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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.

## Obtaining a Proper Cutaneous Lymphoma Diagnosis: It's More Than Skin Deep

### Steven Horwitz, MD



**Steven Horwitz** is an Attending Physician in the Department of Medicine at Memorial Sloan-Kettering Cancer Center in New York City. He grew up in Cleveland, Ohio and earned his medical degree at Case Western Reserve. Dr. Horwitz

completed an internship and residency in internal medicine at the University of Rochester/Strong Memorial Hospital in Rochester, New York and then completed a fellowship in medical oncology at Stanford University Medical Center. Dr. Horwitz has a clinical research focus in non-Hodgkin lymphomas, in particular many of the more rare lymphomas such as T-cell lymphomas and lymphomas of the skin.

### Challenges of an Uncommon Disease

Uncommon diseases pose a number of challenges, one of which is the difficulty patients and physicians face in reaching a proper diagnosis. Cutaneous lymphomas (CL) or "skin lymphomas" are a group of uncommon diseases that encompass various disorders with different signs, symptoms and treatment considerations. The most common type of skin lymphoma is cutaneous T-cell lymphoma or CTCL. In the United States, there are about 2,000 to 3,000 new cases per year.<sup>ii</sup> A less common form of skin lymphoma is primary cutaneous B-cell lymphoma<sup>i</sup>; however, both types require equal consideration and physician attention in order to reach a proper diagnosis. A definitive diagnosis will help inform treatment decisions and potentially yield better patient-related outcomes over time.

### Building a Case for Proper Diagnosis

One of the key concepts for patients and their caregivers to understand is that a

clear diagnosis may take time. The best approach is for patients to collaborate and work with their physicians to confirm what disease they have. In milder cases of CL, ruling out non-cancerous reactive processes resulting from medication, external environmental exposure, or inflammatory conditions of the skin is crucial. From there, physicians and patients can determine the appropriate next steps in care, treatment and medication regimen. With a number of different CL types and subtypes, building a case for diagnosis based on multiple elements is vital. Assessment of a patient's symptoms coupled with their history of skin lesions and consistent biopsies are all critical components that help build a patient's individual case and accelerate the diagnostic process.

### Assessing Skin Lesions

By definition, all CLs present skin-related symptoms, the most common of which are skin lesions. When a patient presents with skin lesions, their physician will work to differentiate whether the lesions are the result of a reactive process versus a lymphoma of the skin. A reactive process, which can include the body's response to a bug bite, allergic reaction to medication, or other inflammatory processes of the skin such as eczema or psoriasis, is the gathering of immune system cells, often non-cancerous "T-cell lymphocytes" in the skin to defend against and fight off invading entities; sometimes reactive processes occur for reasons we do not understand. In contrast, skin lymphomas are cancerous proliferations or an excess of malignant T-cell lymphocytes growing

## From the President



**Judy Jones**

As I write this, I am at the World Congress of Dermatology (WCD) in Seoul, Korea during a break between educational sessions. The WCD is the most widely recognized international dermatology gathering and is held every four years. There are 127 member societies from around the globe participating.

The day before the WCD, the International Society of Cutaneous Lymphomas (ISCL) had their annual meeting. Presentations included updates from the related organizations (including the Cutaneous Lymphoma Foundation) and highlights from key scientific meetings.

It is exciting to see that information from around the world is being shared about cutaneous lymphomas. So often, we patients feel there is nobody paying attention to our rare disease, but that is not the case. There are clinical trials and research projects being conducted and information shared to increase the body of knowledge leading to additional research. This results in improved treatments and methods of treating patients.

During the past 13 years, I have seen tremendous growth in the cutaneous lymphoma field. I have also watched the Cutaneous Lymphoma Foundation play a part in this growth. I have worked with a dedicated Board of Directors and two amazing hard-working staff members—Holly Priebe and Amanda Kik— in this growth. This past year we hired a new CEO, Program Director and are adding additional Board members to keep up with this growth. The Foundation has lots of exciting new plans and programs that are getting underway. Funding research has been one of my priorities and we will be determining our research agenda in the next couple of months.

