QUALITY OF LIFE IN CUTANEOUS LYMPHOMA

Cancer patients have a lot to worry about when they are diagnosed with their disease: will this affect how long I live? What kind of treatment do I need to do and for how long? What side effects will I experience with the disease and the treatment? How will the disease and treatment affect my life, my ability to work and function, my family? How much will treatment cost? These concerns contribute to health related quality of life (HR-QoL).

HR-QoL is a critically important issue to patients. It encompasses 1) disease symptoms; 2) emotions (self image/psychosocial state); and 3) function (performance status - ability to carry on activities of daily living). In 1996, the American Society of Clinical Oncology recommended that when judging the effectiveness of a therapy, HR-QoL was more critically important than tumor response and recommended that it be formally measured in all cancer clinical trials.

There are different validated tools (questionnaires) to measure HR-QoL (general, skin, itch). Cutaneous lymphomas patients have not only cancer-related issues that contribute to HR-QoL but also skin-related issues (appearance, itch, skin shedding, wound care, caregiver related issues). In addition, since cutaneous lymphomas are rare diseases, emotional “worry,” financial burden (due to fewer therapies available, lack of generic options, and rising costs of old and new medications) and a sense of isolation also impact HR-QoL.

The 2018 US Cutaneous Lymphoma Consortium Workshop, “Assessing and Improving Quality of Life in Patients with Cutaneous Lymphoma,” was held in February in San Diego, CA. In the morning, Dr. Francesca Sampogna and Dr. Margaret Chren, experts in HR-QoL, reviewed the history and tools used to measure HR-QoL in dermatology and future directions...
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 lymphomas (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.

Cutaneous Lymphoma Foundation

The newsletter of the Cutaneous Lymphoma Foundation has been made possible through the generous support of the following companies:

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“From the minute a new patient or caregiver contacts the Cutaneous Lymphoma Foundation, we embrace them as family and welcome them into our support community.”

Joe Eschens, Esq.
Our Journey with Cutaneous Lymphoma

Shared by Tom & Sarah V.

From Tom:
Sarah and I live in Maryland about an hour outside of Washington, D.C. Around New Year’s Day in 2013, I realized that the red, itchy rash on my trunk, that had bothered me for about a month, wasn’t going away. I went to the doctor, hoping to get a steroid pack to make it go away. A steroid pack was prescribed, but it didn’t work. I then went to another dermatologist near my office. A skin biopsy was taken and two weeks later I was informed that I had mycosis fungoides (MF). The doctor said it’s a cancer I could live with, but that didn’t matter at that point because I was still stuck on the word CANCER. Once the dust settled and Sarah (my wife) and I had researched cutaneous lymphoma, I realized how lucky I was to inadvertently find a doctor who knew about the disease and to get a diagnosis in less than a month. We quickly found the Cutaneous Lymphoma Foundation’s website. It provided us with information that helped calm our fears and the knowledge to move forward, knowing we had the best resource available to guide us on our unintended journey.

I was sent to a hematologist-oncologist and started UVB therapy, but I got worse. Next, I saw our area’s new cutaneous lymphoma specialist who diagnosed me with Sézary syndrome. The sequence of treatments and who ordered what when was blurry, but they included Psoralen and UVA (PUVA) phototherapy, campath (chemotherapy injection), total skin electron beam radiation (TSEB) and romidepsin (drip). The campath worked for 10 weeks, then it stopped. The TSEB burned me terribly by the end of my eight treatments. The recovery from that took a week and is the only time I missed work because of my treatment side effects. Until I started TSEB, my disease was my secret, but I finally had to tell my boss because I was spending too much time away from the office.

In November 2013, my doctor told me that we should start to research a bone marrow transplant, that the Sézary was very aggressive, and it would be my best hope to beat it. That was a very scary directive, because we thought a transplant was a “last ditch” effort to save a life. Although having one did save my life, it turns out that the patient has to be in good health to have one. I had to have a near zero Sézary count, which the romidepsin got me to.

