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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.

Cutaneous T-Cell Lymphoma: A Dermatologist's Perspective

Daniel J. Aires, M.D., J.D.



Daniel J. Aires, M.D., J.D. is Director, Division of Dermatology, at the University of Kansas Medical School.

As a dermatologist, I was trained to identify cutaneous T-cell lymphoma (CTCL) but never expected to make this area a major focus. My interest in CTCL really started when I diagnosed my father's CTCL.

While visiting home in Kansas City, I was asked by my mother to look at my father's persistent hip rash. I told him it looked like CTCL, and he underwent a biopsy that confirmed the diagnosis. He achieved excellent results after treatment with topical steroids and retinoids, narrow-band UVB, and extracorporeal photopheresis. Sadly, several years later he died from an unrelated condition.

Shortly after my father's diagnosis I began working on a CTCL study with leading CTCL researcher Thomas Kupper, MD, Chair of the Brigham & Women's Hospital's Department of Dermatology and Director of the Harvard Skin Disease Research Center. Today, I am Director of the Division of Dermatology at the University of Kansas Medical School.

CTCL Signs and Symptoms

Most people with CTCL first present it to their primary care doctor or dermatologist. I tell patients to watch for:

- Red, scaly rashes in the "bathing suit" area
- Red, scaly rashes anywhere that are spreading and getting worse
- Unexplained itch

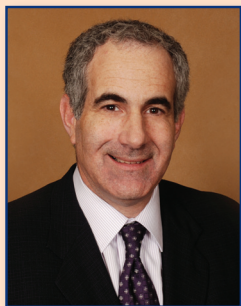
Patients and caregivers who are concerned about a long-term rash should seek out the advice of a dermatologist with experience in CTCL. The best way to definitively diagnose CTCL is through a biopsy. A biopsy is a simple procedure involving the removal of a small piece of skin for testing to determine the presence or extent of disease. Blood tests, such as flow-cytometry, can help determine what stage of disease is present.

To diagnose and treat CTCL, it helps to take a team approach. Patients and caregivers can benefit from treatment at centers with experienced specialists in critical roles. Key healthcare team members include:

- Dermatologists – diagnose CTCL and manage skin-directed treatments
- Dermatopathologists – diagnose CTCL biopsy specimens microscopically
- Oncologists with CTCL expertise – manage extra-corporeal photopheresis and many systemic therapies
- Radiation oncologists – manage radiation therapy
- Primary care physicians – manage medical issues other than CTCL

Based on years of work with leaders in the field, as well as my own experience, I believe that combining treatments often works best. There are many relatively safer treatment options that can be used singly or combined.

From the President



Two Judys, One Journey

When the “two Judys” (Judy Jones and Judy Shea) set off on the road in 1998 to spread the word about the newly-formed Cutaneous Lymphoma Foundation (then the Mycosis Fungoides Foundation), they could have hardly imagined where the journey would lead them and what the horizon would look like in 2012 (for the complete history of the early Foundation years, see www.clfoundation.org/about-the-foundation/about-us/history).

Stuart R. Lessin, M.D.

With Judy Jones’ recent retirement from her founding roles as Foundation Director and President of the Board of Directors, the new leadership of the Cutaneous Lymphoma Foundation is looking at the dawning of a new and exciting era for the Foundation and the cutaneous lymphoma community.

As the new President of the Board of Directors of the Cutaneous Lymphoma Foundation, it is my privilege to serve and continue in the journey that I joined with the “two Judys” from the Foundation’s inception. It is also my distinct pleasure to share with you the enormous opportunities that lie ahead next year and beyond.

The Foundation’s programs and services continue to grow and are reaching more people with cutaneous lymphoma than ever before. Watch for the 2012 publication of the Foundation’s new Patient’s Guide to Understanding Cutaneous Lymphoma. This publication will serve as an authoritative source of information and support for all those diagnosed with cutaneous lymphoma. Plans are underway to have the Guide translated into as many languages as possible so that its impact will be global. The Foundation’s recent re-launching of its web site (www.clfoundation.org) provides more user-friendly information and will serve as an important platform for expanding services.

In 2012 the Foundation will announce plans for a new Research Grant Program. It will represent the first research program dedicated exclusively to cutaneous lymphomas and help support funding scientists and physicians studying cutaneous lymphomas. With ongoing support of donors, the sustainability of this program will leverage federal and industry resources and grow the cutaneous lymphoma research agenda. This is a thrilling example of patient empowerment and an important trend.

As we move forward in the age of globalization, the patient’s voice will have an increasingly important role in biomedical research and health care services. Technologies are enabling a more collaborative approach toward discovery and advancement by bringing together scientists, drug developers, government agencies and patients.

The Cutaneous Lymphoma Foundation now represents the largest non-profit organization supporting cutaneous lymphomas. Its voice has been heard and now the Foundation is poised to assume a leadership role in the cutaneous lymphoma community. So the determined journey of the “two Judys” continues on with the sun rising with rays of hope for all those with cutaneous lymphoma.

Stuart

From the Chief Executive Officer



Let’s Grow Together

With a new year just begun and with so many new, exciting efforts underway, it’s a time of thinking big, making plans, and doing more at the Cutaneous Lymphoma Foundation.

Foundation leadership, staff, volunteers, supporters and partners are working diligently and enthusiastically to bring about important change

and foster dynamic progress in all areas of the Foundation’s work. These areas include advocacy, programs, research, communications, strategic planning and development.

As we strive to do more, one thing is clear: We need your help!

Together, we can accomplish so much more to improve the lives of patients who battle cutaneous lymphoma. Together, our voices can be stronger. Together, our talents can yield better and more extraordinary outcomes. Together, our contributions can be exponentially more powerful.

As you read this edition of our newsletter, you’ll undoubtedly be inspired by the many patients, volunteers, medical professionals and supporters who are coming together to help us grow. If you are inspired to join with us and become more involved, please consider the many opportunities we list on page 14.

As we move forward on our journey, we thank everyone who has played such a vital role in building this Foundation into the largest organization in the world serving people affected by cutaneous lymphoma. And, we look forward to growing our family of partners and supporters so that, together, we can do more. Much has been accomplished, but we have so much more to do.

In closing, I’d like to share one of my favorite quotes by Anne Frank:

How wonderful it is that nobody need wait a single moment before starting to improve the world.

A simple but powerful message, and one that I hope inspires you to take this very moment to come grow together with us at the Cutaneous Lymphoma Foundation.

