



# Forum

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Summer 2011

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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.

## Itching For Answers: Pruritus in Cutaneous Lymphoma Patients

John A. Zic, M.D.



**John A. Zic, M.D.**

Dr. John Zic is an Associate Professor of Medicine in the Division of Dermatology at the Vanderbilt University Medical Center in Nashville, Tennessee. Dr. Zic received his undergraduate degree from the University of Notre Dame and medical degree from the

Vanderbilt University School of Medicine in 1991. He completed his internship in Medicine at the University of Chicago Hospital and his postgraduate training in Dermatology at the University of Illinois at Chicago Hospital. In 1996 he established the Vanderbilt University Cutaneous Lymphoma Clinic. He is presently the chair of the Education Committee and the Pruritus Task Force of the US Cutaneous Lymphoma Consortium.

For most patients with cutaneous T-cell lymphoma or CTCL, itchiness, also known as pruritus, can range in degree from a minor irritation to a tormenting sensation that can significantly decrease an individual's quality of life. CTCL-related itching is particularly vexing since it can start as a small fire and progress into a firestorm. An itch can start in a small patch or plaque and, if scratched, will trigger itching in another area, resulting in a full-blown itching frenzy. In a study by Dr. Marie-France Demierre of the Boston University School of Medicine, 88 percent of CTCL patients ranked pruritus among the top causes of distress associated with the condition.<sup>1</sup>

### When Treatment is Needed

Pruritus can vary in incidence and severity depending on the type of CTCL. Mycosis fungoides (MF), is the most common type of CTCL, and can appear as flat red patches on the body

as well as thicker, raised lesions called plaques. People living with MF typically report various levels of itch, mostly concentrated in plaques, with the most severe levels experienced in advanced cases. The advanced and leukemic form of CTCL is called Sézary syndrome (SS), differentiated by the presence of malignant lymphocytes in the blood and an extensive thin, itchy, reddish colored rash that covers over 80 percent of the body. Sézary syndrome encompasses less than ten percent of CTCL cases, however nearly all afflicted individuals suffer from moderate to severe degrees of pruritus.

### Talking to Your Doctor

Above all, talking to your doctor will help determine the best methods of pruritus management. Pruritus is a physiological condition at its root, and appropriate treatment is more likely to be prescribed if the degree of suffering is quantified. When meeting with your doctor, try to describe the severity of itchiness on a scale of one to ten, with one being little to no itch and ten being unbearable and inhibitive to daily functions. In some cases it may be helpful for patients to take a quality of life survey in order for the doctor to better understand how pruritus impacts the individual on an emotional and functional level. This can result in more effective care and increase the level of communication between doctor and patient.

### Available Treatment Methods

Although a definitive cause for pruritus has yet to be determined, there are various treatments. A common first-line

## From the President and the Medical Advisory Board Chairman



**Michael W. Young**  
*Board President*

As you may have read about in our spring newsletter, Judy Jones, founder of the Cutaneous Lymphoma Foundation, is stepping away from her day-to-day management responsibilities as President of the Board of Directors after more than 13 years of passionate service to patients and others affected by cutaneous lymphoma.

It has been Judy's vision for the last couple years to get the Foundation into a position of success and stability to allow her to prioritize the things she does best to support this wonderful organization and, importantly, enjoy and be with the equally wonderful husband and family who have taken every step of this epic journey of founding and growing an organization which serves a global patient population. With this vision in mind, the Board of Directors has worked together to ensure the Foundation continues to serve the mission and achieve the quality that Judy established.



**Stuart R. Lessin, M.D.**  
*Medical Advisory Board Chairman*

Thanks to Judy's dedicated work, today the Cutaneous Lymphoma Foundation provides access to comprehensive programs, resources and support for all those affected by cutaneous lymphoma. In addition, she led the Foundation to become a major global force for positive change among patients, caregivers, healthcare providers, researchers and policy makers. The work of the Foundation is far from complete and, as we embark on the next phase of the Foundation's journey, we are humbled by the immense impact Judy has had on so many lives, including your Board, and we are most grateful.

The Foundation is in solid and enlightened hands moving forward as a reinvigorated Board of Directors will be working closely with Jennifer Viano, CEO, and her staff to assure that our continued strategic and patient education goals are achieved.

We wish Judy the very best in her transition and are gratified to announce that she will remain connected to the Foundation in her new role as President Emeritus. Judy will be available to advise the Board and to participate in key advocacy and research initiatives as well as potential special projects designed to benefit the global community affected by cutaneous lymphoma. She will also, for now, continue providing online support through the CTCL-MF Listserv and continue to be available through her Foundation email address ([judy@elfoundation.org](mailto:judy@elfoundation.org)).

Please know how much we thank you for your continued goodwill and support as we work to continue all that Judy has done to help patients and others who rely on the Foundation for daily assistance. The Foundation has some very big shoes to fill, but we look forward to working with you to meet or exceed the high standards of patient advocacy, professional communication, and physician networking which Judy set with every phone call, every email, and every warm handshake since setting forth on this journey.

Once again, thank you for your ongoing support. Please feel free to contact us anytime with questions or feedback by phoning us at 248.644.9014 or by emailing us at [info@elfoundation.org](mailto:info@elfoundation.org).

Making sure every person with cutaneous lymphoma gets the best care possible,

A handwritten signature in black ink that reads "Michael".

**Michael W. Young**  
*Board President*

A handwritten signature in black ink that reads "Stuart".

**Stuart R. Lessin, M.D.**  
*Medical Advisory Board Chairman*

# Forum

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**MEDICAL EDITOR**  
Stuart Lessin, M.D.

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## From the Chief Executive Officer



As summer comes to a close and we at the Foundation get ready for a busy fall season of programming for our patients, we are filled with much excitement about all of our important work that helps us make sure that each person with cutaneous lymphoma gets the best care possible.

And, this work is made possible, day by day, by thousands of people who join with us in our mission. These people include our patients, caregivers, healthcare providers, donors, sponsors, advocates, and volunteers. Some people donate their time, some their talents and some their financial support. Together, all of these gifts have sustained and helped grow the Cutaneous Lymphoma Foundation during the past 13 years, and this support is what will continue to bring the Foundation further ahead in its vital work of improving the quality of life of patients living with cutaneous lymphoma.