I have lived with CTCL for 21 years and celebrated my 70th birthday this month. It's time for me to step back and watch them move the Foundation forward to an even greater level of influence in this field. I will be retiring from the Foundation the end of June. I have enjoyed working with some of the most dedicated, caring physicians in the world and will never forget the support I have received from patients, sharing a common disease.

## From the Chief Executive Officer



**Jennifer Viano**

Spring is a truly exciting time at the Cutaneous Lymphoma Foundation. We are doing more than ever before to help patients and others affected by cutaneous lymphoma, and we are so grateful to all of our supporters for making our work possible.

In 2011, we are very pleased to be holding eight Patient Educational Forums across the country, and I know that many of you have already been able to take advantage of attending one of our Forums. In addition to these Forums, we continue to offer many more programs including educational events and teleconferences in partnership with CancerCare and the Lymphoma Research Foundation; our website; printed and electronic newsletters; Foundation representatives available for information and support via phone and email; and much more.

Going forward, we have plans to continue enhancing and expanding all that we do to serve our patients, caregivers and the medical professionals who care for our patients. Patient education and support is truly at the heart of our mission. Each day, through our programs and services, we look forward to helping patients diagnosed with cutaneous lymphoma improve their quality of life and achieve positive outcomes through the resources available at the Foundation.

One of the most important outcomes for any patient is a proper diagnosis, which is why we are focusing on this topic with our feature article "Obtaining a Proper Diagnosis," which has been expertly written by Dr. Steven Horwitz. We at the Foundation extend our most enthusiastic thanks to Dr. Horwitz for contributing this article to our spring newsletter.

Throughout this newsletter we have included articles that we hope arm you with more knowledge about cutaneous lymphoma to help educate and empower you, and we have included articles that we also hope will help you feel more connected to others who share in your journey. You are not alone and, although cutaneous lymphoma is a rare disease, people affected by this disease are walking down a path with thousands of other caring, compassionate people who are bonded with something in common – they all want to do something about cutaneous lymphoma, which is very powerful. We at the Cutaneous Lymphoma Foundation are very excited about being a place where people can mobilize their talents to affect positive change, and we welcome you to contact us anytime to let us know what you may be inspired to become involved with at the Foundation.

In closing, I thank you for being a partner to us in our mission, and I hope to meet many of you at our upcoming Patient Educational Forums.

# Forum

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MEDICAL EDITOR  
Stuart Lessin, M.D.

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## Glossary of Diagnosis and Staging Terms

**Atypical Cells:** Cells with a cancer-like appearance. Term often used to describe CTCL cells.

**CD4:CD8 Ratio:** A measure of two groups of T-lymphocytes (T-cells), determined by monoclonal antibody staining of the CD4 and CD8 proteins on the surface of T-cells. Both CD4 (helper) T-cells and CD8 (suppressor) T-cells work together in the immune system and the CD4:CD8 ratio is a general measure of the status of the immune system. Since CTCL cells are CD4 T-cells, an increased CD4:CD8 ratio can be a marker of CTCL.

**Flow Cytometry:** Laser-based method to detect monoclonal antibody staining of blood cells. Used for immunophenotyping blood in CTCL.

**Gene Rearrangement Analysis:** Molecular testing of DNA for detecting clonal populations of lymphocytes within blood or tissues.

**Immunophenotyping:** Testing with the use of monoclonal antibodies to identify and characterize the proteins on the surface of CTCL cells. Used for diagnosis, staging and monitoring response to treatments.

**PET Scan (Positron Emission Tomography):** Imaging test capable of visualizing metabolically active cells – providing a very sensitive detection of cancer cells. A PET scan can be combined with a CT (Computerized Axial Tomography) scan and provide three dimensional localization of tumors.

**TNM Classification:** A cancer staging system. T stands for tumor, N stands for lymph nodes, and M stands for metastasis. The TNM system scores and categorizes the amount of cancer found at the local site of a tumor origin, regional spread into lymph nodes and distant spread (metastasis) into internal organs.