Jennifer

Forum

The newsletter of the Cutaneous Lymphoma Foundation

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Stuart Lessin, M.D.

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Skin Advocate iPhone App

A new "Skin Advocate iPhone App" has been developed that allows medical professionals and others to quickly and electronically provide patients with information about the Cutaneous Lymphoma Foundation. There is no cost involved. Just search the iPhone App store for "dermatology" or "skin advocate." Visit www.clfoundation.org for additional information or contact us at 248.644.9014 to learn more. Thank you in advance for using this app to refer patients, caregivers and others to the Foundation.

Find Us On Facebook!



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Facebook

Check out the latest news and information from the Cutaneous Lymphoma Foundation by liking us on Facebook!

What Is Cutaneous Lymphoma?

Cutaneous lymphomas are cancers of lymphocytes (white blood cells) that primarily involve the skin. Classification is based on lymphocyte type: B-lymphocytes (B-cell) or T-lymphocytes (T-cell).

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

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

Platinum Supporter



Cutaneous Lymphoma Patient Educational Opportunities

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



March 3: Scottsdale, AZ
Lymphoma Workshop, in collaboration with the Lymphoma Research Foundation



May 5: Columbus, OH
Cutaneous Lymphoma Foundation Patient Educational Forum



March 31: Needham, MA
Lymphoma Workshop, in collaboration with the Lymphoma Research Foundation



May 12: Raleigh, NC
Cutaneous Lymphoma Foundation Patient Educational Forum



April 14: Toronto, ON
Cutaneous Lymphoma Foundation Patient Educational Forum



May 19: Chicago, IL
Lymphoma Workshop, in collaboration with 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 2012 Patient Educational Forums:

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SPONSOR OUR 2012 PATIENT EDUCATIONAL FORUMS

Sponsorship opportunities for our 2012 Patient Educational Forums are available and offer companies valuable benefits that include widespread recognition in Foundation communications to heighten visibility with key audiences, opportunities to connect with Forum participants and exhibit privileges. Please contact Jennifer Viano, CEO, at 248.644.9014, ext. 4 or jennifer@clfoundation.org to learn more and to become a sponsor of our 2012 Patient Educational Forums.

My Personal Journey With Cutaneous Lymphoma



Laurel with her family

Laurel Carlson

Annandale, VA

Much has changed since I learned in my late twenties what caused the red, scaly patches that had

appeared on my hip, stomach and breasts for about five years. It wasn't eczema, psoriasis or tinea, as I and several dermatologists assumed. It's mycosis fungoides, a 1983 biopsy finally revealed.

That was before Google, before medical websites, before the Cutaneous Lymphoma Foundation and before I had two children. But one important thing hasn't changed: I remain at Stage IA of a disease that's far less scary than it seemed 28 years ago.

The dermatologist who took several biopsy samples, a retired Army doctor recommended by a fellow teacher in Washington, D.C., was vaguely familiar with the form of cutaneous T-cell lymphoma (CTCL). When I asked him to simplify medical jargon such as "atypical lymphoid infiltrate," the reply was stark: "It's kind of like saying you have a little cancer." Equally dismaying was his frank response to a question about what to expect: "Nobody really knows."

After confirming the diagnosis at The Johns Hopkins Hospital in Baltimore, I returned to my Washington doctor for UVB phototherapy – though he simply had an old lamp with an ultraviolet bulb that also was used for acne treatment. At his suggestion, I soon found an office with a full-body light box.

Emerging knowledge

Experiences with a series of dermatologists during the 1980s and 1990s showed uncertainty about how to treat CTCL, a term introduced at a 1979 National Cancer Institute workshop. Even at The George Washington University Medical Center, burns resulted from light machines that weren't calibrated. Things seemed nebulous and foggy. I felt terribly alone.

With relatively limited attention paid to this "orphan disease" then, I watched online for news about clinical trials, other research and treatment options. I wondered whether to see an oncologist or have blood screening. I learned the meaning of medical terms, navigating a new language and unfamiliar terrain – much like the foreign-born adults in my English classes at Fairfax County Public Schools in northern Virginia.

In the late 1990s, I found the CTCL-MF Listserv that Judy Jones had recently helped start. That led me to her new Cutaneous Lymphoma Foundation, which promoted the online discussion community.

It was like an epiphany. Being able to read what other people were going through was so wonderful – just what I had been looking for. Judy was such an inspiration and called me "a poster child for CTCL" when she encouraged me to post on the CTCL-MF Listserv.

I was definitely the veteran and was glad to share what I knew. I still try to offer reassurance and perspective when I see posts from someone who sounds depressed or is in the early freaking-out phase.

Beach and poolside therapy

Through the years, I've been treated by about eight dermatologists – mainly receiving UVB phototherapy three times a week. Our family dutifully took post-winter trips south so I could "roast in the sun," as we joked, and wear skimpier swimsuits than I was comfortable with back home. These formal and informal ultraviolet ray treatments worked well, and I sometimes went as long as three years with no outbreak.

After receiving care from Dr. Mervyn Elgart, former dermatology chairman at George Washington University, I now see Dr. Carol McNeely, one of his private practice associates in the capital district. We switched in 2007 from light therapy to Clobetasol, a prescription ointment or cream that didn't exist in 1983.

The UVB regimen resumed in 2009 after two atypically large spots of discolored skin appeared on my stomach and nearby. They disappeared with the phototherapy, and Clobetasol currently is my only treatment. I see Dr. McNeely twice a year or when I have a flare-up.

Time to speak up

This disease never defined me or restricted what I do. But it has been a very bizarre thing to live with for three decades. It wasn't something I discussed because it was too weird to explain, too hard to describe. But people would ask about my tan and where we had vacationed, and it did seem like I had a secret life.

Now, after living normally for this long and raising a daughter who's 27 and a son who's 23, I'm becoming more vocal. That's partly why I joined the Cutaneous Lymphoma Foundation Board of Directors in October 2011, a step encouraged by Claudia Day, a patient and former board member, when we reunited six months earlier at a Cutaneous Lymphoma Foundation patient education forum in Virginia. We originally met at a 2003 lunch in Washington organized by Judy.

This is my disease and my time to become more vocal. At age 57, nearly 30 years after being diagnosed, I want to support work to reduce or eliminate the number of people who spend years being misdiagnosed. With current medical advances and the Internet presence of organizations such as ours, there's no excuse for dermatologists to be unfamiliar with CTCL.