In this summer issue of Forum, you will read about many extraordinary people doing impressive work and living remarkable lives that help us advance the mission of the Foundation. We are so grateful for their partnership, involvement and support. And, we are grateful to you, our newsletter reader, for being a part of our journey and the success of the Foundation.

The future of the Cutaneous Lymphoma Foundation promises to deliver much continued success and progress for the patients we serve. The Foundation's Board of Directors, staff, volunteers, supporters and so many other partners in our mission are all poised to work together to grow the programs and services of the Foundation. Together, we will accomplish great things! If you are interested in becoming involved with us, please contact me at 248.644.9014, ext. 4 or [jennifer@clfoundation.org](mailto:jennifer@clfoundation.org).

In closing, I want to personally thank Judy Jones for her extraordinary leadership and dedication to building this outstanding organization. As she transitions to her new role as President Emeritus, I wish Judy all the best, and I look forward to our ongoing work with her.

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

**Platinum Supporter**



**Gold Supporter**



## Cutaneous Lymphoma Patient Educational Opportunities

For more information and to register for these FREE events, visit [www.clfoundation.org](http://www.clfoundation.org) or call (248)644-9014



### September 10: Kansas City

Cutaneous Lymphoma Foundation Patient Educational Forum



### October 12: Teleconference

Part II: Update on Peripheral T-Cell Lymphoma

In Collaboration with CancerCare and the Lymphoma Research Foundation



### September 14: Teleconference

Part I: Update on Cutaneous T-Cell Lymphoma

In Collaboration with CancerCare and the Lymphoma Research Foundation



### October 22: Pittsburgh

14th Annual Brian V. Jegasothy Support Group for CTCL



### September 24: Seattle

Lymphoma Workshop, in collaboration with the Lymphoma Research Foundation



### October 29: Minneapolis

Lymphoma Workshop, in collaboration with the Lymphoma Research Foundation



### September 30 - October 2: Brooklyn

North American Educational Forum on Lymphoma, in collaboration with the Lymphoma Research Foundation



### November 5: Tampa

Cutaneous Lymphoma Foundation Patient Educational Forum



### October 8: New Orleans

Cutaneous Lymphoma Foundation Patient Educational Forum



### November 16: Teleconference

Part III: Managing Treatment Side Effects

In Collaboration with CancerCare and the Lymphoma Research Foundation

Patient Educational Forums provide exceptional opportunities for people with cutaneous lymphoma to receive accurate information about treatment options, access experts in the field and connect with other people with similar experiences.

Cutaneous Lymphoma Foundation Patient Educational Forums key features:

- Half-day to day-long event
- Held in cities throughout North America
- Professional and lay speakers
- Format includes lectures, Q&A sessions and small-group discussions
- Objectives:
  - Learn more about cutaneous lymphoma
  - Develop a better understanding of diagnostic tests
  - Learn about treatments available for different disease stages
  - Identify resources for treatment and support

The Cutaneous Lymphoma Foundation extends its thanks to the following generous supporters of our 2011 Patient Educational Forums:

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## My Personal Journey With Cutaneous Lymphoma



*Geraldine with her husband, Bob.*

### Geraldine Barton

Putnam County, NY

As a psychologist by profession and a researcher by nature, in an average day, I probably Google at least thirty topics. I didn't Google at all,

though, after a biopsy suggested I had mycosis fungoides (MF), the most common type of cutaneous T-cell lymphoma (CTCL), until I was definitively diagnosed a month later. I knew that if I found something frightening, I would get lost in the "what ifs." So, to manage my fear, I asked my husband, Bob, as well as a close friend to sift information and tell me what I needed to know – especially anything reassuring.

They quickly found and relied on the Cutaneous Lymphoma Foundation website for clear, authoritative facts, introducing me to a community that remains an important source of information and support.

A cancer diagnosis was the last thing I expected in August 2010 when I went to the fourth dermatologist, looking for something to clear my persistent rashes. Over several years, doctors had thought my two slowly spreading rashes to be anything from a recurrence of eczema, to an allergy, to ringworm. None of the prescription creams made the slightest difference, and I had resigned myself to living with these rashes. After seeing a women's magazine skin care article with a photo of a rash resembling mine (which was not MF), I found the fourth dermatologist – Dr. Yolanda Cestero, with an office in Westchester County, north of New York City. She suggested a biopsy, an abrupt change of direction. Three weeks later, when she told me it seemed I had something called mycosis fungoides, my first thought was, "Oh, so it's a fungus. Good, she'll prescribe a fungus cream and I'll get rid of it." Her next words, "It's a form of cancer," made my heart stop. I was only slightly reassured when she told me, "You will be fine but you must be treated."

Dr. Cestero, who's affiliated with Memorial Sloan-Kettering Cancer Center in Manhattan, referred me to two specialists there – Dr. Patricia Myskowski, a dermatological immunologist, and Dr. Steven Horwitz, an oncologist who treats lymphoma. I spent a rough month awaiting the day of my appointment, September 23, 2010. To make it through, I drew on everything I knew about stress management, and on prayer. I only resumed breathing when they told me I could expect a normal, productive lifespan. Drs. Myskowski and Horwitz work as a well-coordinated team, and I feel I am in the best of hands.

For my condition, which is between stage 1A and 1B, the doctors

prescribe a corticosteroid cream called Clobetasol propionate. The rashes cleared after several months of applying it twice daily. Splotches occasionally show up in new areas, leading my husband to joke, "the cancer is on the run."

I return to Memorial Sloan-Kettering for evaluation every four months and live without restrictions. I see myself as the same person I was before, with plenty of life ahead. I have a Honda that shows 135,000 miles on the odometer. I expect to drive it a lot longer, but it requires maintenance. If you have the privilege of living a certain number of years, you will require maintenance, just like my Honda. I like to view this as part of my maintenance. There's no guarantee the cancer won't advance, but the odds are very good and that sustains optimism.