**Tumor Burden:** A term used to describe the amount of cancer present in skin, lymph nodes, blood and internal organs. Tumor burden correlates with stage.

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

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## 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 15: Pittsburgh

14th Annual Brian V. Jegasothy Support Group for CTCL



### September 14: Teleconference

Part I: Update on Cutaneous T-Cell Lymphoma

In Collaboration with CancerCare and the Lymphoma Research Foundation



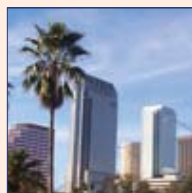
### October 29: Minneapolis

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 12: 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



### October 12: Teleconference

Part II: Update on Peripheral T-Cell Lymphoma

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



### Marlene Klotz

Boca Raton, FL

**M**y story is pretty much like all the others.

Even a top-flight dermatologist in New York told me that my skin condition was due to using strong detergents or taking very hot

showers. Rather than send me for a second opinion, she kept prescribing cortisone creams that made no difference at all.

One day, I jumped into the swimming pool at my home in Florida to cool off. Later on, when I undressed to shower, I was surprised to see that the skin across my backside looked red hot, as if someone had taken an iron and pressed it against my skin.

At first I thought about waiting until my husband and I went back to New York to see my dermatologist, but I decided that perhaps I would just see any old doctor in the neighborhood because it was more convenient.

I chose a dermatologist from the yellow pages. His advertisement made me laugh. It said, "I cure hard-to-cure rashes." Whew! One phone call, and I was in his office two days later. However, that's when the laughter stopped. Dr. Buchbinder checked my rash and proceeded to do several biopsies. The burning and itching that followed the biopsies lasted for several days, and the area was quite sore.

Several days later, Dr. Buchbinder called me and said that the biopsies revealed a diagnosis of cutaneous T-cell lymphoma (CTCL). Of course, hearing the word lymphoma made me think of everything under the sun, so to speak. I went back to his office, thanked him, and then carefully folded the lab reports into a compartment of my handbag for later use.

The minute I returned home, I immediately picked up the phone and started making long distance calls to my primary care physician in Manhattan. After leaving Florida for New York, I visited my internist, and he then sent me to a hematologist/oncologist to double-check the biopsies and blood work. My poor internist explained that he never had a patient with CTCL and, so, he apologized for letting me slip through the cracks. I was not at all annoyed. He was sincere and truthful.

After visiting my internist's office, I made contact with Memorial Sloan Kettering, getting in touch with the department familiar with treating CTCL. There I was prescribed nitrogen mustard, which caused an allergic reaction that resulted in severe itching on one area of my skin. The itch almost drove me batty.

As luck would have it, I noticed that Dr. David Ramsay, a top CTCL specialist, was listed as a scientific advisor on one of Memorial Sloan Kettering's brochures.\* I was thrilled to see that his office was in the same building where I had my prescription for nitrogen mustard filled.

Dr. Ramsay became my saving grace from the moment I met him. He decided upon a course of treatment for me that began with narrow band (light box) treatments three times per week. A few months later, I am happy to report that I went into remission, and this is my present condition.

Dr. Ramsay, whom I visit a couple of times per year, says that I will have maintenance treatments for the rest of my life, but that I will die with CTCL and not from it! We have many interesting conversations during each visit, and my trust in him is so great that I never question his advice.

In many ways, I feel blessed to have responded to my treatment without major problems. I feel much empathy for fellow patients who have such troublesome issues with this complex form of cancer.

Throughout my journey with CTCL, it has been a comfort to me to have the Cutaneous Lymphoma Foundation as a resource. The Foundation is a place that I have often turned to for information and support, and I believe that one of its most valuable offerings is the CTCL-MF Online Support Group (listserv). The listserv allows us to express our concerns with others who are in a position to understand. As a positive thinker, I think that perhaps one positive aspect that comes with having CTCL has been finding so many people who are caring individuals such as those who participate on the listserv. If you are a patient or a caregiver, I definitely encourage you to join the listserv.