I'm thrilled to be part of a Foundation that effectively educates and supports doctors as well as patients.

Skin-Directed Therapies



Marianne C. Tawa RN, MSN, ANP

Nurse Practitioner, Dermatology and Cutaneous Oncology, Dana Farber Cancer Institute

In most clinical situations, treatment of cutaneous T-cell lymphoma (CTCL) is tailored to the stage and particular features of the disease, general health concerns, and lifestyle considerations. Patients with disease limited to the skin (stages I and II) can often achieve clinical response with one of the readily available skin-directed therapies.

This approach to treatment is supported by the understanding that the malignant T-cells spend the majority of their time in the skin because of the homing tendencies to antigens and are dependent on the skin for survival. Thus, therapies can be delivered efficiently to the target organ, namely the skin.

Topical Corticosteroids

Topical corticosteroids are the cornerstone of treatment for a myriad of skin disorders, both acute and chronic in their origins. These agents are employed first line in the treatment of CTCL because of ease of administration and product accessibility.

Topical corticosteroids possess multiple immunomodulatory and anti-inflammatory effects. In early-stage disease, topical corticosteroid therapy has proven to be a mainstay for both induction and maintenance of clinical remissions. Topical corticosteroids are packaged in a variety of vehicle systems including creams, ointments, lotions, foams, gels and solutions.

Clinicians may recommend alternating a stronger potency (class I) agent with a lesser potent (class III or IV) agent over time in efforts to diminish side effect profiles as well as provide opportunity for longer duration of treatment. Local side effects from topical corticosteroids include skin atrophy (thinning), striae (stretch marks), bruising, acne and dilated blood vessels. Suppression of the adrenal gland is a very rare consequence of prolonged topical corticosteroid application.

Topical Chemotherapy: Nitrogen Mustard and Carmustine

The alkylating agents nitrogen mustard (NM) (also known as mechlorethamine) and carmustine (also known as bichloronitrosourea or BCNU) are cytotoxic chemotherapeutic agents employed for topical management of CTCL. During the past four decades, they have been used widely for the treatment of early stages (IA, IB, and IIA) CTCL.

Topical Nitrogen Mustard (NM) therapy requires thoughtful collaboration among the patient, clinician, and compounding pharmacist. A 10mg formulation of NM is dissolved in water, ointment or gel base. Typically, patients apply a thin film at bedtime to all skin surfaces excluding eyelids, lips, and genital region. They should be advised to wash their hands with soap and water after the application process.

The most frequent complication associated with NM therapy is the development of an irritant reaction characterized by skin redness and itching. This reaction can be addressed with product dilution and subsequent desensitization. Drug cessation is warranted if a true allergic reaction with hive-like response occurs. Patients with CTCL who demonstrate clinical clearing of patch and plaque lesions for the duration of NM therapy for 6-12 months may taper the frequency of treatments over time to a less cumbersome schedule. Less frequently encountered toxicities of NM therapy include potential for bone marrow suppression and secondary skin cancers.

Carmustine is available in powder and ointment forms. Local application site redness can develop, although irritant and contact reactions occur less often. In current practice, carmustine is rarely, if ever, selected as an alternative to NM.

Topical Retinoid: Bexarotene Gel

The synthetic retinoid (vitamin A derived chemical) agent bexarotene (Targretin[®], Eisai Pharmaceuticals) selectively binds and activates retinoid X receptors (RXRs). These receptors function as transcription factors that regulate expression of genes that control cellular differentiation and proliferation. The precise mechanism of action for RXRs in the management of CTCL remains unclear. Redness, itching, and pain at the application site may occur in the initial weeks of therapy.

For some patients the solution to this problem may be titration of bexarotene with careful and conservative drug application ranging from less frequent every other day to more frequent twice to four times daily over time. In clinical practice, the topical retinoid class of drugs is considered second line therapy for patients who have demonstrated persistent disease after treatment with topical corticosteroids or other conservative skin directed therapies.

Phototherapy: Broadband Ultraviolet B (290-320nm), Narrowband UVB (311nm) and Psoralen with UVA (320-400nm)

Ultraviolet light therapy is one of the most widely used skin-directed therapies for early stage CTCL. Radiation within the ultraviolet B (290-320 nm) and UVA (320-400nm) spectrums is prescribed for a host of T-cell mediated skin diseases including psoriasis, vitiligo and cutaneous graft-versus-host-disease.

In early stage CTCL, phototherapy is typically selected when skin involvement is diffuse and/or topical treatments have proven to be impractical. The benefits of UVA and UVB have been described for decades as the correlation between CTCL manifestations in covered areas of the body (e.g., bather's trunk, flanks and folds) and sparing in sun-exposed skin was observed.

Patients often share subjective reports of improvement in their skin during the summer months or following a tropical vacation. The mechanism of action for ultraviolet light therapy is broad with effects produced on cell surface membrane proteins causing apoptosis (cell death). In general, UVB reaches the more superficial skin layer of the epidermis, while UVA penetrates deeper into the dermis. Both broad and narrow band UVB therapies are carried out in dermatology practices equipped with specially calibrated "light boxes." UVB therapy does not require administration of an oral sensitizing agent in order to produce beneficial effects in the skin. It is a reasonable choice for therapy when the lesions are thin and do not involve the hair follicle (folliculotropic mycosis fungoides).

Patients are exposed to the UVB spectrum in a graduated fashion at increased doses with treatments taking place two to three days per week. The goal of therapy is clinical response with an eventual taper to a more manageable schedule of one day per week. One of the major hindrances to phototherapy is the time requirements for patient visits, which may disrupt work or home life. In addition, access to a treatment center may be geographically challenging for patients who reside in rural or remote areas. Redness and burning can be problematic in certain fair complexioned individuals; therefore, patients should be assessed prior to each treatment.

Psoralen and UVA (PUVA) phototherapy involves the combination of the photosensitizing agent 8-methoxypsoralen with UVA light. UVA radiation has a longer wave length than UVB and can penetrate window glass and, likewise, can penetrate the larger and thicker lesions of CTCL. Patients ingest the psoralen 1 ½ to 2 hours before exposure to an escalating dose of UVA light. Treatments are delivered three days per week initially until a maximal response is achieved. Over time, patients will reduce the frequency of treatments to a less cumbersome maintenance schedule. Toxicities of PUVA include burning, nausea related to psoralen administration, and increased risk of skin cancers. Patients are expected to wear UVA eye protection up to 24 hours following treatment because of the small but theoretical risk of cataract formation.

