



# Forum

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Spring 2009

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## The Importance of Participating in Clinical Trials

**Enrolling in cancer trials gives CTCL patients the opportunity not only to help find more effective treatment options for themselves, but for others facing the disease as well.** *By Jo Cavallo*

Despite the fact that virtually every cancer treatment available today is the direct result of findings from clinical trials, the number of patients enrolling in clinical studies remains remarkably small. According to the Coalition of Cancer Cooperative Groups, of the 1.3 million people who will be diagnosed with cancer this year, only three percent to five percent will participate in clinical trials. With rare cancers like cutaneous T-cell lymphoma (CTCL), which accounts for about two percent to three percent of all cases of non-Hodgkin lymphoma, the number of patients with the disease is already so small, it's often difficult to find enough eligible patients to enroll in clinical studies. When you couple that fact with a general reluctance of some patients to participate in research trials, the pool of people to draw from shrinks even further and the result is having an impact on drug advancement in cutaneous T-cell lymphoma.

"Some trials have taken far longer than originally anticipated to complete," says Gary S. Wood, M.D., Johnson Professor and chairman, Department of Dermatology, University of Wisconsin at Madison, and president of the International Society for Cutaneous Lymphomas. "Other trials have failed

because they were terminated prior to completion. Sometimes it's because accrual is too slow and sometimes it's for other reasons such as the results weren't showing much benefit or a major side effect problem emerged."

The reasons why CTCL patients may be hesitant to enroll in research studies vary. In some instances, geography is a factor because the study center may be

inconveniently located from the patient's home. Potential medical costs not covered by the study or by a patient's health insurance is another reason study enrollments can get derailed. Yet

*"This is a time when in five years there could be drastically different therapies than there are right now," says Dr. Wood.*

another obstacle is a lack of urgency by patients with early-stage disease on the need to try an experimental drug, especially if there are other drugs available that have already been FDA approved.

"A major problem is that patients see clinical studies as experimentation and they would rather try something that's tried and true and that's already been used in hundreds or thousands of patients and has been shown to be safe and effective," says Amit Pandya, M.D., professor, Department of Dermatology, University of Texas Southwestern Medical Center at Dallas. "With CTCL, we have about six or seven treatments that are pretty effective for the three-fourths of CTCL patients with

*"Clinical Trials" continued on page 6*

## Forum

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Because each person's body and response to treatment is different, no individual should indulge in self-diagnosis or embark upon any course of medical treatment that is described in *Forum* without first consulting with his or her physician.

Cutaneous Lymphoma Foundation is not responsible for the medical care or treatment of any individual.

## From the President



We've been busy! In five months, we have held seven patient educational forums across the United States, attended three major medical meetings and walked the Hill in Washington advocating for increased funding for research. And, I managed

to walk (not run) the "Music Moves Us" 10K event in Huntsville, Alabama, to increase awareness for cutaneous lymphoma.

In our "spare time," we have been developing the program for the first ever Cutaneous Lymphoma Summit. Program chairs Stuart Lessin, MD and Pierluigi Porcu, MD have invited speaking faculty that includes the world's top cutaneous lymphoma leaders, clinicians and experts to provide an outstanding scientific program. The outcome of this program will give us a roadmap to focus on what needs to be done to move forward in the understanding of cutaneous lymphomas.

With all the experts in town, we have also been able to organize an exceptional program for social workers, dermatology and oncology nurses. We will have a concurrent patient educational program with networking time built in so you will be able to rub elbows with physicians and other patients that understand the disease. There are breakout sessions scheduled for lymphomatoid papulosis, cutaneous B-cell lymphoma, and parents of children with mycosis fungoides.

The field of cutaneous lymphomas is very exciting right now. I have seen so many changes in the past 10 years and know that the Summit will only increase the speed at which we are moving forward toward better diagnosis, more effective treatments and our march toward the cure.