A wise man once said, "We read to remind us that we are not alone." I hope that reading my story has helped to make you feel that you are not alone in your journey with CTCL. We are all traveling down this path together.

*\*Dr. Ramsay is now at the New York University School of Medicine.*

## Recent Patient Educational Forum Highlights

The Cutaneous Lymphoma Foundation recently held three very successful Patient Educational Forums in Los Angeles, CA, Atlanta, GA, and Washington, DC.

Each forum provided patients and their caregivers with exceptional opportunities to receive accurate information about cutaneous lymphoma, learn about treatment options available at different stages, access experts in the field, and connect with other people who are experiencing similar symptoms and quality of life concerns.

### Los Angeles, CA

On Saturday, January 15, 2011, we partnered with the UCLA Health System to hold a Patient Educational Forum at the UCLA Tom Bradley International Hall in Los Angeles, CA.

This forum welcomed over 60 participants and featured expert physician and patient support speakers including **Melvin Chiu, M.D.**, Assistant Clinical Professor of Dermatology and Director of the UCLA Psoriasis and Phototherapy Center; **Georgia and Steve Froberg**, Caregiver and Patient Speakers; **Judy Jones**, President, Cutaneous Lymphoma Foundation; and **Lauren Pinter-Brown, M.D., F.A.C.P.**, Director, UCLA Lymphoma Program and Clinical Professor of Medicine, Director, Geffen School of Medicine at UCLA.

### Atlanta, GA

On Saturday, February 19, 2011, we partnered with the Winship Cancer Institute at Emory University to hold a Patient Educational Forum at the Hilton Garden Inn in Atlanta, GA.

This forum welcomed over 50 participants and featured expert physician and patient support speakers including **Yolanda Cheatham**, Patient Speaker; **Natia Esiashvili, M.D.**, Assistant Professor, Department of Radiation Oncology, Winship Cancer Institute at Emory University; **Judy Jones**, President, Cutaneous Lymphoma Foundation; **Mary Jo Lechowicz, M.D.**, Assistant Professor of Hematology and Medical Oncology, Winship Cancer Institute at Emory University; and **Sareeta Parker, M.D.**, Associate Professor of Dermatology, Co-Director of Dermatology, Clinical and Outcomes Research Unit, Chief of Grady Dermatology, Winship Cancer Institute at Emory University.

### Washington, DC

On Saturday, April 9, 2011, we partnered with the Washington Cancer Institute at the Washington Hospital Center to hold a Patient Educational Forum at the Doubletree Hilton in Washington, DC.

This forum welcomed approximately 70 participants and featured expert physician and patient support speakers including **David Lamb**, Patient Speaker, Journalist and Author; **Stuart R. Lessin, M.D.**, Professor Emeritus, Fox Chase Cancer Center; **Lynn McKinley-Grant, M.D.**, Director of Cutaneous Lymphoma Clinic, Washington Cancer Institute, Washington, Hospital Center and Associate Professor, Georgetown University, Department of Medicine, Division of Dermatology; **Lauren Pinter-Brown, M.D., F.A.C.P.**, Director, UCLA Lymphoma Program and Clinical Professor of Medicine, Director, Geffen School of Medicine at UCLA; **Sandra Swain, M.D.**, Medical Director, Washington Cancer Institute, Washington Hospital Center, 2012 President, American Society of Clinical Oncology; and **Jennifer A. Viano**, Chief Executive Officer, Cutaneous Lymphoma Foundation.



David Lamb speaks passionately about his experience with cutaneous lymphoma at the DC forum



Dr. Lynn McKinley-Grant presents to guests at the DC forum



Dr. Lynn McKinley-Grant, Dr. Stuart Lessin and Dr. Lauren Pinter-Brown participate in a Q & A panel at the DC forum



Guests at the DC forum enjoy reading Foundation materials

## Recent Patient Educational Forum Highlights, Continued

Following are some comments we received from evaluations filled out by our Forum attendees:

"I most enjoyed meeting other people with this disease. The speakers were very good."