Radiation

Radiation therapy shares a long history in the management of lymphomas with CTCL as the first variant to be treated dating back to the early 20th century. Photons initially were employed, but by the 1940's Trump and colleagues replaced photon-based radiation with radiation from accelerated electrons in efforts to more effectively deliver treatment to a wide field, such as the skin surface, while ensuring patient safety.

Over the past fifty years, total skin electron beam therapy (TSEBT) has undergone multiple modifications with the goal of delivering a sufficient dose to the target tissue while minimizing radiation damage to normal skin. The premise for electron therapy in CTCL is to produce direct toxicity to tumor cells within the target volume.

Candidates for TSEBT are those patients who have extensive skin involvement of their CTCL lesions or have exhausted other conventional skin-directed therapies such as topicals and phototherapy. The depth of penetration for electrons is quite minimal, approximating only 5mm; therefore, radiation effects are produced only as deep as the dermal skin layer.

TSEBT is typically administered over a 9-10-week period. Patients receiving TSEBT assume six standing positions during the course of therapy. Contact lenses, goggles, and shields for the finger and toe nail plates are placed prior to radiation exposure to ensure protection to these important structures. Patients are assessed at weekly intervals for findings of redness, swelling, blisters and infection. In some instances, treatment schedules may be interrupted for short recovery periods. The side effect profile for TSEBT includes itching, dry skin, fissuring, dilated blood vessels, fatigue, temperature dysregulation, sun sensitivity, rash, skin infections, brittle nails, hair loss, and skin cancers. Patients are instructed throughout the course of TSEBT, and for a period of time thereafter, to keep the skin well-hydrated with moisturizers, apply UVA/UVB blocking sun screens, wear sunglasses, and consider photo-protective garments for outdoor exposures.

Highlights from the 53rd Annual Meeting of the American Society of Hematology (ASH), December 2011



Pierluigi Porcu, M.D.

Pierluigi Porcu, M.D. is Associate Professor of Internal Medicine, Division of Hematology, Ohio State University Comprehensive Cancer Center (OSUCCC) where he 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 including participation in many of the Cutaneous Lymphoma Foundation's past Patient Educational Forums along with serving as a Co-Chair of the Foundation's Cutaneous Lymphoma Summit held in October 2009.

The 53rd Annual Meeting of the American Society of Hematology (ASH) convened in San Diego, CA, December 10-13, 2011. The meeting was attended by more than 21,000 participants from around the globe. The scientific program, which typically covers all areas of benign and malignant hematology, included presentations on cutaneous T-cell lymphomas (CTCL) and highlighted advances in basic research, new treatments, and symptom management.

Results of a Phase II clinical trial of intravenous pegylated liposomal doxorubicin (PLD) followed by oral bexarotene (Targetin®) in patients with advanced CTCL were presented by Dr. Strauss of Memorial Sloan Kettering Cancer Center (MSKCC) and colleagues. PLD is a new formulation of the old anti-cancer drug doxorubicin (Adriamycin®), which is safer and has better skin distribution than the unmodified drug, and has shown promise in CTCL. Patients received 16 weeks of PLD followed by 16 weeks of oral bexarotene. In total, 37 patients with advanced CTCL (including Sezary syndrome) were treated, with responses observed in about 40%. Some responses were durable, but in most patients the disease came back relatively quickly (5 months). Moderate to severe toxicity was observed in a third of the patients. The investigators could not tell if the addition of bexarotene was beneficial. Overall, LPD is an active drug, but should be considered in patients with advanced CTCL who do not have other treatment options and are not eligible for clinical trials. Access to the drug may also be problematic due to a recent shortage.

Dr. Christiane Querfeld of MSKCC and colleagues presented results of a Phase II clinical trial of the new oral drug lenalidomide (Revlimid®) in patients with CTCL. As observed in other types of lymphoma and leukemia, at higher doses the drug caused inflammation and flare up reactions, requiring dose adjustments. The response rate was about 30%, which is comparable to other drugs recently approved for T-cell lymphoma, such as romidepsin (Istodax®), vorinostat (Zolinza®), and pralatrexate (Folotyn®). Side effects were manageable and not severe. Lenalidomide remains experimental in CTCL.

Finally, investigators from New York University presented their post-marketing experience with the newly-approved drug romidepsin (Istodax®) in the management of CTCL. In a group of heavily pre-treated patients that included Sezary syndrome, they observed very satisfactory responses and tolerable toxicity. There were no significant cardiovascular side effects and responses were observed in patients who had been previously treated with other HDAC inhibitors. Improvement of pruritus (itching) was consistently observed.

In the important fight to improve symptom control in CTCL, a group of investigators from Emory, Boston, and Stanford University introduced a new Quality of Life (QoL) instrument. They collected detailed information using four different methods (one interview and three self-administered questionnaires) and compared them. A representative sample of CTCL patients of different age, gender and ethnicity was studied. The investigators observed that no single questionnaire captured the whole gamut of concerns and symptoms. A majority of patients expressed concern with pruritus and worries that the condition was serious or would get worse. Importantly, the open-ended interviews revealed that patients had concerns not always captured by the questionnaires, such as: 1) treatment was time-intensive; 2) dry mouth and skin; 3) frustration at delay in diagnosis; and 4) burden on family. The researchers will continue to work on improved QoL instruments based on these data.

Several advances in laboratory research in CTCL were presented.

Dr. Salvia Jain of New York University Cancer Center presented a new bio-luminescent animal model of Sezary syndrome that allows for direct tracking of human disease in the mouse and will be very helpful in designing and assessing new treatment strategies for this aggressive type of CTCL. This important work, completed under the mentorship of Dr. Owen O'Connor, was noted and recognized by the Cutaneous Lymphoma Foundation with Dr. Jain being nominated as the first recipient of its new ASH Young Investigator Award.

Another laboratory presentation that is sure to have a significant impact on the future treatment of CTCL was given by Dr. Wen-Kai Weng and colleagues from Stanford University. These investigators developed a sophisticated method to specifically identify and monitor extremely small numbers of residual CTCL cells in the blood of individual patients after bone marrow transplantation, observing in some cases a complete disappearance of all CTCL cells from the blood. This technology opens the door to a patient-specific quantification of tumor cells in the blood and a definition of minimal residual disease.