We began to plan the transplant at Johns Hopkins in Baltimore. My son Eric was chosen to be my half-match donor. I had my transplant on August 8, 2014. It was one of the scariest and yet most anticlimactic days of my life! Scary for obvious reasons, anticlimactic because the transplant was unceremonious, and no different than anything else that hooked up to my Hickman catheter. The bag was hung-up and for the next four hours my new stem cells dripped into my body. And that was it!

We lived in Baltimore for two months following the transplant and moved back home in early October. I was able to begin to work part-time from home in November and went back full time in March 2015. Nearly four years later, I have been “upgraded.” That means, unfortunately for me, the transplant didn’t get me to a “cure” and I am at stage IB mycosis fungoides. I manage with hexabrevine, a host of other meds to counteract its side effects, and steroid creams.

From Sarah:
We never expected to need to learn a new vocabulary and join a wonderful patient networking group. It’s like being a new parent – you learn as you go; there is no manual.

Thank goodness for the Cutaneous Lymphoma Foundation and its website, which I found about 15 minutes after hearing Tom’s diagnosis. It has provided great comfort with all the information available on it. Living with the current diagnosis has actually been the hardest part. With Sézary syndrome, we were focused on a goal – get to transplant – so any changes Tom experienced made us focus all the more. Now, with MF, it’s the changes in his skin and blood work that cause us anxiety. I’ve learned to manage my fears and not let my brain run with them. I just have to remember “it’s livable,” which is something I didn’t know before Tom’s diagnosis. As for Tom, he’s living with it, which is the best news of all!

In 2005, the Cutaneous Lymphoma Foundation partnered with Dr. Demierre to survey the CLF community about their HR-QoL. Nearly 1000 patients and caregivers answered the survey which demonstrated that health distress was significant in cutaneous lymphoma patients (94% of patients were worried about prognosis), and significant numbers of patients reported emotional and functional impact (itch, condition affecting choice of clothing, sleep/energy, relationships, up to 88%) and unrecognized financial burden (61%) from managing their condition. More recent studies have focused on the effects of treatment on cutaneous lymphoma HR-QoL, disease-related itch, and a few clinical trials have incorporated HR-QoL assessments, usually itch assessments (Visual Analog Scale, VAS, for pruritus). However, these studies all used different HR-QoL instruments. There is no uniform consensus on which and how many HR-QoL instruments should be used in clinical practice or in clinical trials for cutaneous lymphomas.

Dr. Marie-France Demierre, Michael W. Young (CLF Board Member), and Judy Jones (CLF Founder)

Our Journey with Cutaneous Lymphoma...continued from page 1

Living With Cutaneous Lymphoma

in medicine. HR-QoL was an understudied area in cutaneous lymphomas until the early 2000’s when the late Dr. Marie-France Demierre, Director of the Cutaneous Lymphoma Program at Boston University Medical Center, published several studies examining HR-QoL in cutaneous T-cell lymphoma. She advocated the use of both general cancer HR-QoL tools (FACT-G) and skin disease HR-QoL tools (Skindex-29) to accurately measure HR-QoL in the cutaneous lymphoma patient population. She demonstrated that cutaneous lymphoma patients reported worse HR-QoL than healthy volunteers and patients with non-melanoma skin cancers. In addition, cutaneous lymphoma patients with more advanced stage disease reported worse HR-QoL than early stage patients. While every physician and patient would unanimously agree that HR-QoL should be considered every time treatment goals are discussed, unfortunately it is still not routinely formally measured in clinical practice or in clinical trials in cutaneous lymphomas. Ideally, a combination of instruments should be used to best capture the various cancer-related, skin-related, itch-related, and financial stressors of living with cutaneous lymphoma. The workshop had an important message: if you are a physician, take the time to give it out the HR-QoL questionnaires; and, if you are a patient, take the time to fill it out. These can help your doctor better understand the true impact of your condition and treatments on your daily life.

References:
1 Demierre et al. Arch Dermatol, 2005
2 Demierre et al. Cancer, 2006
4 Wright et al. J Pain Sympt Mgmt, 2009
5 Towner et al. Value Health, 2015

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“I’ve learned to manage my fears and not let my brain run with them.”
Our Journey...