"I learned that cutaneous lymphoma is rare and hard to diagnose and that many people had gone to several doctors before being diagnosed. This was important information for me since I've been going through this for four and a half years, living with uncertainty, and not knowing what to do next. Now, after attending the conference, I know that this is a common problem, and I now have doctors' names who understand this disease. I now feel that I have what I need to take the next step."

"I enjoyed feeling the support behind the fight against this disease and also learning about the updates and advances in treatments."

"The event was informative and every minute of the time scheduled was utilized. Thanks!"

*The Cutaneous Lymphoma Foundation extends its sincere thanks and gratitude to the UCLA Health System, the Winship Cancer Institute at Emory University and the Washington Cancer Institute at the Washington Hospital Center, and to all of our Patient Educational Forum supporters for helping us bring these vital educational opportunities to our patients and their caregivers.*



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## Exploratory Pilot Study of Brentuximab Vedotin (SGN-35)

Dr. Youn Kim of the Stanford Cancer Center is leading an investigator-initiated study along with Memorial-Sloan Kettering Cancer Center, exploring the clinical efficacy of SGN-35 in mycosis fungoides and Sézary syndrome. Developed by Seattle Genetics Inc, SGN-35 is a novel antibody-drug-conjugate. Prior studies of SGN-35 in patients with Hodgkin disease and anaplastic large cell lymphoma have demonstrated promising results.

This exploratory study seeks to treat patients with mycosis fungoides and Sézary syndrome who have not responded after at least one standard systemic therapy. The goal of this study is to explore the clinical activity of SGN-35 in patients with mycosis fungoides and Sézary syndrome. Patients will receive the investigational medication by infusion every 3 weeks (1 cycle). Each patient will be treated for 6 cycles, and depending on clinical response at that time, may be treated for an additional 6 cycles in an effort to obtain the best clinical response.



**For more information, contact Katherine Sutherland, PA-C, Stanford Multidisciplinary Cutaneous Lymphoma Group, [kcs@stanford.edu](mailto:kcs@stanford.edu), (650) 421-3419.**

## Mustargen® Shortage Update

Lundbeck, manufacturer of Nitrogen Mustard (Mustargen®), is currently working closely with the U.S. Food and Drug Administration to gain approval of the transfer of production of Mustargen to a new manufacturing site after the company's previous contractor discontinued commercial manufacturing of the product.

Lundbeck is doing everything it can to minimize this disruption in supply and expects Mustargen® to be available again during the second half of 2011. Additional updates will be provided as they become available.

## Cutaneous Lymphoma Foundation Attendance at Medical Meetings

At the Cutaneous Lymphoma Foundation, an important part of fulfilling our mission includes participation in medical meetings relevant to the cutaneous lymphoma community. Our participation in these meetings allows us to achieve many objectives including educating the medical community about cutaneous lymphoma and the resources available at the Cutaneous Lymphoma Foundation.

Following are meetings recently attended by Foundation representatives:

- **American Society of Hematology Annual Meeting, December 2010**
- **T-Cell Lymphoma Forum, January 2011**
- **American Academy of Dermatology Annual Meeting, February 2011**
- **Dermatology Nurses Association Annual Meeting, March 2011**



### 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.



## My Personal Journey With Cutaneous Lymphoma



*Cathy, far back with hat, with friends on the North Rim heading down into the Grand Canyon*

**Cathy Cheshier**  
Glendale, AZ

“Sit here” the nurse said as she pointed to a chair against the wall next to the laboratory sink.

My daughter, who was with me, found another chair in the small room, sat down and tried to

get comfortable. The nurse looked over my file, took my blood pressure and began to ask me routine questions, like “How are you doing?” She was kind, but I was ready to get on with why I was there.

I found myself nodding in response to the nurse as a matter of routine. I now knew all the answers to her questions. I had experience. Lately I had seen several doctors trying to find an answer for a series of health issues. I was now seeing a hematologist/oncologist because I had a high platelet count and, during the course of questioning, I mentioned: “Oh, by the way, I have this rash on my, well – my derriere!”