Continued on page 15

My Personal Journey With Cutaneous Lymphoma



Joseph Eischens

Kansas City, MO

Gathering information, evaluating facts and interpreting those facts are essential functions of my work as an attorney. But when it came to learning about my own skin rash diagnosis, I was unprepared, unnerved and very scared at first.

After a 2003 biopsy of inflamed skin samples confirmed mycosis fungoides, a form of cutaneous T-cell lymphoma (CTCL), my wife Patty and I naturally jumped on the Internet. Big mistake! Random searching can be the worst way to start. We found distressing pictures and alarming stories, but initially not reassurance about a non-fatal diagnosis that is manageable.

So it was a huge relief to see more even-handed information from respected medical websites and then the Cutaneous Lymphoma Foundation when we looked for treatment options. The outstanding CTCL-MF Listserv, promoted by the Foundation, showed fellow patients' real life experiences and brought me into a supportive online community. During those early months after my diagnosis, Judy Jones' compassionate insights gave me hope and understanding that I also could tackle this head on.

Symptoms originally had appeared about five years earlier in the form of red, scaly patches under my arms and along my belt line. Several dermatologists unsuccessfully tried basic treatments for psoriasis and eczema before Dr. David O'Connell of suburban Kansas City suggested the biopsy that identified the condition.

Difficult news

Hearing "lymphoma" eight years ago at age 38 was a shock. The "C-word" scared me more than anything before. My dad had died from cancer in 2000, one of my closest friends died of an aggressive cancer in 2001 and my mother was struggling with chemotherapy treatments for her lung cancer. She eventually passed in 2004. Other family members had received cancer diagnoses, but none with the rare type I have. And my children were just 6 and 3 then.

Though his diagnosis was a key contribution to my care, Dr. O'Connell wasn't equipped to treat CTCL so I started seeing another top dermatologist in the area. The treatment worked for several years, though the side effects really inhibited me on treatment days and a 45 minute, one-way drive cut into business time significantly. So when red spots reappeared this year, I was ready for something different and less disruptive.

The Cutaneous Lymphoma Foundation came through again. It held a patient education forum in Kansas City this past September, just a half-mile from the downtown law firm where I'm one of three partners. One of the presenters, Dr. Daniel Aires, is director of dermatology at the University of Kansas Cancer Center. He has written and lectured about skin cancer, and treated CTCL in his own father – all of which really impressed me.

Different UV therapy

We spoke during breaks at the forum and Dr. Aires got me into his office soon afterward. My new treatment – the same one Dr. Aires used with his dad – involves UVB narrowband light therapy and Targretin® gel, a topical retinoid. I go three mornings a week and feel fine because there's no nausea or fatigue – unlike with Psoralen capsules. Having to leave on the slippery Targretin® and Desonide cream, a corticosteroid, is the only drawback – but I am certainly not complaining!

I live a full, active life that includes spinning and weight workouts at a gym, as well as coaching my 11-year-old daughter's basketball team and 14-year-old son's baseball team. We love family ski vacations in Park City, Utah, and beach vacations to Mexico or Florida.

This journey has brought a deeper appreciation of my parents' unbelievable strength while suffering through medical adversity and a closer understanding of what they went through. Their perseverance and positive outlook, and my wife's tremendous love, support and patience have guided my personal journey with this disease. Although not a strongly spiritual person, I know that support and prayers from friends and family members contribute to my positive outlook. I also firmly believe that the anointing of the sick sacrament I received from our Catholic priest guided me spiritually, psychologically and emotionally through initial dark days of unknowns and self-pity.

My medical outlook remains promising and my personal perspective is that "every day is the gift of a new day" – a cliché that I know is a true and guiding mantra. Though I'm just 46 and expect to be around a long while, we've expedited things we want to do as a family – such as a three-week trip through Europe next summer.

After the Kansas City patient forum connected me with an excellent new doctor and medical team, I realized that I've been blessed and that it is time to start giving back by becoming more involved in the Cutaneous Lymphoma Foundation's advocacy work and perhaps joining the board of directors. Every day is indeed a new opportunity to embrace life and share the gifts granted to me.

Good Skin Care Tips



Cutaneous lymphoma, as well as some treatments for this disease, can make skin dry, itchy, and scaly. Following you will find a variety of tips that can help you with your skin care:

Moisturizing

Moisturizing is one of the most important components of good skin care. Adequate moisturizing plays a key role in keeping skin healthy, by thickening the barrier function as well as keeping you comfortable. Decreasing dryness can alleviate some of the itching that are often experienced. A simple, effective way to decrease dryness is to frequently apply moisturizers or emollients.

With so many different moisturizers on the market today, it can be difficult to decide which ones to use. Here are some tips to follow when comparing products:

- Ointments and creams provide the greatest moisturizing power. They are the best moisturizing products to use on skin because they contain a high content of oil that leads to greater penetration and more staying power.
- Avoid lotions as they are made with mostly water and little oil. Avoid gels as they contain alcohol or acetone that can be drying to skin. Avoid moisturizers that contain perfume and dyes.
- Apply moisturizers frequently, at least 2 to 3 times daily, to keep skin from drying. You may need to try different products before finding the ones that work best for you.

Moisturize the skin while damp because moisturizing lotions and lubricating ointments can trap water against the skin and provide longer relief from dryness. When skin gets dry and flaky, apply a lubricating ointment with lanolin such as petroleum jelly or Aquaphor™. Patients often need to lubricate and moisturize skin many times daily.

Bathing

Another important consideration is bathing. Bathing or showering in lukewarm – not hot – water is recommended as hot water tends to melt the natural oils from our skin and can leave our skin drier than before. Hot water also causes a surge of blood flow to the skin, which can increase itching once patients emerge from the shower or bath. Be sure to keep baths and showers brief, no longer than 15 minutes.

Also, the best time to apply moisturizers/emollients is after bathing, when skin is still moist. Applying moisturizer (or topical medication in an emollient) on damp skin helps seal hydration into the skin's outer layers.

Soaps and Cleansers

With regard to soaps or cleansers, less is better. Try a moisturizing soap that contains extra oils. Avoid heavily-fragranced soaps because to infuse a product with fragrance it must first be dissolved in alcohol, which is drying to the skin. Choose soaps and moisturizers that are labeled fragrance-free. Dove™, Eucerin™, Lubriderm™, Curel™, and Cetaphil™ are some examples. Avoid antibacterial or deodorant soaps, as they may be too drying for cutaneous lymphoma patients.