## More Ways to Give

**The Cutaneous Lymphoma Foundation is pleased to announce our admittance in the 2009 Combined Federal Campaign (CFC) for workplace giving.** CFC is the world's largest and most successful annual workplace charity campaign, with some 260 CFC campaigns throughout the country and internationally to help to raise millions of dollars each year. Pledges made by Federal civilian, postal and military donors during the campaign season (September 1st to December 31st) support eligible nonprofit organizations that provide health and human service benefits throughout the world. Our donor code is 12294.

**The Cutaneous Lymphoma Foundation is also eligible for United Way funds.** Donating to the Cutaneous Lymphoma Foundation through the United Way is an easy and convenient way to support the important work of the Foundation. It's simple and convenient and can really make a difference. Through the Donor Choice Program, you can designate all or a portion of your donation to the Foundation. Simply write in "Cutaneous Lymphoma Foundation" on the Donor Choice Option form and your gift will be sent to our office. Be sure to include our mailing address and phone number, PO Box 374, Birmingham, MI 48012, 248-644-9014 and our federal tax ID# of 38-3443135.

### **Good news for individuals 70½ or older with individual retirement accounts!**

The President has signed into law a two-year extension of the IRA Rollover provision which will be made retroactive to Jan. 1, 2008, and will apply to gifts made from that date through Dec. 31, 2009.

## Music Moves Fundraisers to Support Cutaneous Lymphoma Foundation

Throughout his life, and especially during his illness, Leroy Jefferson Williams, Jr. would often say, "life is a challenge." When he passed due to complications of cutaneous t-cell lymphoma, his family established the Leroy Jefferson Williams, Jr. Foundation, Inc. This year they initiated the "Music Moves Me" 10K walk, jog, and run event to raise public awareness of cutaneous lymphoma. As you can see by the pictures, this was a great event with amazing volunteers, good weather and great music along the way.

Thanks to Ellery Williams, who worked with his mom, Geraldine, and sisters, Hope, Erin and Heather for the enormous amount of work they did to honor Leroy. Because of their efforts, the Cutaneous Lymphoma Foundation has added additional funds to be able to raise awareness of this disease.

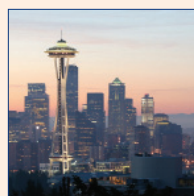
Not everyone is able to plan a project as elaborate as the William's family, but there are lots of things that you can do to help us to promote awareness of cutaneous lymphomas. Kids can have a lemonade stand and take donations and pass out our brochure. You can run or walk and collect contributions. Those nickels and dimes add up and pretty soon we are able to put it together to fund research that may unlock the key to this disease.



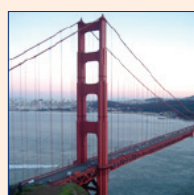
## Cutaneous Lymphoma Patient Educational Opportunities



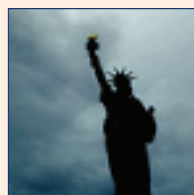
**September 10, 2009**  
**Boston, Massachusetts**  
Improving Access To Effective Therapies For Cutaneous Lymphoma Patients



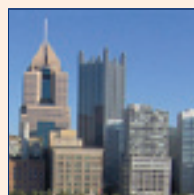
**September 26, 2009**  
**Seattle, Washington**  
Lymphoma Workshop, presented in partnership with the Lymphoma Research Foundation



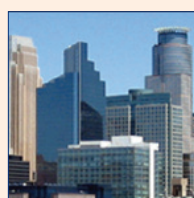
**October 3, 2009**  
**San Francisco, California**  
Lymphoma Workshop, presented in partnership with the Lymphoma Research Foundation



**October 10, 2009**  
**New York, New York**  
Cutaneous Lymphoma Summit



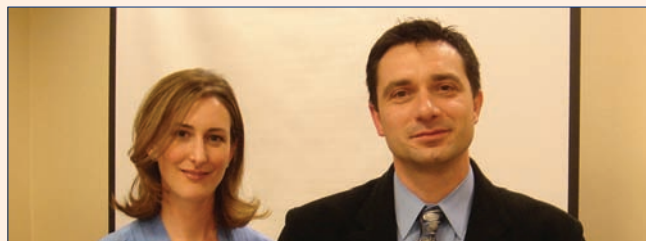
**October 24, 2009**  
**Pittsburgh, PA**  
12th Annual Brian V. Jegasothy Support Group for CTCL, presented in partnership with the University of Pittsburgh Medical Center