Surprised at this, the doctor asked to see it. I shyly pulled down the corner of my pants to reveal a bright red, scaly patch and added: “Would you like to see another one that makes a matching pair?”

It was his intense look at my matching pair that made me sense that these two red patches I had always thought were eczema might not be eczema after all. He left the room and came back a few minutes later to say that he had made a call to a dermatologist who would be calling me to make an appointment for a biopsy. Within five minutes my phone rang. I was both delighted to know that I had found a really good doctor who followed through and alarmed that the doctor’s office was calling so quickly.

Very soon after the diagnosis of cutaneous T-cell lymphoma (CTCL), I found myself falling into a ‘pity party’ made up of one: me! I researched CTCL and didn’t focus on things like it’s indolent, and there’s only a 10% chance of advancement. Rather, I focused on the fact that I had cancer and that it is not curable. I wanted to stay in my pity party.

However, through my research, I found the Cutaneous Lymphoma Foundation and learned about an educational

forum being held in Scottsdale, AZ. I could not believe my good fortune. I attended the forum, not knowing just how good it would turn out to be. I found solace and comfort there and, importantly, I found others who were experiencing similar circumstances. I asked questions and, although I did not fully understand the answers, I was learning. I found this experience to be one of the most valuable in my journey as I learned more than I could possibly have gathered on my own. And, I found a new doctor! Dr. Clara Curiel was the specialist speaking at the forum, and she made such an impression on me that I quickly made an appointment with her (even though she practices in Tucson, which is 125 miles away from where I live).

Through the Foundation’s website I joined the CTCL-MF listserv and, through it, I learn a great deal from posts by many other diagnosed people worldwide who are experiencing many of the same feelings and symptoms that I am experiencing. I read it faithfully every day.

With a desire to feel better and get out of my pity party concerning my diagnosis with CTCL, I actually began to feel adventurous and decided to take up hiking again – something I used to love to do. So, I called up my girlfriend hiker, and we began hiking regularly.

Beginning to be consistent with my hikes, it was not good enough that I just hiked – no, I needed a goal. So, my first goal, which was in year two of my diagnosis, was to hike Havasupai Falls on the western end of the Grand Canyon – a 10 mile hike in and a 10 mile hike out. What a beautiful and wonderful experience. Well worth the hike.

Now, with this goal behind me, and looking ahead, I needed something new to spur me on. So, my girlfriend and I decided we would hike from the North Rim to the South Rim of the Grand Canyon. We decided to break up the hike in a three-night stay at camping sites within the canyon including one night at Phantom Ranch. Excitedly, I made the reservations one year in advance in September 2009 to accomplish the hike in September 2010. This would put me in year three of diagnosis and within weeks of my 60th birthday! I would have a year to train.

Finally, it was September 7, 2010: D-Day. Four ladies left Phoenix for the adventure of a lifetime. Our average age was 62 and we received great joy out of sharing this fact with anybody who said to us: “You are doing what?” We spent the

*“My Personal Journey...” – Continued on Page 10*

## My Personal Journey With Cutaneous Lymphoma, Continued

first night on the North Rim and early the next morning started our ascent into the incredibly expansive Grand Canyon, each of us carrying a pack that weighed an average of 28 lbs. Four days later we ascended out of the Canyon to the South Rim – in good shape, too, except for a few bandaged toes and lots of exhaustion. We did it!

That experience was the most grueling and difficult physical endeavor of my life but, without a doubt, one of the most gratifying, too.

Bouts of pity still crop up especially when I see my 'cheeks' in the mirror, or now seeing new larger areas on my neck and chest. To know that this is cancer is discouraging. I have decided, however, through my faith in a Creator bigger than me, that I can choose what to think on and so I have made a decision to dwell on what is good and trustworthy and live my life fully alive. John Eldredge, noted author says, "Don't ask yourself what the world needs. Ask yourself what makes you come alive and go do that because what the world needs is people who have come alive."

I choose to live, and I hope you are choosing to live, too!