- 1998 - The Mycosis Fungoides Foundation was established and incorporated and received non-profit status early the following year.
- Approximately 1999 - Mycosis Fungoides Fast Facts, the first disease-specific pamphlet with basic information for new patients and their families, was published, distributed and made available to physicians’ offices nationwide.
- 2001 - Published its first periodic newsletter, the MFF Forum, with articles primarily of interest to patients, including research developments and treatment information, was published.
- 2002 - The Foundation established its first Board of Directors and Medical Advisory Board; original website was published on the Internet.
- 2003 - The Foundation hosted its inaugural Cutaneous Lymphoma Symposium as part of the IID meeting; offered a Young Investigator Award to presenting researcher for travel to SID annual meeting.
- 2005 - To more accurately reflect the range of illnesses and true nature of the disease, the Mycosis Fungoides Foundation changed its name to the Cutaneous Lymphoma Foundation.
- 2006 - Patient Educational Forums were introduced offering expert clinical information and networking opportunities.
- 2009 - The Foundation hosted the Cutaneous Lymphoma Summit in New York City. The 3-day meeting was an inclusive gathering to identify unifying issues important to all stakeholders. The event was the first of its kind within the cutaneous lymphoma community and included a medical professional conference, a Patient Educational Forum and evening gala. Critical topics addressed at the Summit were published as Proceedings From the Cutaneous Lymphoma Summit 2009.
- 2012 - A Patient’s Guide to Understanding Cutaneous Lymphoma was published and the CLARIONS (Curing Cutaneous Lymphoma by Advancing Research, Innovation and Offering New Solutions) research award was launched.
- 2013 - The first annual 2-Day Patient Conferences was held, providing clinical and health/wellness information; and the first CLARIONS research grants were awarded.
- 2015 - The first annual research report was published. The report included a synopsis of the cutaneous lymphoma research of the CLARIONS and Young Investigator recipients. CLF began to livestream Patient Educational Events on the Internet via webcasts.
- 2017 - The CLF’s Medical Advisory and Research Advisory Councils were reorganized with new members joining each. The first patient educational events were held outside of continental America.

CELEBRATING 20 YEARS OF SERVICE:
CUTANEOUS LYMPHOMA FOUNDATION ANNIVERSARY

Where we began...
The Cutaneous Lymphoma Foundation originated from one feeling: frustration.

When Judy Jones was diagnosed with cutaneous T-cell lymphoma (CTCL) in 1990, she went from feeling that her world was falling apart to learning to live with the disease. Her search for information to help her with this journey quickly turned to frustration - she had never heard of CTCL, knew no one else with CTCL, and could find no information. Judy wondered how other people were coping with a disease about which they knew nothing. In 1996, she created and went on-line with the CTCL-MF Listserv, an online support group. The listserv grew fast as the word got out, as the Internet increased in size and people became computer literate.

Meanwhile, Judith Shea’s husband, Lee Allen Cohen, was diagnosed with Sézary syndrome in 1994 and passed away in 1996. Once again, frustration abounded. Frustrated by the lack of information and support during her husband’s illness, Judith created the Lee Allen Cohen Fund in his memory. Her goal was to find a way to use this legacy to provide information and support to others with CTCL diseases. Mr. Cohen’s physician was Dr. Stuart Lessin, a dermatologist treating CTCL patients in Philadelphia, and Judith met with him several times to discuss ways to reach her goal.

In 1998, Dr. Lessin was also frustrated. He felt that a patient advocacy group could call attention to the need for education and research in this field. After receiving information about the CTCL-MF Listserv from one of his patients, he called Judy Jones and suggested that she consider starting a foundation. Remembering Judith’s goals, he also called her to discuss the idea of a foundation for cutaneous lymphoma patients. Dr. Lessin then suggested that the two “Judys” talk and consider attending the upcoming American Academy of Dermatology (AAD) meeting to assess the support of other physicians. During the AAD meeting, they met with the International Society of Cutaneous Lymphomas (ISCL) and other patient advocacy groups and determined that, yes, this foundation was needed.

Using the funds from the Lee Allen Cohen memorial as seed money, a foundation was created. Frustration had found its purpose and the Mycosis Fungoides Foundation was founded.