Inevitably, my outlook has changed – in a positive way. The diagnosis has been really mobilizing, a push to think how I'll fill the rest of my life with the most meaning. I'm more careful with those I love. I've gotten serious about a couple of important projects that I'd been putting off. Bob and I are talking about returning to Italy, where we celebrated an anniversary two years ago, to watch a vintage car race next May.

I've drawn on my training as a psychologist to get through the diagnosis and everyday living with cutaneous lymphoma. I use relaxation and stress management techniques and focus on those things I can control, instead of allowing myself to dwell on the "what ifs." Reaching out to family and friends is incredibly helpful, as is helping others. I have been focusing, also, on making better choices about the chemicals that go on and in my body. I'm nourishing myself well, choosing organic foods when possible. I've been experimenting with making "home brew" skin cream, using organic, non-toxic and healing ingredients, and this has made a big difference in supporting my skin and controlling itching and flaking. These are things I can control and the sense that I'm doing something positive helps enormously.

I also rely on the CTCL-MF Listserv, which my doctors recommended as a constructive resource. In a world where it seems no one has heard of cutaneous lymphoma, it was an enormous relief and inspiration to find others coping with the diagnosis. I check discussion list e-mails for patient updates, treatment comments and news from clinical trials. I've established an email friendship with a woman from the listserv who lives on Long Island, and we hope to meet at some point. Susan Thornton, the Cutaneous Lymphoma Foundation's new Management Consultant for Programs and Services, who is also a longtime Foundation friend and supporter, also has been very helpful and reassuring. The Foundation is a vital resource and, like many others, I feel moved to help support its work.

As a next step, I hope to attend the Foundation's Patient Education Forum in New Orleans this October – a good reason for a fall trip.

## Cutaneous Lymphoma Foundation Recognized by International Society for Cutaneous Lymphomas at World Congress of Dermatology

The Cutaneous Lymphoma Foundation participated in this year's annual meeting of the International Society for Cutaneous Lymphomas (ISCL) on May 24, 2011 in Seoul, Korea as part of the 22nd World Congress of Dermatology.

The ISCL is dedicated to fostering regional and national collaborations among physicians and scientists in cutaneous lymphoma. Its program included reports from recent scientific meetings by representatives from the United States Cutaneous Lymphoma Consortium (USCLC), the European Research Organization on Treatment of Cancer (EORTC) and the Cutaneous Lymphoma Foundation.

Judy Jones, President Emeritus, represented the Cutaneous Lymphoma Foundation and reported on the Foundation's strategic goals, including:

1. Promote awareness and education to foster increased knowledge and understanding about cutaneous lymphoma.
2. Advance patient care and support to address the challenges of each person whose life is affected by a diagnosis of cutaneous lymphoma.
3. Facilitate research designed to lead toward important discoveries for improved treatment therapies and a cure.
4. Mobilize the talents and resources of people who want to do something about cutaneous lymphoma.
5. Sustain the Cutaneous Lymphoma Foundation to ensure current and long-term viability.

She emphasized the continuing need and great opportunity for international collaboration among patient advocates and the medical-scientific community for advancing patient education, support and services. Judy's presentation was extremely well-received by the international audience and stimulated discussions of new international collaborations. Her participation and inclusion in the ISCL program represented a great milestone in the growth and recognition of the Cutaneous Lymphoma Foundation and its impact on the cutaneous lymphoma community.

Reports of clinical trials were very encouraging as the pipeline of new and potential drugs for treating cutaneous lymphomas is expanding. This represents a decade-long trend since pharmaceutical companies are realizing that cutaneous lymphoma represents an excellent model for drug development of immunotherapies and targeted therapies ("smart-drugs").

It was also announced that the 2nd World Congress of Cutaneous Lymphomas will be held February 6-11, 2013 in Berlin, Germany.

The World Congress of Dermatology (WCD) is the most widely recognized international dermatology gathering and is held every four years. This year's WCD was the largest international medical meeting in Korea's history, bringing together an international audience of 12,000 attendees from more than 110 different countries.



### Farewell to Amanda Kik

All of us at the Cutaneous Lymphoma Foundation bid Amanda Kik, Director of Communications, a fond farewell as she leaves the Foundation to pursue more closely the work that she is passionate about with the nonprofit organization that she and her husband founded, the Institute for Sustainable Living, Art & Natural Design (ISLAND).

In Amanda's words, "It has been an honor to work with the Cutaneous Lymphoma Foundation during the last thirteen years and, throughout my time serving the Foundation, I have been touched by so many patients, caregivers, medical professionals, board members, staff and colleagues who drive forward the mission of the Foundation each day. I am grateful to have had the opportunity to serve the Foundation, and I look forward to staying in touch."

We at the Foundation thank Amanda for her extraordinary contributions, her dedicated service and her passion for making sure that each person with cutaneous lymphoma gets the best care possible.

**We will miss you greatly, Amanda, and we wish you all the best.**

## My Personal Journey With Cutaneous Lymphoma



*Rick in Italy during a recent trip.*

### Rick Kitchen

Columbus, OH

I enjoy deep-dive research into unfamiliar topics, but I never expected the compellingly personal project that began four years ago.

As a high school special education teacher for 17 years and now a part-time master's degree student, I value discovering information, finding reliable sources and evaluating information. And now that I'm the research subject, there's nothing academic about understanding my cutaneous T-cell lymphoma (CTCL).

The first lesson was what I thought was a mild eczema condition that showed up on my torso turned out to provide a break. It gave a head-start on my journey with CTCL because I already had a longtime dermatologist for various minor dermatological issues over the years. So when a couple of itchy red spots stayed on my torso, I went back to Dr. Mark Bechtel, Director of Dermatology at the Ohio State University Medical Center. His physician's assistant initially suspected an eczema flare-up and prescribed a cream. I returned in three weeks when the odd patches had grown beyond the original diameter of two to three inches, and that's when Dr. Bechtel took samples for a biopsy – my first sign of something serious.

The learning curve got steeper a week later as he delivered news that was scary at first. I thought, "What in the world is cutaneous T-cell lymphoma?" I had never heard of it and my parents confirmed no one in our family had this rare disease. To find out more, I started at the Cutaneous Lymphoma Foundation website, which I was steered to by a flyer at my doctor's office. That was helpful preparation for the first visit to the advanced specialist he recommended.