Laundry Detergents

Be advised that laundry detergents can affect skin as well. Choose a fragrance-free detergent. Fabric softeners often have fragrances, too, so look for fragrance-free fabric softener. Fabric softener sheets added to the dryer are often the worst product for people with sensitive skin because the fragrances directly coat clothing, which comes into direct contact with the skin and can be a constant source of irritation.

Sun Protection

Too much sun is damaging to skin. Use sunscreen, wear a hat with a brim, and consider wearing long-sleeves and pants year-round. If you receive light therapy as part of your treatment, your doctor may advise you to wear UV-blocking sunglasses. However, for some people with cutaneous lymphoma, small amounts of sunlight may actually be good for your skin. Discuss with your doctor which protocol is best for you.

Additional Tips

Other tips for keeping skin comfortable include:

- Wearing loose-fitting, comfortable fabrics that 'breathe.' Cotton is best. Avoid rough, scratchy fabrics like wool.
- Avoid tight-fitting clothing.
- Do not scrub skin or rub harshly.
- Keep fingernails short to prevent infection and skin damage.
- Avoid getting over-heated. Sweating worsens itch.
- Find ways to manage stress as stress can trigger flare-ups in cutaneous lymphoma and increase itching.

Please visit www.clfoundation.org for additional and updated information.

Cutaneous T-Cell Lymphoma: A Dermatologist's Perspective, Continued

Currently, some of these relatively safer treatment options include:

- **Topical steroids that can treat CTCL and bothersome symptoms such as itch**
- **Topical retinoids that can treat CTCL and also help reduce side effects of topical steroids**
- **Phototherapy (light-box), using special lights that reduce CTCL cells**
- **Extracorporeal photopheresis that effectively gives the blood a sun-tan**
- **Less-toxic systemic therapies such as oral retinoids and HDAC inhibitors**
- **Radiation therapy, such as total-skin electron beam**

When these relatively safer therapies can no longer control progression, some patients can benefit from traditional cancer chemotherapies or bone marrow/stem cell transplantation.

Patients can also consider clinical trials. For more information about CTCL clinical trials, please visit the Cutaneous Lymphoma Foundation's website at www.clfoundation.org.

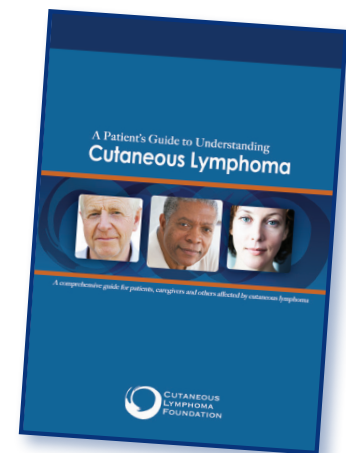
Finally, there is no need to fight CTCL alone. The Cutaneous Lymphoma Foundation is the leading provider of advocacy, education, and support for CTCL patients and caregivers. For more information, please visit www.clfoundation.org. I also strongly encourage patients and their caregivers and supporters to directly contact their congressional representatives to advocate for continued funding for the National Institutes of Health (NIH) since that's where the breakthroughs will originate.

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Coming Soon: Our New "Patient's Guide to Understanding Cutaneous Lymphoma"

The Cutaneous Lymphoma Foundation will soon be publishing a new "Patient's Guide to Understanding Cutaneous Lymphoma," which will feature comprehensive information about cutaneous lymphoma, treatment options, treatment side effects, tips for good skin care, communicating effectively with your healthcare team, and much more.

This Guide will be sent to every person on our mailing list and it will be available for download on our website. We project distribution of our Guide in April 2012 and look forward to staying in touch with news on the availability of this new Guide.

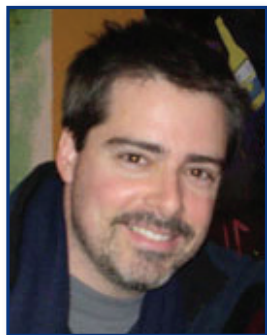


New CTCL Fact Sheet From The LLS Available in English and Spanish

The Leukemia and Lymphoma Society (LLS) has published a new fact sheet on cutaneous T-cell lymphoma (CTCL) available in both English and Spanish. This comprehensive fact sheet includes information on the various forms of CTCL, stages, treatment options, and resources available for help.

You can download these fact sheets easily on our website at www.clfoundation.org (click on Programs and Resources and then Additional Resources) or contact The LLS at 914.949.5213.

My Personal Journey With Cutaneous Lymphoma



Kory Floyd, PhD

Gilbert, AZ

When personal and professional interests intersect, it's energizing – even if disease is involved.

As a social scientist at Arizona State University, I study how emotional support and communication help people cope with health challenges – a discipline that gained special resonance after I

was diagnosed with cutaneous B-cell lymphoma in 2005 at age 36. My research specialty suddenly was vividly intimate.

The diagnosis came after my primary care physician and a dermatologist had been stumped by what caused a red bump on my left forearm. It didn't itch or hurt, and I waited four or five months before asking my doctor to take a look. He suspected an infected hair follicle and tried several antibiotics, which had no effect. The next step was a dermatologist, who took a biopsy. When a local lab couldn't identify the sample conclusively, she sent it to a Mayo Clinic branch in Scottsdale, Arizona.

"I have some interesting news," the doctor said after seeing the results. "It's a cutaneous lymphoma, which is rare – and it's the B-cell type, which is even rarer." She hadn't seen a case before, was unsure how to proceed and recommended that I see an oncologist.

Treatment decisions

The University of Arizona in Tucson, two hours from my home near Phoenix, has our state's only comprehensive cancer center designated by the National Cancer Institute. I saw a specialist in this type of lymphoma, who concluded I have a low-grade, non-aggressive form of cancer.

I was practically hyperventilating when that news came by phone, but the stress eased when further tests led three other oncologists to agree I had a mild form of the disease.

Radiation therapy began quickly under the guidance of Dr. Michael Long, a local oncologist and hematologist, with brief daily sessions lasting six weeks. The lesion received low-dose exposure for about 10 seconds each time, a tactic aimed at reducing side effects – though fatigue began after five weeks. I continued working and just had to avoid sun exposure on that arm – which meant wearing long sleeves outside despite summer temperatures above 100 degrees.