### Welcome New Board Member Dr. Pierluigi Porcu

The Cutaneous Lymphoma Foundation is very pleased to announce that Dr. Pierluigi Porcu, Associate Professor of Internal Medicine, Division of Hematology, Ohio State University Comprehensive Cancer Center (OSUCCC), has joined our Board of Directors. At the OSUCCC, Dr. Porcu is co-leader of the Cutaneous Lymphoma Program and a member of the Viral Oncology Group of the OSUCCC where he conducts clinical and translational research in lymphoma.

Dr. Porcu has worked extensively in the field of cancer and lymphoma education participating in many of our Foundation's past Patient Educational Forums along with serving as a Chair of our Cutaneous Lymphoma Summit held in October 2009. In addition, Dr. Porcu is a member of the Foundation's Medical Advisory Board.

Dr. Porcu is married to Rosanna and they have four children, Sebastiano, Agata, Matilde and Beatrice. Recreationally, Dr. Porcu is an avid biker and has participated in Pelotonia, a grass-roots, community-supported bike ride in southern Ohio that raises funds to support cancer research at the OSUCCC. Dr. Porcu's team, Team CTCL, has raised approximately \$25,000 in the past two years.

## Help Us Go Green



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 quarterly 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.

## Obtaining a Proper Cutaneous Lymphoma Diagnosis: It's More Than Skin Deep, Continued

within the skin. Since reactive processes and other types of inflammation can trigger symptoms similar to those of CLs, a physician's expertise in conjunction with testing will help make the critical differentiation between the two. In some cases, test results may not be conclusive, which means they cannot clearly differentiate between a skin lymphoma versus reactive process. When a diagnosis is not definitive, the patient should discuss options with their physician. Certain patients may wish or receive the recommendation to seek relief from symptoms by starting a non-lymphoma specific treatment such as a topical lotion, steroid cream or ointment, or even ultraviolet light therapy. Others may prefer or obtain a recommendation to have the physician take additional biopsies of the skin lesion to try to yield more conclusive results. However, to conduct an effective biopsy, the patient will need to be off topical steroids and ultraviolet light treatment regimens. While these treatments may provide temporary symptom relief, they can also mask potential symptoms of skin lymphomas and thus delay a patient's definitive diagnosis.

### The Role of Consistent Biopsies

Consistent biopsies over time are an integral step in obtaining a proper diagnosis. A biopsy is a simple outpatient procedure that involves removing a small sample of tissue from the skin for examination. When a biopsy is performed, local anesthetic is given prior to the procedure. Following the procedure, the skin is sewn together with a couple of stitches, leaving a very small, almost invisible, scar. A patient's doctor, in conjunction with a pathologist, who is an expert in reading biopsy results, will work together to render the proper diagnosis. The pathologist analyzes the biological tissue and reviews all test results. Typically, the presence of an excess number of certain kinds of T-lymphocyte cells that are arranged in certain patterns within the biological tissue often gives strong clues or indicates to the pathologist that a patient has a skin lymphoma. A definitive diagnosis cannot be obtained without a biopsy and multiple biopsies are necessary to confirm the presence of excess T-lymphocyte cells and these consistent patterns.

### Patients and Caregivers Working Together to Fight Cutaneous Lymphoma

CL is sometimes a progressive and most often an incurable disease. In certain cases, the disease may be mild and, even without strong treatment, may not progress over time, which is why it's imperative to find a balance between knowing what a patient has and seeking treatment. A clear diagnosis may take time, so patients and their caregivers will require patience and persistence. Accuracy in determining whether a patient has CL, and which subset of CL, is paramount in determining the best course of care and treatment. A premature diagnosis could expose the patient to insufficient or unnecessary medication regimens. Organizations like the Cutaneous Lymphoma Foundation can help patients collaborate with their physicians and offer guidance on how to best engage in open communication. If a patient is ever dissatisfied with their diagnosis, they should seek a second opinion, conduct research and visit a cancer center that sees a high volume of CL patients. With or without a clear diagnosis, patients should remain under the care of an experienced physician they trust to foster understanding of their disease, diminish frustrations and ensure the road to diagnosis is as manageable as possible.

i Cutaneous T-Cell Lymphoma. The Leukemia & Lymphoma Society Website. Available at: [http://www.leukemia-lymphoma.org/attachments/National/br\\_1163608564.pdf](http://www.leukemia-lymphoma.org/attachments/National/br_1163608564.pdf). Accessed on February 21, 2011. ii Criscione, V. D. et al. Arch Dermatol 2007;143:854-859.