Dr. Pierluigi Porcu, Associate Professor of Internal Medicine, Division of Hematology, Ohio State University Comprehensive Cancer Center, explained that I have Stage IA non-Hodgkin lymphoma – "not the major league version," he reassured me. It's just on the skin, not blood-borne or in the lymph nodes. I'm thankful for that as well as lesson number two: Living in Columbus, my hometown, brings access to nationally prominent CTCL clinical studies and treatment programs.

The other half of my care team is Dr. Henry Wong, Associate Professor, Dermatology, Ohio State University Comprehensive Cancer Center. He and Dr. Porcu direct a multidisciplinary

CTCL clinic and they, along with Dr. Bechtel, coordinated my treatment, which began with ultraviolet light therapy known as narrowband UVB. Two or three times a week for three months, I stood in what I call "the box" – sort of like an upright tanning booth – for full-body exposure designed to slow the unwelcome skin cells' growth. The slightly raised patches, called plaques, almost disappeared.

When they began returning, I was switched to a prescription gel called Targretin, applied nightly for about six months. It burns quite a bit, but it works and is needed only occasionally now. The patches were essentially gone, but they have come back twice – apparently aggravated by stress. Otherwise, I just go for a checkup every six months.

Support also comes from the Cutaneous Lymphoma Foundation, which has clear information that educated me and eased early anxiety. In 2007, soon after I suddenly entered this unknown area, I participated in two teleconferences. It was reassuring to hear Judy Jones, a patient and founder, give perspective about the many different stages of CTCL. In the second teleconference, I heard Dr. Porcu after having met him, which reinforced that I'm in the right hands.

Blood tests are still negative and my disease is pretty mild, though the doctors don't minimize the situation. I won't ask again about remission, a word they don't use. This thing will always be inside me, so I'm more determined to live well and do my part to help researchers.

I enjoy spending time with family and friends as well as hiking, biking and enjoying wildlife. I also have a lot of interest in teaching about health and wellness as a Personal Trainer, and I serve as an EMT under a physician for high school athletics. I also enjoy watching college basketball and football along with NASCAR. Last year I tried zip-lining in southern Ohio, and this year I took my first two foreign trips to see a school and friends in Honduras and my brother and sister-in-law in Italy during a break from their Air Force service in Afghanistan.

I began social work studies at Ohio State this summer to earn a master's degree in 2014. I'd like to work in hospitals, at least on a part-time basis, especially now that I know amazing things happen there. My heart still wants to continue to work with students in a school setting as a teacher or social worker or even possibly in a private practice someday. At 44, I'm looking forward to using my new knowledge for my current career as a teacher as well as having it open up new doors for me both professionally and personally.

Also, importantly, my faith in Christ has given me strength and confidence as I faced the adversity in my life. Like the drivers I cheer during NASCAR races, I'm ready for whatever turns and tests the road ahead brings.

## Making Connections

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Living with cutaneous lymphoma (CL) can often make you feel isolated. With approximately 30,000 people in the US and Canada living with this rare and chronic disease<sup>[i]</sup>, it can be a challenge to find another person with the same condition, challenges, and information needs. Still, as is true with all medical conditions, it's important that people living with CL be able to find one another to share information, resources, experiences, and advice.

The Cutaneous Lymphoma Foundation provides extensive resources for newly diagnosed patients, CL survivors and caregivers. These resources are easily accessible by calling (248) 644-9014 or visiting [www.clfoundation.org](http://www.clfoundation.org).

### In-Person Support

Meeting others in person can be an important part of building a support network. There may be resources right in your local community that you can take advantage of. Whether the in-person groups you identify are CL-specific or generally focused on lymphoma or cancer, making the commitment to share your experiences, strengths and challenges with other patients can help increase your sense of connectedness and reduce feelings of isolation.

The Cutaneous Lymphoma Foundation is a great source for information about available face-to-face meetings or support groups in your area. You may even be inspired to plan one yourself! Patients and caregivers have often planned meetings together after they have met via the CTCL-MF Listserv or at a Patient Educational Forum held by the Foundation. These local get-togethers are usually held in a home or a restaurant and include a handful of people living with CL and caregivers.

The Foundation also holds support group meetings for patients and caregivers at each of its Patient Educational Forums, which are held during the year in locations throughout the United States and Canada. Visit [www.clfoundation.org](http://www.clfoundation.org) or call (248) 644-9014 to learn more about upcoming Forums and be sure to attend one if you can. These Forums provide exceptional opportunities to increase your knowledge about cutaneous lymphoma and experience the connections that are made in the support sessions.

Other organizations such as CancerCare ([www.cancercare.org](http://www.cancercare.org)), Cancer Support Community ([www.thewellnesscommunity.org](http://www.thewellnesscommunity.org)), The Leukemia & Lymphoma Society ([www.lls.org](http://www.lls.org)), and the Lymphoma Research Foundation ([www.lymphoma.org](http://www.lymphoma.org)) offer many free support services for people living with cancer and have local chapters throughout the US. In addition to the more traditional support offered by these organizations, some of these groups also offer activities, classes and social events, which allow attendees to network and develop friendships.

### Online Support

Online resources are easily accessible and they are a wonderful tool to complement in-person support groups for both patients and caregivers. With the advent of the internet, a growing trend called “peer-to-peer health care” shows that one-in-five internet users go online seeking others with similar health concerns in an effort to reduce the sense of isolation.<sup>[ii],[iii]</sup>

Support communities such as chat rooms, forums or even listservs can directly link people living with CL to one another via the Internet. These communities are easy to access, often not limited to time of day, can be international in scope, and may offer privacy settings depending on the user's preference. Judy Jones, Founder and President Emeritus of the Cutaneous Lymphoma Foundation, started the CTCL-MF Listserv, an online support group in 1996; the listserv is hosted by the Association for Cancer Online Resources (ACOR) and is free for all users. Today, there are more than 750 members from 20 different countries who participate and seek support.