Radiation eliminated the first lesion and was resumed a year later when a new one appeared on my right arm and another showed up on my right leg. The brief daily treatments were a familiar six-week routine that seemed effective again.

Change of direction

When another set of raised lesions appeared on my right arm eight

months later in 2007, Dr. Long suggested a "watch and wait" strategy rather than risking potential harm from repeated radiation that didn't prevent recurrence. I returned to the University of Arizona and saw a different lymphoma specialist, who endorsed the same recommendation after consulting an oncology team at Stanford University in California.

I also had done research, applying academic discipline to a narrowly focused inquiry more compelling than most. Nothing in medical literature contradicted what initially seemed like an offbeat approach, and the only clinical trials were too limited to be statistically significant. Also, as a scientist I know that just because something sounds odd doesn't mean it's unwise.

Our standby strategy has been in place for four years, with arm lesions coming and going. Sometimes they're barely visible, and many days I don't even think about the disease.

Dr. Long performs a checkup and blood test every six to eight months, and a PET scan every 18 months confirms the lymphoma hasn't progressed.

Interests intersect

I appreciate my oncologist's communication style and openness to dialogue about treatment, which includes soliciting other opinions. His frankness and confidence are reassuring, while also merging with my academic interest. This convergence opens the door for collaborations with the Cutaneous Lymphoma Foundation.

My work explores how communication and behavior have a positive or negative impact on quality of life after treatment for serious conditions. I've studied patients with other types of cancer, including recent research with colleagues on testicular cancer survivors. Clearly, this topic has a much more immediate poignancy now. I've become more deeply invested in the pursuit of knowledge.

I learned about the Foundation during 2011 while doing research and began exploring possible collaborations with Jennifer Viano, chief executive officer. In addition to designing data collection methods for quality of life research, I see opportunities to do other interesting things together.

As part of a committee, I hope to contribute meaningfully to patients' and families' knowledge about the interplay between emotional support and health. My findings appear in book chapters, journal articles and conference presentations, but I'm not often able to get them directly into the hands of patients and caregivers. It's important to recognize that family members cope with our diseases, too. Their social support needs differ, and I also want to help them through the Cutaneous Lymphoma Foundation.

I want to contribute and learn, using whatever is in my arsenal as a professional and a patient to help others along any point of the cutaneous lymphoma continuum.

Reach Out And Touch Someone: Why Affection Is Good For You

By Kory Floyd, PhD, Professor and Associate Director, Hugh Downs School of Human Communication, Arizona State University

He goes by the name Juan Mann, and he has certainly made a difference.

In January 2004, he left behind his life in London and returned home to Sydney, Australia. It was a lonely time for the 22-year-old bachelor. His parents had divorced, his grandmother had fallen ill, and he had recently ended a promising relationship with his fiancée. One night, feeling dejected and alone, he went to a party hoping to cheer himself up. Sometime that evening, a complete stranger approached him and gave him a hug. That small gesture had a profound effect. “I felt like a king!” he recalls. “It was the greatest thing that ever happened.”



Mann decided to pay his good fortune forward. In July 2004, he took to the streets with a cardboard sign advertising “Free Hugs.” He admits feeling terrified at first. When an elderly woman approached and accepted his offer, a social movement was born. The Free Hugs Campaign now stretches across Australia and New Zealand, Asia, Europe, the Middle East, Africa, the United States and Canada, and Latin America. A video of Mann’s efforts, featuring music by the Australian rock band Sick Puppies, has been viewed over 70 million times on YouTube. Inspired by what Juan Mann could do, people everywhere started spreading the love. Free hug events have occurred in the most diverse of places, from Taiwan, Israel, and Uganda to Malta, India, and the Dominican Republic. That includes the United States, where free huggers can be found from San Diego to Boston, Seattle to Boca Raton.

Like Juan Mann, every one of us faces trying times. Perhaps we struggle in this slow economy or worry about seemingly insurmountable problems such as world hunger. Maybe we find our work unfulfilling and believe our talents are being wasted because of a lack of opportunity. Many of us, myself included, also manage cutaneous lymphoma and have to deal with the discomfort of both the condition itself and the treatment.

You’ve no doubt noticed that during times of stress, many of us have a natural tendency to reach out to others for support. When you’re diagnosed with cancer—or when you’re just having a discouraging day—communicating with a loved one feels like the right move. And in fact, a great deal of science suggests that it is.

According to UCLA social psychologist Shelley Taylor, we have more options for responding to distress than just fight or flight. Taylor says we also “tend and befriend” as a way to calm ourselves. Tending refers to taking care of people who need us (such as our children), and befriending means reinforcing the strength of our friendships and close interpersonal bonds. When we do those things, our bodies respond by lowering our levels of the stress hormone cortisol and increasing our levels of the feel-good hormone oxytocin. Together, those two reactions allow us to recover from stressful events faster and more fully than we otherwise would.

That means Juan Mann was on to something. When he received a hug from a stranger at a party and it made him feel elated, he was experiencing the very stress-alleviating effect that supportive, affectionate communication has been shown to have.

We’ve just emerged from the holiday season, which for many people is a particularly stressful time of year. Whether you’re still feeling the stress of the holidays or you’ve moved on to the new year’s challenges, take a cue from science and remember that we can calm our own stress—and that of others—by making the effort to express our love to those we care for. A simple gesture of affection and support may not change the challenges we face, but it may change everything about the way we feel.

Giving and Getting Involved

Are you looking for ways that you can make a difference, help patients and support our life-changing work? We hope so and we're excited to share the opportunities below that highlight some of the most important ways that you can become involved in all that we do to make sure that each person with cutaneous lymphoma gets the best care possible.

Give To Our 2011-2012 Annual Fund Campaign

Our Annual Fund Campaign raises the vital unrestricted support needed to fund all of the programs that we provide throughout the year.

We need your help to reach our goal of \$200,000 by June 30, 2012.

We're over half way there! With your help, we can reach or exceed our goal.

If you haven't yet given to this campaign, we thank you very much for considering a gift. If you have already given, THANK YOU so much for your support and, if you are inspired to give again, your additional support would be greatly appreciated.

You can make your gift via any of the following options:

Online: Visit www.clfoundation.org and click DONATE

Phone: 248.644.9014

Mail: Send a check to PO Box 374, Birmingham, MI 48012



Share Your Story

Sharing your story is a fantastic way for you to help others who are traveling down the same path that you are — whether you are a patient, caregiver, healthcare provider or a supporter of our work. Patients and others who read our newsletter or visit our website often tell us that one of their favorite features of our communications are the stories of the lives of people who are affected by cutaneous lymphoma. Contact us at info@clfoundation.org or 248.644.9014 if you would like to share your story.