The Cutaneous Lymphoma Foundation originated from one feeling: frustration.
**SKIN CARE CORNER**

**Q&A**

**What is erythroderma? What are your skin care recommendations for it?**

When eighty percent (80%) or more of a person’s skin is affected by generalized redness, inflammation, and scaling, dermatologists describe this as erythroderma. Erythroderma is defined as abnormal redness of the skin over widespread areas of the body. Although there are multiple possible causes of erythroderma, including drug reactions or severe psoriasis, the presence of erythroderma is particularly important to recognize in mycosis fungoides (MF) and Sézary syndrome (SS). Patients who are erythrodermic secondary to MF/SS often suffer from severe itching all over their bodies, which can interfere with sleep or otherwise impact their daily lives. Their skin may also feel tight or painful, and they often feel very sensitive to cold temperatures. The presence of erythroderma is associated with more advanced disease, and erythrodermic MF patients have a higher risk of lymphoma involvement outside of the skin compared to those patients with less extensive skin involvement.

For patients suffering from erythroderma secondary to MF/SS, it is most important to be closely followed by an experienced dermatologist or oncologist. In addition to the medications that might be prescribed to treat their condition, patients may benefit from steps at home to care for their skin. Good nutrition and hydration are important because erythroderma causes a person’s body to lose water and expend a lot of energy. Generous applications of petroleum jelly or other bland moisturizer, as well as topical steroids if prescribed by the person’s doctor, can help provide comfort and support the barrier function of the skin. Because skin infections can be a big problem for these patients, measures to reduce bacteria on the skin (such as dilute bleach baths, antibiotics, or antibacterial soaps) might also be recommended.

**“Good nutrition and hydration are important because erythroderma causes a person’s body to lose water and expend a lot of energy.”**

_Edith V. Bowers MD, PhD_  
Assistant Professor of Dermatology  
University of North Carolina at Chapel Hill

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**CUTANEOUS LYMPHOMA FOUNDATION**

**ISSUE 3, 2018**

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**CLINICAL TRIAL UPDATE: SOLAR**

A clinical trial to test a new investigational drug called Cobomarsen for the potential treatment of cutaneous T-cell lymphoma (CTCL), mycosis fungoides subtype, is now actively recruiting patients for the study.

The SOLAR trial is open across the United States and in several other countries using a drug designed to inhibit a molecule called miR-155. This molecule is found at high levels in certain types of cancer, including mycosis fungoides. miR-155 may be important for cancer cells to survive and grow.

The study will randomly assign eligible patients to receive either the new drug (Cobomarsen) or Vorinostat (a drug that has been approved for the treatment of mycosis fungoides). For more information about this clinical trial you can reach out to the company’s Medical & Patient Liaison team at (720) 643-5200 or go online: www.miragen.com/patients.

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**From the CEO...continued from page 3**

to everyone, no matter where they live around the world, and have funded close to $500,000 in cutaneous lymphoma specific research grants.

For me personally, this year culminates in celebrating not only where we have been, but looking ahead to where we are going. Here are a few highlights you may not be aware of. Our Medical Advisory Council was reorganized (led by Dr. Ellen Kim) and has an incredible roster of dedicated clinicians who are diligently working to keep our materials up-to-date and providing us with guidance on how we can bring clinical trial and treatment center information to you in a better way. Our newly created Research Advisory Council, led by Drs. Pierluigi Porcu and Christine Eichens, is hard at work figuring out how the CLF can best continue to support and advance research initiatives in cutaneous lymphoma. This year, we also presented the patient perspective at two major cutaneous lymphoma scientific meetings, raising the importance of issues and challenges all of you face every day to the clinical and scientific community. Special thanks to the individuals who volunteered to share their stories. You made a big impact!

It is an exciting time for us in the world of cutaneous lymphoma. There are more clinical trials going on now than ever before. More researchers are doing in-depth studies on the disease biology, impact of treatments, and uncovering the nuances about this rare group of diseases that makes it so challenging to treat. And, there are other challenges facing us as a community like the increasing cost of treatments, and access to specialists and treatment centers. These are issues we all face in some way, no matter where in the world we may live.