**November 14, 2009**  
**Bloomington, Minnesota**  
Lymphoma Workshop, presented in partnership with the Lymphoma Research Foundation



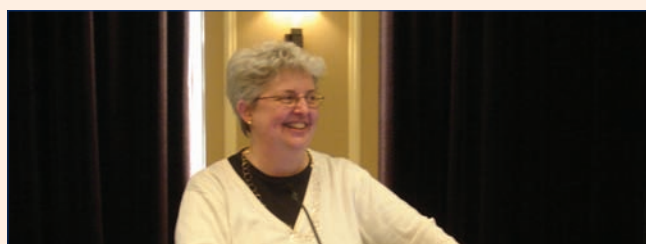
**November 19, 2009**  
**Chicago, Illinois**  
Cutaneous Lymphoma Patient Educational Forum



*Toni-An Lupinacci, RN, and Andrei Shustov, MD at the Seattle Cutaneous Lymphoma Patient Educational Forum.*



*Drs. Frank Glass, Lubomir Sokol, and Hernani Cauling at the Tampa Cutaneous Lymphoma Patient Educational Forum.*



*Claudia Day, Cutaneous Lymphoma Foundation Board member, speaking at the Tampa Cutaneous Lymphoma Patient Educational Forum.*

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 Education 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:
  - Develop a better understanding of diagnostic tests.
  - Learn about treatments available for different disease stages.
  - Identify resources for treatment and support.

For more information, visit [www.clfoundation.org](http://www.clfoundation.org)  
or call (248)644-9014

## Cutaneous Lymphoma Summit 2009

community ✦ cooperation ✦ cure

October 9-11, 2009  
New York City

### Cutaneous Lymphoma Summit 2009

October 9-11, 2009 New York City

Hosted by the Cutaneous Lymphoma Foundation, this unprecedented meeting will serve as an essential annual gathering for all stakeholders in cutaneous lymphoma.

The three day meeting will include scientific and nursing programs, a Saturday evening celebratory dinner, and a Cutaneous Lymphoma Patient Educational Forum.

#### Keynote Speakers

**Richard L. Edelson, M.D., Yale University, New Haven, CT**  
*Immunobiology & Immunotherapy of CTCL*

**Paul A. Bunn, Jr., M.D., University of Colorado, Denver, CO**  
*A Roadmap for Clinical Research in Cutaneous Lymphomas*

**Youn Kim, M.D., Stanford University, Palo Alto, CA**  
*Multi-disciplinary Care in Cutaneous Lymphomas*

#### Program Chairs



Stuart Lessin,  
M.D., Fox Chase  
Cancer Center



Pierluigi Porcu, M.D.,  
The Ohio State  
University

Program chairs Stuart Lessin, MD and Pierluigi Porcu, MD have invited speaking faculty that includes the world's top cutaneous lymphoma leaders, clinicians and experts in patient support issues.

In addition to the scientific program, there will be a day-long Cutaneous Lymphoma Patient Educational Forum, which is an exceptional opportunity for patients, providing access to top experts in the field, and connecting patients to patients that understand their unique experiences.

[www.clfoundation.org](http://www.clfoundation.org)



**CUTANEOUS  
LYMPHOMA  
FOUNDATION**

“Clinical Trials” continued from front page stage 1A, 1B or 2A disease.”

Another problem for CTCL investigators is that even when patients do enroll in clinical trials, they sometimes leave the study early, which can alter the trial results, potentially making a drug appear less effective than it was. “If treatment side effects are worse than the patient anticipated that would be a reason to drop out,” says Dr. Wood. “At the other extreme, if patients are doing remarkably well they may say, ‘I feel wonderful, I don’t have any more lesions and I’m going my merry way.’ But for the patient’s own personal well-being and for the good of future patients and for investigators to be able to analyze the trial, it’s important not to lose patients, because once patients have received a certain amount of therapy, they are included in the overall response rates and they may be counted in a way that makes the drug look less effective than it really was.” The result, says Dr. Wood, is that more patients may have to be enrolled, prolonging the study and causing increasing costs.