Members who join the listserv express how valuable their participation has been with helping them learn about cutaneous lymphoma from others, receive tips on how to cope with symptoms, share their own experiences, and build friendships. You can join the CTCL-MF Listserv by visiting [www.clfoundation.org/support/online\\_support.htm](http://www.clfoundation.org/support/online_support.htm). Additional listservs available to join at that website link include the CTCL-MF Parent Online Support Group; the Mycosis-Fungoides UK Online Support Group; and the Lymphomatoid Papulosis Online Support Group.

## Reliable Resources

Be mindful that support groups or online peer communities may not provide the most accurate information. Peer venues can often provide overwhelming amounts of information and personal experiences, so remember to take everything with a grain of salt. People living with CL should utilize these venues for more practical, day-to-day support and, most importantly, for peer support. **We want to stress that remaining in close contact and under the care of a trusted physician is of paramount importance.**

In addition, you should identify a few highly credible and reliable sources, such as the Cutaneous Lymphoma Foundation ([www.clfoundation.org](http://www.clfoundation.org)), American Cancer Society ([www.acs.org](http://www.acs.org)), or National Cancer Institute ([www.cancer.gov](http://www.cancer.gov)), to draw on for accurate information about treatments, symptoms, clinical trials and the like.



## Supportive Counseling

People living with CL also need to listen to their individual emotional needs. Supportive counseling can be a helpful way to maintain balanced emotional health. If you think you might benefit from counseling, take some time to explore your options. Many healthcare insurance plans provide mental health benefits that may include visits with a psychiatrist, psychologist, social worker or licensed counselor. In addition, many treatment centers and community organizations provide support services at low or no cost.

## Building Community

Being part of the CL community can include supporting each other and sharing fears, emotions, knowledge and triumphs. For many it means mentoring the newly-diagnosed and/or loved ones and, for others, it means being mentored. However you choose to connect to the CL community, know that you are not alone and there are many hands reaching out to support you and your loved ones as you find your own way in the journey with CL.

*i About Cutaneous Lymphoma. Cutaneous Lymphoma Foundation Website. Available at: [http://www.clfoundation.org/CLF\\_Board\\_Nominations\\_Information.pdf](http://www.clfoundation.org/CLF_Board_Nominations_Information.pdf). Accessed on April 21, 2011.*

*ii Peer-to-peer Healthcare. Pew Internet & American Life Project Website. Available at: <http://www.pewinternet.org/Reports/2011/P2PHealthcare.aspx>. Accessed on April 20, 2011.*

*iii Patients Seek Moral and Medical Support Online. NPR Website. Available at: <http://www.npr.org/2011/03/03/134235469/More-Patients-Seeking-Medical-Support-Online>. Accessed on April 20, 2011.*

**WHATEVER SUPPORT MEANS TO YOU, we would love to know! We invite you to email us at [info@clfoundation.org](mailto:info@clfoundation.org) sharing a description of what the Cutaneous Lymphoma Foundation and our cutaneous lymphoma support community means to you. Please also submit a photo, too, if you are amenable as we have plans to publish some of the comments we receive in future newsletters.**



The Patient Resource Cancer Guides are free publications that were created to empower and prepare newly diagnosed and newly restaged cancer patients to become their own advocates. Now in its fourth year, this comprehensive resource helps these patients and their families map the cancer journey.

**To request your free copy visit [www.PatientResource.net](http://www.PatientResource.net) or call (816) 333-3595, ext. 26.**

## Welcome Susan Thornton

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Susan Thornton joined the Cutaneous Lymphoma Foundation in June 2011 as its new Management Consultant of Programs and Services. As a cutaneous lymphoma patient and longtime Foundation friend, Susan brings tremendous passion to her role as she combines those characteristics with her impressive professional experience, which includes 27 years of marketing and program management in the healthcare technology industry as well as serving on various non-profit boards including the Eastern Pennsylvania Chapter of The Leukemia & Lymphoma Society and Tristate Multisport Association.

As our new Management Consultant of Programs and Services, Susan will be working closely with our Foundation leaders and staff to plan, manage, implement, enhance and grow the many programs we offer at Foundation.

“It’s so exciting to have the opportunity to work directly for the Foundation. I feel so fortunate to be able to bring my years of healthcare marketing and program management experience to this position and share my own personal experience living with cutaneous lymphoma for 20+ years with fellow patients.”

Susan eagerly anticipates meeting many of you at our upcoming Patient Educational Forums and she looks forward to her work each day making sure that each person with cutaneous lymphoma gets the best care possible.

Susan invites you to be in touch with her via phone at 248.644.9014, ext. 3, or via email at [susan@clfoundation.org](mailto:susan@clfoundation.org).

## Needs Assessment Update

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A very special THANK YOU is extended to everyone who participated in our recent needs assessment, which surveyed patients, caregivers and medical professionals. We are excited to report that over 350 patients responded and many of the physicians, nurses and other medical professionals who care for our patients submitted needs assessment surveys, as well.

Please know how much we appreciate your input and, right now, we are reviewing your responses line by line, and we will be preparing a full report detailing outcomes from this assessment, which we expect to publish later this year.

In general, you have provided us with positive feedback about how valuable you feel the Foundation has been and continues to be in your life. However, you have identified some important areas for us to consider enhancing and improving including easier and expanded access to information, physicians, treatments, and programs.

After our needs assessment data has been analyzed, our team will use the data to improve the current programs and services that we provide based on the outcomes those we serve have identified as the most important to their quality of life.

And, last but not least, CONGRATULATIONS to the four patient winners of our Target gift cards, who were chosen randomly from both the online and paper surveys:

Patricia Gracalnoe, Victorville, CA  
Donna Griggs, Kings Mountain, NC

William Hollie, Naples, FL  
Gary Muzzelo, Northampton, PA

Thank you again to everyone who participated in our needs assessment. We look forward to staying in touch to share results of our needs assessment and to providing each participant with a post-assessment report once it is published.

## Help Us Go Green

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With your help, the Cutaneous Lymphoma Foundation can save thousands of dollars each year while also benefiting our environment through a reduction in paper usage.