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### Cutaneous Lymphoma Awareness Increased in USA Today Supplement

The Cutaneous Lymphoma Foundation placed an advertisement in a "Healthy Skin" supplement that was featured in a March 2011 edition of USA Today (see below). This ad reached approximately 1.1 million readers in the targeted markets of New York, Chicago, Los Angeles and Northern Florida.

Judy Jones, President of the Cutaneous Lymphoma Foundation and President of the Coalition of Skin Diseases, authored a comprehensive overview on skin disease that appeared on page two of the supplement. The Foundation's ad - along with many other ads placed by patient advocacy organizations that help people affected by skin disease - appeared on page three of the supplement. Please visit [www.clfoundation.org](http://www.clfoundation.org) to view the entire supplement including Judy's article on skin disease.



**Skin disease** is more prevalent than anyone ever imagined and carries with it serious medical consequences.

Let your skin reflect the beauty within you

At any given time, one in every three people in the United States suffers from a skin disease. The American Academy of Dermatology Association and the Society for Investigative Dermatology commissioned a study by the Lewin Group to quantify the burden of skin disease. This study shows that skin disease is more prevalent than anyone ever imagined—and carries serious medical and financial consequences. This study analyzed 22 skin diseases (prescription drugs, hospital and doctor visits, nursing care and over the counter products) and over the counter products) and found that the direct costs totaled \$2.4 billion. The total indirect costs associated with lost productivity of not being able to work and taking time for doctors' visits totaled \$10.2 billion. Cost is not the only issue with

skin diseases. Since most skin diseases are visible, there are psychological issues that may severely affect quality of life. Picture the adolescent that has severe acne, the young man who no longer feels comfortable going to the gym to work out because of skin rashes, the child who has deformities and others that have chronic blistering or are unable to sweat. This supplement highlights a few of the more common skin diseases: rosacea, eczema and skin cancer, as well as the importance of loving the skin you're in. There are thousands of other skin diseases, some that are relatively easy to treat and curable. Some are rare, have few treatment options and patients will live with them their entire life.

"Picture the adolescent that has severe acne, the young man who no longer feels comfortable going to the gym, the child that has deformities ..."



**You're not alone**  
Many patients with skin disease may think they are the on-

ly ones affected and feel very alone if they don't know anyone else with their disease. There is support available in many different ways through patient advocacy groups. Many of the members of the Coalition of Skin Diseases have patient education meetings, online support groups and disease specific information on their websites. Educating yourself will give you more information about treatments available and suggestions about living with your disease. Their websites will give you additional resources that may be helpful. The Coalition of Skin Diseases (CSD) is a voluntary coalition of patient advocacy groups addressing the needs and concerns of millions of people whose lives are affected by skin disease. For a list of members of the Coalition of Skin Diseases and how to contact them for more information, go to [www.coalitionofskindiseases.org](http://www.coalitionofskindiseases.org).

AN INDEPENDENT SUPPLEMENT BY MEDIAPLANET TO USA TODAY  
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**Cutaneous Lymphoma Foundation**  
Do you have a persistent rash or abnormal skin lesions? Cutaneous T-cell lymphoma (CTCL) is a rare and treatable form of blood cancer that typically presents first as a rash, lesion or plaque on the skin. Since 1998, the Cutaneous Lymphoma Foundation has been helping patients, caregivers and physicians improve CTCL diagnosis and treatment while offering a wide range of programs, support and resources. A stubborn skin irritation may turn out to be CTCL. Visit [www.clfoundation.org](http://www.clfoundation.org) and talk to your doctor to learn more about CTCL, its symptoms and how to get help.  
[www.clfoundation.org](http://www.clfoundation.org) • 248.644.9014