**The Urgency Is Now**

Although currently there are about a half-dozen FDA-approved treatments on the market for CTCL, according to Dr. Wood, only about 50 percent of patients respond to any one agent, making it even more imperative to find more effective therapies. And while there are several classes of drugs being tested in CTCL, including the histone deacetylase inhibitors Suberoylanilide Hydroxamic Acid (SAHA) and Romidepsin (depsipeptide); immunomodulatory agents such as Revlimid (lenalidomide); new monoclonal antibodies like HuMax-CD4 and idiotype vaccines, novel drugs could be studied and approved faster if more people enrolled in clinical studies, says Dr. Wood. Besides new agents being tested, new delivery systems are being explored as well.

“There are some drugs being designed to work in the skin and then be broken down before they are absorbed in the blood stream to lessen side effects. We’re also going to see nanotechnology advances in which very small particles of conventional agents can be delivered more efficiently to the cancer, making the drug more effective,” says Dr. Wood.

**Easing Patients’ Concerns About Clinical Trials**

Doctors can help eliminate patients’ concerns and fears about participating in a clinical trial, says Dr. Pandya, by thoroughly explaining the trial protocol and what the study hopes to accomplish. “Patients need to know from the beginning every detail about the trial so they understand how many times they have to go to the study center for treatment, how long the treatment visits last, how the treatment is given and how often lab tests will need to be done,” says Dr. Pandya. Reassuring patients that during a clinical trial they will always be given an active drug—either the new treatment or the current standard of care—and not a placebo, which is never used in cancer trials, can also help alleviate patients’ fears, says Dr. Pandya.

With so much active research in CTCL currently taking place both in basic and translational research, says Dr. Wood, the potential for a host of new agents to move into clinical trials and eventually into the hands of patients over the next few years has never looked better. “This is a time when in five years there could be drastically different therapies than there are right now,” says Dr. Wood. “I think that it would definitely help advance the field more quickly if more people could participate in clinical trials.”

**Can You Recognize This Skin Disease?**

The Coalition of Skin Diseases (CSD) recently produced a 4-color poster which was mailed to more than 4,000 U.S. dermatologists for their examining room walls. The poster has photos from the 16 different skin diseases that the CSD represents, including cutaneous lymphoma. Bullet points describing cutaneous lymphoma, a photo of an affected person, and the Cutaneous



Lymphoma Foundation’s website are on the poster.

The 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. The Cutaneous Lymphoma Foundation has been an active member of the CSD, working together to foster physician education, generate awareness of skin disease, and working to increase the pace of discover or a cure.

This poster is a great awareness tool for cutaneous lymphoma for both the general public and the dermatology community. The Cutaneous Lymphoma Foundation is grateful to the Vaseline Skin Fund for financially supporting this project.

## Camp Discovery 2009

The American Academy of Dermatology (Academy) is proud to offer four camping sessions this year for young people with chronic skin conditions who are between the ages of 8 and 16. Under the expert care of dermatologists and nurses, Camp Discovery gives campers the opportunity to spend a week with other young people with skin conditions, while participating in everything from swimming and fishing to horse-back riding to lots of camp games and activities. All campers must be referred by their dermatologist.

There is no fee to attend this very special camp. Full scholarships, including transportation, are provided by the Academy through generous donations from its members, outside organizations and individuals.

2009 Dates:

- July 5 - 10, Teen Camp in Crosslake, Minnesota (ages 15 - 16)
- July 11 - 17, Junior Camp in Crosslake, Minnesota (ages 10 - 14)
- August 9 - 14, Camp Dermadillo, Burton, Texas (ages 9 - 16)
- August 15 - 22, Camp Horizon, Millville, Pennsylvania (ages 8 - 13)

For more information about attending or volunteering please visit their Web site at [campdiscovery.org](http://campdiscovery.org) or contact Janine Mueller at 847/240-1737 or [jmueller@aad.org](mailto:jmueller@aad.org).