**How can you help?** Visit [www.clfoundation.org](http://www.clfoundation.org) and look for the “**Help Us Go Green**” information on the home page to email us and let us know that you would like to begin receiving our printed newsletter, the Forum, electronically or simply send us an email at [info@clfoundation.org](mailto:info@clfoundation.org) with the subject line “**Go Green.**” Your next edition will then arrive in your email’s inbox instead of your mailbox.

## Itching For Answers: Pruritus in Cutaneous Lymphoma Patients, Continued

treatment is antihistamines, which counteract the reactions that occur when histamines are released in the skin, thereby blocking redness, swelling, and itchiness. For most pruritus sufferers, itching becomes noticeably greater just prior to falling asleep, so sedative antihistamines can be particularly effective.

Neurontin (gabapentin), marketed as an anticonvulsant for individuals prone to seizures, has been shown to be effective in treating pruritus. Gabapentin can relieve itching sensations by blocking the effect of specific neurotransmitters and subduing neuronal hyperexcitability.<sup>ii</sup>

Emend (aprepitant) is another prescription medication used for preventing chemotherapy-induced nausea and vomiting, shown to be effective in reducing pruritus. CTCL patients, particularly those with SS, have notably high levels of the neuropeptide “substance P.” Aprepitant works by blocking certain receptors in the brainstem including a substance P receptor, which is also linked to feelings of nausea. Although the research is fairly new, this drug has shown dramatic itch suppression in several severe cases of SS.<sup>iii</sup> There is no generic form of Emend, so insurance coverage may be an issue. Similarly, an antidepressant called Remeron (mirtazamine) has been shown in case studies to relieve pruritus.<sup>iv</sup>

Phototherapy is a viable first-line treatment option for patients with MF, especially those patients suffering with pruritus. One of the most effective phototherapy treatments is psoralen plus ultraviolet A (PUVA) which, when utilized in early stage MF, can yield significant improvement including long-lasting disease-free intervals. Narrow-band UVB phototherapy has also proven effective, when administered in thrice weekly sessions of UVB exposure until lesions regress. Common criticisms of phototherapy include a slow response time as well as increasing itch following the first treatments. Additionally, phototherapy has a low response rate for those with SS.

Topical steroids may be effective when used in conjunction with other treatment methods, but tend to be impractical in treating severe cases due to the large surface area. The most effective over-the-counter lotions for less severe cases are those that contain menthol, as its cooling properties can overpower the itching sensation. Much in the same way, applying an ice pack at the onset of an itch may temporarily suppress the discomfort. Be cautious of using analgesics, as they have been shown to aggravate itching episodes. Also, some relief has been reported through alternative methods, such as acupuncture and biofeedback.

To make the most out of whichever treatment method is selected by you and your doctor, good skin care is an important component. There are many simple and inexpensive strategies that can be used to minimize the discomfort caused by pruritus, such as taking a lukewarm shower rather than a steaming hot bath since high temperature water can wash off a layer of hydrating oils that develop naturally on skin. Additionally, washing with fragrance-free soap and applying fragrance-free moisturizing lotion or petroleum jelly, particularly when skin is still moist, can extend hydrating effects and result in reduced itch.

Based on this summary review, it is clear we have more work to do to better understand the root causes of CTCL-related pruritus. Based on the clinical research ongoing with various systemic, phototherapeutic and topical treatments, we are learning more every day. It is also encouraging to know that pruritus has been identified as a main area of focus by the US Cutaneous Lymphoma Consortium. In addition to frequent and specific communication with your medical team, you should visit the Cutaneous Lymphoma Foundation website ([www.clfoundation.org](http://www.clfoundation.org)) for more information about pruritus and CTCL.

<sup>i</sup> Demierre, M. (2010, September). *Mycosis fungoides and Sézary syndrome: the burden of pruritus*. *Community Oncology*, 7(9), 399-404.

<sup>ii</sup> *The Cutting Edge: Efficacy of Gabapentin in the Management of Pruritus of Unknown Origin*. American Medical Association Website. Available at: <http://archderm.ama-assn.org/cgi/reprint/141/12/1507.pdf>. Accessed on June 21, 2011.

<sup>iii</sup> Booken, N., Heck, M., Nicolay, J. P., Klemke, C. D., Goerdts, S., & Utikal, J. (2011, January 28). *Oral aprepitant in the therapy of refractory pruritus in erythrodermic cutaneous T-cell lymphoma*. *British Journal of Dermatology*, 164(3), 665-667.

<sup>iv</sup> *Clinical Note: Mirtazapine for Pruritus*. *Journal of Pain and Symptom Management Website*. Available at: <http://my.clevelandclinic.org/Documents/Services/Mirtazapine.pdf>. Accessed on June 21, 2011.

## Understanding Itch



**Ethan A. Lerner, MD/PhD** is an Associate Professor of Dermatology at Harvard Medical School. His research group at Massachusetts General Hospital in Boston is devoted to understanding the basic mechanisms of itch. He is grateful to the National Institutes of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) for support.

Most people with cutaneous T-cell lymphoma or CTCL have itching but few have been successful in finding relief from this symptom. Why aren't there good drugs available to relieve itch?

The reason is that remarkably little was known or investigated about the basic mechanisms that underlie itch until the past several years. The medical community may not have recognized the widespread nature and importance of the problem and the fascination that comes along with understanding itch. That is now changing rapidly. A brief overview of the past, present and future is presented here.

The sensation of itch begins when keratinocytes, a type of skin cell, and sensory nerves in the skin are stimulated and communicate with each other. The result is that a signal is transmitted along these nerves to what is essentially a way station just outside the spinal cord. At this way station, called the dorsal root ganglion, a signal is passed to another set of nerves that run from the spinal cord to the brain. The brain interprets the signal as the sensation of itch and tells you to scratch.

What stimulates the keratinocytes or nerves in the skin or spinal cord and what exactly is being stimulated on them? This is where there has been substantial progress in the past few years. Physicians and patients alike were long frustrated by the limited relief brought by anti-histamines. When histamine is injected into the skin, the sensation of itch ensues and a hive develops. But most itches are not associated with hives. Thus, something other than histamine must be causing itch.