That’s why we continue to keep an eye on not only clinical information, but other issues that impact the ability for everyone to get the proper diagnosis, treatment, and hopefully the best outcomes.

There is much more work yet to be done. We look toward a future where every person is able to be quickly and properly diagnosed and have access to treatments and specialists all within their financial capacity. Perhaps one day, even curing cutaneous lymphoma for good.

It’s why we are grateful, especially at this time of year, that you are part of our community. It’s because of you that we have been successful these last 20 years and it will be your ideas, input and continued investment in our services that will make the next 20 years even better.

I wish you and your family a wonderful, joyful holiday season, along with a healthy, happy year ahead.

Thank you for your inspiration - you keep us moving forward.

In gratitude,

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20-20-20 CAMPAIGN RAISES $14,000 IN CELEBRATION OF 20TH ANNIVERSARY

This September, more than twenty members of the cutaneous lymphoma community banded together to raise awareness and funds in the Cutaneous Lymphoma Foundation’s national fundraiser, the 20-20-20 Campaign. The premise of the campaign was for each fundraising partner to donate $20 and then ask 20 of their friends and family to also donate $20 in celebration of the Foundation’s 20th Anniversary.

Thanks to the overwhelming support of our fundraising partners and their communities, the 20-20-20 Campaign raised over $14,000. These funds will directly support CLF’s ongoing programs and services such as connecting patients with specialists to obtain a proper diagnosis and access to the best treatments, and providing accurate, responsive, and individualized support to all patients. Finally, CLF will continue to fund and support scientific research and innovative projects specific to cutaneous lymphoma.

Special recognition goes to the 20-20-20 Campaign’s top fundraiser John Conley. A big thank you to Laurel Carlson, Michael Grayeb, Claire Quenzler, John Robbins, Jon Rockman, Angie Seitz, Marianne Tawa and Susan Thornton for exceeding their fundraising goal.

Even though this national fundraiser is over, we encourage you as members of our cutaneous lymphoma community to continue to talk to your friends and family about the resources and connections you’ve had thanks to your involvement in the Foundation. Their support and participation in our organization will help us expand our mission.

SUPPORT THE CUTANEOUS LYMPHOMA FOUNDATION

www.clfoundation.org/giving-online

From the Board President...
continued from page 3

a reliable journey. Your gift helps support our website and assures that we are able to continue to unite the cutaneous lymphoma community worldwide.

Several times throughout the year we sponsor and host amazing educational programs during which world-renowned medical and industry professionals share their wisdom and advice with patients, caregivers, and other medical professionals looking to learn more about cutaneous lymphomas. We offer 1-day Patient Educational Forums, “Answers from the Experts” evenings during which patients get to ask doctors direct questions, and our 2-Day Patient Educational Conference, which is the most comprehensive program we offer, during which attendees participate in a weekend-long, deep-dive, emotional and inspirational cutaneous lymphoma educational retreat. (If you haven’t attended one of these programs in the past, please make an effort to do so in 2019. I guarantee that you will be blown away!) If it weren’t for the generosity of our donors and corporate partners, we would have to charge each attendee to attend one of these events anywhere between $40 and $180. With your support, we are able to provide these events at no cost to our guests! Your gift will ensure that we are able to continue to offer these live educational programs without causing financial burden on our patients and their families.

During this season of giving, please consider making a donation to the Cutaneous Lymphoma Foundation. As always, our dedicated staff is happy to assist you with determining the most meaningful method to help you accomplish your philanthropic goals. Year-end contributions, IRA distributions, memorials, and estate gifts are a few of the most common ways the Foundation receives contributions each year. If you have any questions about giving opportunities that support the CLF, please call and ask.

We are eternally grateful for your continued support and look forward to providing YOU, our community, with the best in 2019 and for many years to come.

All the best,

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.
• Have questions answered about the different types of cutaneous lymphoma, treatments, and 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!
SAVE THE DATE:
2-DAY PATIENT CONFERENCE
JUNE 22-23, 2019

Plan now to join the Cutaneous Lymphoma Foundation in Manhattan Beach, California for our 7th Annual Patient Conference!

Watch our website and eNews for more details!

We look forward to another exciting weekend to learn, connect and celebrate!