### Cutaneous Lymphoma Foundation Presents Young Investigator Award

The Cutaneous T-cell Lymphoma Symposium hosted by the CLF in conjunction with the ISCL, was held at the annual Society of Investigative Dermatology meeting on May 7, 2009 in Montevallo, Alabama. Sam Hwang, MD/PhD (Medical College of Wisconsin, Milwaukee, Wisconsin) and Gary Wood, MD (University of Wisconsin, Madison, Wisconsin) co-chaired the symposium. Fourteen state of the art research papers were presented and discussed. The 7th annual Cutaneous Lymphoma Foundation Young Investigator Award was presented to Chunlei Zhang, MD/PhD, University of Texas, Houston, Texas for his research

related to the mechanism of action of an experimental drug, Panobinostat, currently in clinical trials in CTCL. Dr. Zhang's research career has focused on CTCL pathogenesis and translational drug discovery and will improve rational study design and treatment for CTCL patients. It is exciting to see that there is this much quality research in the field today that will benefit future patients.

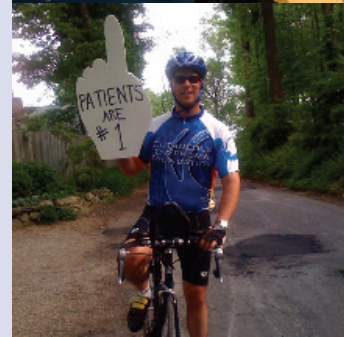
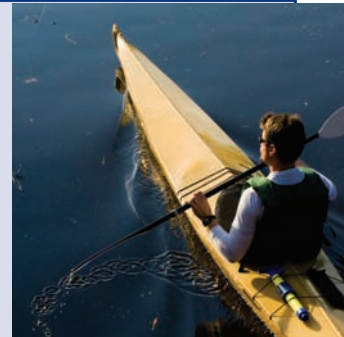


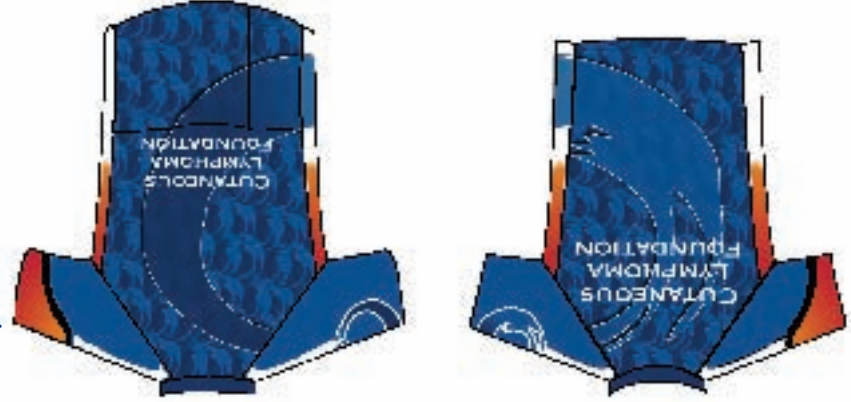
### Team Kayaks and Bikes from Plattsburgh to Manhattan to Raise Awareness of CTCL

To raise awareness about cutaneous T-cell lymphoma (CTCL), a three-person team will bike and kayak in parallel from Plattsburgh in upstate New York's Adirondack region to Manhattan.

During the first week of June, from the 4th to the 7th, Kieran O'Kane (kayak), Bob Wells (bike) and Brace Krag (bike) will cover 55-75 miles per day, depending on conditions.

While awareness about melanoma is growing, many people have never heard of CTCL, due to its lower prevalence. CTCL can be just as difficult to discover and just as deadly. Awareness and early intervention can radically alter the course of this disease.





Jerseys are available for \$92 plus shipping and handling. Please allow 4-6 weeks for delivery.

Order your own Cutaneous Lymphoma Foundation Jersey. Simply visit [www.clfoundation.org](http://www.clfoundation.org) and click on "Shop" or call 248-644-9014.

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