It was only in 2008 that researchers found that there were two pathways in the skin that led to itch. One pathway depended on histamine while the other was independent of histamine. At the same time, our research group was studying the pods of a tropical plant known to cause intense itching but not hives. We identified a protein from the plant that was responsible for the itch. We went on to show that there was an equivalent protein in people. The human protein is called cathepsin S. Cathepsin S is a protease, meaning that it cuts other proteins. Cathepsin S was known to be involved in inflammation. Since proteases are good targets for drug development (all of the drugs for HIV are against viral proteases) and inflammation is important, drugs that target cathepsin S are under development. Maybe these will be useful for itch.

But where does cathepsin S come from?

T-cells, which are the tumor cell in CTCL, produce cytokines, similar to hormones. Certain cytokines induce keratinocytes to make cathepsin S. Keratinocytes also make several other proteases including ones called kallikreins. And what do these proteases have to do with itch? Well, they act on something called a receptor that is present on both keratinocytes and nerves. The particular receptor is called protease-activated receptor 2, or PAR2, and several years ago it was found that PAR2 is important in mediating itch. T-cells can also make a molecule called interleukin-31 or IL-31. IL-31 binds to its own receptor on keratinocytes and sensory nerves and appears to be important in atopic dermatitis, or eczema. The role of IL-31 in CTCL needs to be investigated.



The above is a snapshot of just some of the work happening in itch in the skin. Already there are drugs in development that target proteases and drugs that target IL-31. And what about the spinal cord? Exciting research in the past few years has uncovered a molecule and receptor in the spinal cord that are important to itch. The molecule is a small protein called gastrin-releasing peptide or GRP and its receptor is called the gastrin-releasing peptide receptor or GRPR. And where did GRP come from? It was first identified in the skin of frogs and called bombesin, but that's a story for another day.

## Empower Yourself With Comprehensive Medical Documentation

Empowered patients are those who become active members of their healthcare team. Obtaining and keeping copies of your medical records including images (X-rays, scans, CT, MRI) and lab results is good advice for any person receiving medical attention. For those who have chronic and/or rare conditions, it is even more crucial that these medical records are preserved. By keeping a copy of your records, you can reduce unnecessary duplication of tests and assist new physicians or specialists in seeing the full picture of your health.



One option for storing and transporting your records to and from appointments is to purchase an art portfolio holder. These carrying cases are usually sold in art supply stores and can easily accommodate large images and documents while providing privacy and protecting the items from the elements. Another idea is to keep electronic copies of this information (password-protected) on a thumb drive that you can easily take with you to appointments.

There are also pre-made cancer patient/survivor binders available. Live Strong ([www.livestrong.org](http://www.livestrong.org), 866-235-7205) provides a Survivorship Notebook that includes pre-defined tabs for organizing various types of information such as Health Journal, Medical Record Treatment Summary, Physical Topics, etc. Along with each chapter, there are forms you can fill out as well as instructions and useful information. The Survivorship Notebook is free to cancer patients and survivors.

Cancer101 ([www.Cancer101.org](http://www.Cancer101.org)) also provides a free Cancer Planner for patients and survivors (\$18 shipping charge). This is a three-ring binder with a large number of tabs to capture details of your cancer journey and treatments, which is incorporated into a clear portfolio that includes divided sections to hold documents.

Or, you can choose to create your own cancer journey binder. Be creative and have fun, but remember to also be practical and thorough. You can include photos, letters, and notes of encouragement as well as the medical-specific topics such as treatments, medical tests/results, summary of appointments/hospital stays, names/phone numbers of physicians/other clinicians, insurance information, calendar for appointments/scheduling, and perhaps even maps/local restaurants or areas of interest near the hospital or doctor's office that you enjoy.

Either way, it will benefit you in the long-run to have all your medical and pertinent personal information captured and stored all in one place so that it is easily accessible by you or your loved ones if you need it. Especially for patients with cutaneous lymphoma who are typically managing their disease over the course of many years where treatments change, physicians may change, too, so it is a very good idea to have your history handy so you can proactively manage your health.

If you join us at any of our upcoming Patient Educational Forums, you will have the opportunity to review the Live Strong and Cancer101 books so that you can take a look at them yourself before you decide if they meet your personal needs.

And, keep in touch to let us know what works! If something works well for you, it might help someone else. We are always interested in learning about what is helping our patients and sharing this information so please email us at [info@clfoundation.org](mailto:info@clfoundation.org) to share your thoughts anytime.

## 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.

## Young Investigator Award Presented at the Society for Investigative Dermatology's Annual Meeting



Judy Jones, CLF Founder and President Emeritus; Larisa Geskin, MD, University of Pittsburgh; Oleg Akilov, MD, University of Pittsburgh; and Jennifer Viano, CLF CEO.

The Society of Investigative Dermatology's Annual Meeting convened this year on May 4-8 in Phoenix, AZ. Many Cutaneous Lymphoma Foundation representatives attended the meeting including Stuart Lessin, MD, Member, Board of Directors and Chairperson, Medical Advisory Board; Pierluigi Porcu, MD, Member, Board of Directors; Judy Jones, Founder and President Emeritus; and Jennifer Viano, CEO.

On May 5 during the CTCL Symposium, co-sponsored by the Cutaneous Lymphoma Foundation and the International Society for Cutaneous Lymphomas, Jennifer Viano presented the Foundation's Young Investigator Award to Dr. Oleg Akilov, Research Instructor and Cutaneous Oncology Clinical Fellow at the University of Pittsburgh Medical Center's Department of Dermatology. Dr. Akilov was selected as this year's award recipient for his outstanding work related to a newly-discovered heat shock protein in mycosis fungoides (MF), which can serve as a new therapeutic target for immunotherapy in patients with tumor-stage MF.

The Cutaneous Lymphoma Foundation established the Young Investigator Award as part of its mission to promote awareness and education, advance patient care and facilitate research in cutaneous lymphoma. This annual award is given to new physicians and scientists in the field of cutaneous lymphoma to support travel to the SID Annual Meeting along with participation in the concurrent CTCL Symposium.