Become An Advocate

Becoming an advocate for people affected by cutaneous lymphoma is a very important way that you can become involved in supporting patients with cutaneous lymphoma.

You can participate by visiting the **ADVOCACY** section of our website often to monitor advocacy news and action alerts that you can participate in, and we also invite you to contact us at info@clfoundation.org or 248.644.9014 if you are interested in being contacted for special advocacy events, such as Capitol Hill days, and other advocacy efforts that arise where we are in need of people who can serve as Foundation ambassadors at these events.

Organize A Fundraiser

Organizing a fundraiser to benefit the Foundation is a great way to support our mission and your efforts can also help build significant awareness for cutaneous lymphoma as well. Event organizers and fundraisers range from individuals to families to companies and community groups. A few fundraiser ideas include a walk/run/bike event, dinner party, golf tournament, seasonal/birthday celebrations where donations are made in lieu of gifts, and company jeans days. For more information about organizing a fundraiser, visit www.clfoundation.org or phone us at 248.644.9014.

Fourth Annual Music Moves Me Run

Saturday, May 12, 2012, Huntsville, AL

In 2011, over 500 runners participated in the Third Annual Music Moves Run. This exciting event is organized by the Leroy Jefferson Williams, Jr. Foundation, Inc., a nonprofit organization founded in 2008 to continue the legacy of the late Leroy Jefferson Williams, Jr., who passed away due to complications of cutaneous T-cell lymphoma.

The Music Moves Me Run includes live music along the entire course, awards, prizes and a post-race party. The atmosphere is very entertaining, and a portion of proceeds from the event is donated to the Cutaneous Lymphoma Foundation.

REGISTRATION IS OPEN FOR THE 2012 EVENT! Visit www.musicmovesme10k.org to learn more and to register.

Highlights from the ASH Annual Meeting, Continued

Finally, investigators from the University of Texas, MD Anderson Cancer Center studied the immune effects of the new anti-CCR4 monoclonal antibody KW-0761, which is showing promise in the treatment of CTCL, including Sezary syndrome. Using patient samples from a Phase I/II clinical trial, Dr. Xiao Ni and colleagues observed that the administration of KW-0761 led in many cases to a decrease in a subset of blood T-cells called Treg cells, which can dampen the host immune response against CTCL. These researchers, therefore, suggest that KW-0761, in addition to a direct anti-tumor effect, may have benefit in CTCL patients by decreasing the number of circulating Treg cells. While these results are very interesting, this hypothesis needs to be confirmed.

2010-2011 Annual Report: Serving People Touched By Cutaneous Lymphoma

The Cutaneous Lymphoma Foundation's mission of supporting every person with cutaneous lymphoma by promoting awareness and education, advancing patient care, and facilitating research, was carried out in extraordinary ways during our past fiscal year. Our 2010-2011 Annual Report is now available, which highlights the remarkable progress made. You can download the report online at <http://www.clfoundation.org/about-the-foundation/financial-information>.

We hope you enjoy reading about all that we were able to accomplish together. With the help of our many dedicated volunteers, donors, corporate and community partners, our vital programs and services continued and grew in some very exciting ways. On behalf of the patients and others we serve, thank you for being a part of our caring, compassionate community. Thousands of patients, caregivers, loved ones, medical professionals, researchers and others from across the world are benefiting from your support.



2011 American Society of Hematology Young Investigator Award Recipient

We are pleased to announce that Salvia Jain, MD was selected as the Foundation's 2011 American Society of Hematology (ASH) Young Investigator Award recipient.

Dr. Jain is a Hematology/Oncology Fellow at NYU Langone Medical Center working with Dr. Owen A. O'Connor, MD, PhD, Professor of Medicine and Pharmacology, Deputy Cancer Center Director, New York University Cancer Institute, Chief, Division of Hematology and Medical Oncology, NYU Langone Medical Center. While at NYU, Dr. Jain has been working to develop novel therapies for the treatment of cutaneous T-cell lymphoma (CTCL).

Her abstract entitled "Validation of a Novel Bioluminescent Mouse Model of Sezary Syndrome for Preclinical Screening" was presented at the ASH Annual Meeting and reviewed in conjunction with selection of Dr. Jain for this award. Dr. Jain has also received two recent awards recognizing her work in CTCL research including the ECOG Young Investigator and ASH Abstract Achievement.

The Foundation presented Dr. Jain with this award at a special reception at the ASH Annual Meeting in December 2011. Photos from the event are below. Congratulations, Dr. Jain, and best wishes from all of us at the Cutaneous Lymphoma Foundation.



Foundation leaders join with Dr. Jain as she accepts her award. From left to right: Jennifer Viano, CEO; Dr. Stuart Lessin, Foundation President; Dr. Salvia Jain; Dr. Pierluigi Porcu, Foundation Director; and Susan Thornton, Foundation Management Consultant for Programs and Services.



Dr. Stuart Lessin, Foundation President, presents Dr. Jain with her award.



Dr. Pierluigi Porcu, Foundation Director; Dr. Steven Rosen, Director of the Robert H. Lurie Comprehensive Cancer Center at Northwestern University; Michael Young, Foundation Director; and Dr. Stuart Lessin, Foundation President, celebrate at the reception.



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Celebrate Rare Disease Day on February 29, 2012

There are approximately 7,000 rare diseases identified in the U.S. Rare diseases can be chronic, debilitating and life-altering. People living with rare diseases, like cutaneous lymphoma, experience difficult challenges such as delayed diagnosis, misdiagnosis, physical and emotional effects, financial issues, and a lack of support services.

Join the Cutaneous Lymphoma Foundation in celebration of the fifth annual Rare Disease Day, a day to recognize all of the rare diseases. Rare Disease Day was established to raise awareness with the public about rare diseases, challenges encountered by those affected, the importance of research to develop diagnostics and treatments, and the impact of these diseases on patients' lives.

Representatives from the Cutaneous Lymphoma Foundation will be in attendance at various events sponsored by the National Institutes of Health (NIH) and the Food & Drug Administration (FDA) to help increase awareness for cutaneous lymphoma, share patient experiences, and advocate for positive change.

To learn more and to find out how you can become involved, visit www.rarediseaseday.org.

