is normal, not scaly or itchy.

If the scalp is scaly and itchy, there are a number of shampoos that can help with discomfort. Tar shampoos (Neutrogena T/Gel® or other over the counter tar shampoo) left on the scalp for 5 minutes before thorough rinsing can be helpful for scaliness and itching. Shampoo with salicylic acid can be helpful for removing excessive scales. If scaliness and itching persists despite using tar shampoo, prescription topical steroid solution can be applied and massaged onto the scalp to decrease scaliness and itching.

***And, what is the difference between pruritic and lesional?***

Pruritic means itchy. Lesional is an adjective that defines an abnormal area on the skin that has a rash or growth. Pruritic lesional skin is a specific site on the skin that is itchy.

*Answer provided by:*  
 Henry K. Wong, MD, PhD  
 Professor and Chairman  
 Department of Dermatology  
 University of Arkansas for Medical Sciences College of Medicine

Information researched and compiled by:  
 Meredith deH. Haab, Ed.D., M.ED.



The 2-Day program was balanced with clinical presentations and wellness information on both days.



Allister Benjamin Chase, MSN, FNP-BC, AOCNP, leads a break-out session discussing early stages of cutaneous lymphoma with patients during the lunch hour.



The Celebration of Life Reception was held outdoors in the beautiful California weather. Many people attended and mingled with event speakers, CLF Board Members & staff, and new friends!



Hilary Romkey displays the ladies' Wallaroo® hats that were raffled at the end of the event.

## Highlights from the 2017 2-Day Patient Conference Los Angeles, CA

### Which Type of Doctor?...continued

enhance the care of our cutaneous lymphoma patients. It is also important to note, based upon your specific diagnosis, you may also be referred to a radiation oncologist, who will work together with your physician to develop a treatment plan for parts of the disease to be treated with radiation.

If you are unable to see a cutaneous lymphoma expert or specialist, you should establish care with your local dermatologist or hematologist/oncologist. I recommend discussing with them whether they are comfortable treating your specific diagnosis. You can also provide them with the Cutaneous Lymphoma Foundation website, as there are educational materials not only for patients but also for physicians. Additionally, many physicians have reached out to me for consultations over email and the phone. If you are unable to travel to a specialist, your local physician may be able to speak with one to help better guide your care. ☺

### Caregiver Journey...continued

Jeff tries to get to the Patient Forums when he can, and sometimes, I tag along too - most recently in Memphis, TN. I find sharing with other patients and family members, as well as hearing from leading specialists, to be a humbling and inspiring experience. By connecting with others living with this frustrating and bizarre condition, I realise we are not alone and good lives can be enjoyed again once you find the right care.

However, I still find it incredibly frustrating that because of its rarity, it will not occur to many general physicians to look for cutaneous lymphoma over more generalised skin conditions, and that despite all the constant testing, it cannot be definitive for a long time. Once you do get there, encouragingly, treatments can be returned to time and again, and better options are coming on-line all the time.

By Jeff's diagnosis, I increasingly acknowledge what my priorities in life are, and try not to 'sweat the small stuff' so much. The Foundation, a touchstone for advice and support for us, has been partially responsible for that. ☺



CUTANEOUS LYMPHOMA FOUNDATION

PO Box 374  
Birmingham, MI 48012

**TIME SENSITIVE MATERIALS ENCLOSED**

## **New in September!**

Same web address...New Look!

Through the generous support of the Spatz Family Foundation, Actelion Pharmaceuticals, Celgene Corporation and Kyowa Kirin Pharmaceutical Development, the Cutaneous Lymphoma Foundation has updated and added enhanced features to our website. Here are a few features we're excited about:

- Mobile-friendly
- New features to help you find the resources you need
- Updated look and enhanced video experience



**Just One**  
*makes a difference*

For almost 20 years, the Cutaneous Lymphoma Foundation has been making a difference in the lives of those living with this rare group of diseases.

In the beginning, it took JustOne. One doctor, one caregiver and one passionate patient.....that's all it took to start a global community that supports, connects and educates people around the world.

Starting September 14th, the CLF will launch the JustOne Campaign. Watch for announcements through email and social media with details about how you can help make a difference, or contact Tina Collins, Community Director, at [tina@clfoundation.org](mailto:tina@clfoundation.org) or call (248) 664-9014.