For more information about this Young Investigator Award and others that the Foundation may be establishing in the future, visit [www.clfoundation.org](http://www.clfoundation.org) or contact us at 248.644.9014 or [info@clfoundation.org](mailto:info@clfoundation.org).

## The Tax-Free IRA Charitable Gift Rollover Can Benefit You and the Cutaneous Lymphoma Foundation



**L**ate last year, President Obama signed a tax relief act which provided, among many other things, an extension of the IRA Charitable Rollover, which was great news for both charities and donors.

By utilizing the IRA Charitable Rollover, certain taxpayers may be able to help the Cutaneous Lymphoma Foundation and reduce their tax liability. The law provides that, for 2011, an individual who is at least 70 1/2 years old and owns a traditional IRA or Roth IRA may instruct their IRA trustee to distribute directly to a qualified charity, such as the Cutaneous Lymphoma Foundation, up to \$100,000 as a current gift.

While no charitable deduction is allowed, the gift is excluded from the donor's taxable income and it counts towards the IRA owner's mandatory annual required minimum distribution.

Please note that the IRA trustee must make the transfer to the charity; if the IRA owner withdraws the funds and then contributes to the charity, the gift will not qualify and the withdrawal will be taxed to the IRA owner. Also, the normal ceilings on contribution deductions do not apply to these IRA gifts.

This provision is a wonderful way to satisfy an IRA owner's minimum distribution requirement while also benefiting the Cutaneous Lymphoma Foundation. It may be particularly advantageous if the IRA owner doesn't need all the minimum distribution required to be withdrawn from the IRA or if the IRA owner would not be able to deduct all of his or her charitable gifts because of the deduction limitations.

Thank you for considering this opportunity for support of the Cutaneous Lymphoma Foundation. If you would like additional information about this or other ways to support the Foundation, please contact Jennifer Viano, CEO, at 248.644.9014, ext. 4.

***The above summary is provided for informational purposes only and is not intended to be legal, tax or investment advice. Please contact your attorney or financial advisor for counsel related to your personal circumstances.***

## One Voice Against Cancer

On May 23-24, 2011, Susan Thornton, cutaneous lymphoma patient and the Foundation's new Management Consultant for Programs and Services, participated in the One Voice Against Cancer (OVAC) Lobby Day in Washington, DC.

OVAC is the nation's largest coalition of organizations advocating against cancer and OVAC Lobby Day is one of the largest cancer advocacy events on Capitol Hill. The Foundation was invited to join through its partnership with the American Academy of Dermatology and, during this event, 40 cancer organizations descend on Capitol Hill to send one cohesive message to Congress about the importance of federal funding for cancer research and prevention programs.

During her visit, Susan met with many legislative staff members including those for Senators Bob Casey and Pat Toomey to advocate for the five areas of focus discussed during OVAC visits:

1. Support funding for the National Institutes of Health (NIH), National Cancer Institute and National Institute on Minority Health and Health Disparities.
2. Support funding for the Centers for Disease Control (CDC) cancer programs and keep these programs intact while other chronic disease programs are potentially reorganized.
3. Support funding for the Health Resources and Services Administration patient navigator program to help cancer patients navigate the health care system and overcome barriers to access cancer care.
4. Support funding for the Food and Drug Administration (FDA) to further integrate cutting-edge science that will streamline the translation of cancer research from early-stage discovery to clinical application.
5. Support funding for the Caroline Price Walker Conquer Childhood Cancer Act.

Because the economic climate is poor, OVAC members' visits were of particular importance as many line items in the federal budget that help cancer patients may be decreased including funding of research at the NIH, funding of cancer prevention efforts at the CDC and funding of cancer drug approvals through the FDA.

In meetings with the legislative staff members, Susan was able to heighten awareness for the Cutaneous Lymphoma Foundation, discuss the burden of cutaneous lymphomas on people suffering with its debilitating effects, and encourage continued and increased financial support for federal programs that can help those affected by cutaneous lymphoma.



*Susan Thornton in front of the U.S. Capitol.*

## Music Moves Me Run Raises Awareness and Funding for Cutaneous Lymphoma

Several hundred runners participated in the Third Annual Music Moves Me Run held on May 14, 2011 in Huntsville, AL, an exciting event organized by the Leroy Jefferson Williams, Jr. Foundation, Inc., a nonprofit organization founded in 2008 to continue the legacy of the late Leroy Williams, Jr., who passed away due to complications of cutaneous T-cell lymphoma.



A portion of the proceeds from this event benefit the Cutaneous Lymphoma Foundation. A very special thank you is extended to Mr. Ellery Williams and all event supporters and participants for their support of this event.

This one-of-a-kind race includes live music at key sites on the course, motivating participants to keep going. Local bands entertain racers and observers alike. Organizers are already planning the 2012 race so stay tuned to our website, newsletter and e-newsletter for details on how you can register for next year's Music Moves Me Run!

TIME SENSITIVE MATERIALS ENCLOSED

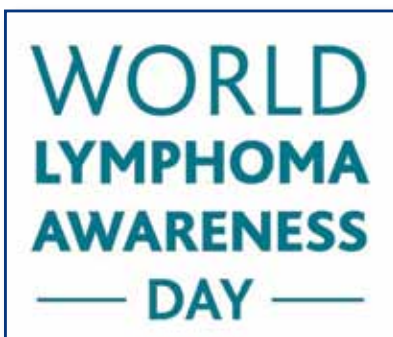
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## World Lymphoma Awareness Day

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World Lymphoma Awareness Day (WLAD) is held on September 15 every year and is a day dedicated to raising awareness of lymphoma, an increasingly common form of cancer. It is a global initiative hosted by the Lymphoma Coalition, a non-profit network organisation of 50 lymphoma patient organisations from 37 countries around the world.

Why have WLAD?

Lymphomas do not have a known cause and they are very complex as there are over 40 sub-types. Over one million people worldwide live with lymphoma and nearly 1,000 people are diagnosed with the disease every day, but there continues to be very little awareness of the signs and symptoms of lymphoma. For more information on WLAD, please visit the Lymphoma Coalition's website at [www.lymphomacoalition.org](http://www.lymphomacoalition.org).



*Making sure each person with cutaneous lymphoma gets the best care possible*

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