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## 2009 Cutaneous Lymphoma Summit is a Landmark Success for Patients!

After over two years of dedicated development, the Cutaneous Lymphoma Foundation's 2009 Cutaneous Lymphoma Summit was held at the New York Hilton in Manhattan on October 9-11, 2009. Nearly 100 of the world's leading clinicians in the field of cutaneous lymphomas and over 100 patients and patient family members convening at the two-day event created a high energy and hope-filled conference unlike any seen before.

The goals of this conference were to build on previous successful meetings that largely focused on dermatology, oncology, or patient topics and enhance their value by bringing these individual groups all together to address common research and treatment issues. With cutaneous lymphomas, each patient crosses a "bridge" that is supported by the expertise of many clinicians—dermatologists, oncologists, hematologists, dermatopathologists, nurses, pharmacists, and social workers. Each of these "pillars" was well represented at this meeting, with the intended result being better access and care for patients suffering with cutaneous lymphomas. This was clearly in line with the mission of the Cutaneous Lymphoma Foundation, which is "to make sure every patient with cutaneous lymphoma gets the best care possible."



Cutaneous Lymphoma Summit speaking faculty

The meeting fused four innovative parts together; a two-day scientific program, a well-attended Cutaneous Lymphoma Patient Educational Forum, a nursing care update, and a celebratory dinner held on Saturday night.

- The Scientific Program was developed and expertly led by co-chairs Stuart R. Lessin, MD (an outstanding dermatologist and head of the Cutaneous Lymphoma Foundation Medical Advisory Board from Fox Chase Cancer Center) and Pierluigi Porcu, MD (a prominent oncologist from The Ohio State University Comprehensive Cancer Center).
- The 28-person faculty for this conference was a veritable "who's who" of this disease and included leadership of several key groups doing clinical research to find better treatments for cutaneous lymphoma. These groups included

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## 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



Living in Michigan, I have the privilege of watching the leaves turn from green to a magnificent show of yellows, oranges and reds. It signals the end of the harvest season and a time to give thanks. With the grandkids arriving for Thanksgiving, there will be a flurry of activity, which is exciting and all-consuming for a short period of time. When

it's over, I can reflect back over the memories and prepare for the coming winter.

The Cutaneous Lymphoma Foundation mimics life. The Cutaneous Lymphoma Summit, which has been exciting and all-consuming this year, was a success. We are now preparing for the next step—publishing the proceedings and writing a white paper that will give us a roadmap to where we need to go next to answer some of the questions that are still unanswered about this disease.

In “real life,” we look at our health insurance (or lack of health insurance) and try to make decisions that are best for us and our families. The Cutaneous Lymphoma Foundation does this also, just on a larger scale. I've spent more time in Washington, D.C. this year addressing health care reform. There are many issues that affect rare diseases and it's important our voices are heard. We work with several different groups that have an impact on our needs (blood cancer, skin disease and rare disease advocacy organizations). There are many topics that affect us: accessibility to treatment and clinical trials, insurance for pre-existing conditions and life-time caps on insurance payouts as well as countless others. I can assure you, your voices are being heard and we will continue to follow issues that affect our patients.

As we continue working on the day-to-day business of the Foundation, we are looking ahead to our 2010 calendar and planning. Funds are a little tighter this year and we need to determine what we're doing that's effective and look at ways to cut back without sacrificing our goal to make sure every person with cutaneous lymphoma gets the best care possible. We've built a strong organization that is growing, but it's a tough economic market.

This is your organization and we welcome your input. Take a minute to send an email or letter and let us know what we're doing right, and what you don't like. What if we had all the time and resources in the world? What would you like to see us do?

I am truly thankful to have the Cutaneous Lymphoma Foundation that has given me so much over the years, when I needed emotional support dealing with my disease. If we have helped you this year, I hope you will take time to remember the Cutaneous Lymphoma Foundation in your end of the year giving so we can continue to help you and others in 2010.

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the International Society of Cutaneous Lymphomas (ISCL), The United States Cutaneous Lymphoma Consortium (USCLC), and the Cutaneous Lymphoma Task Force of the European Organization for Research and Treatment of Cancer (EORTC). If you are being treated at any major cutaneous lymphoma center in the US, chances are your doctor may have been at the Summit.

- Saturday’s Patient Educational Forum was a wonderful opportunity for patients and their families or caregivers to get up-to-date information on research initiatives, the latest treatments, and to meet some of the best clinicians and allied health professionals in the field today. In particular, breakout sessions which addressed important topics such as childhood mycosis fungoides, issues for young adults, rare manifestations such as lymphomatoid papulosis and anaplastic T-cell lymphomas, and daily living with chronic disease were a highlight of the patient sessions.
- Attending nurses and other allied healthcare providers were brought up-to-date on Sunday morning by a world-class faculty team including a nursing faculty panel comprised of Sue McCann, RN, MSN (University of Pittsburgh Medical Center), Susan Booher, MS, RN (National Cancer Institute) and Marianne Tawa, MSN, RN, ANP (Dana-Farber Cancer Institute). Classification and treatment updates were provided by Drs. Elise Olsen (Duke University Medical Center) and Larisa Geskin (University of Pittsburgh Medical Center), and an outstanding session on the quality of life issues, so important to patients, was given by Marie-France Demierre, MD (Boston University School of Medicine). Leora Lowenthal, LCSW, OSW-C (NYU), a member of the Cutaneous Lymphoma Foundation Board of Directors, addressed the oncology social work perspective.
- A very special evening was held to mark the many accomplishments of the first decade of the Cutaneous Lymphoma Foundation. At this celebratory dinner, the co-founder, current president, and moving force behind the Foundation, Judy Jones, was recognized by the Board of Directors and the attendees for her devotion, vision, and boundless energy over the past ten years. She was given a book signed by each of the Board Members as a memento of this special occasion while a

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Kevin Cooper, MD, speaks to medical professionals



Medical professionals listen during the Scientific Program at the Cutaneous Lymphoma Summit



Martin Weinstock, MD and Stuart Lessin, MD, share a panel with Richard Edleson, MD



Madeline Duvic, MD, asks a clarifying question of a panel of physicians



Jennifer Mills from the Lymphoma Research Foundation interviews Martin Weinstock, MD for a forthcoming webcast



Cutaneous Lymphoma Foundation board, staff, and Summit chairmen



Judy Jones, Cutaneous Lymphoma Foundation founder, is honored at the Summit dinner



Stuart Lessin, MD, co-chairman of the Summit



Marianne Tawa, RN, MSN, ANP, speaks during the Nursing Program



Pierluigi Porcu, MD, co-chairman of the Summit

"Summit" continued from page 3

multimedia collage of collected photos from the past ten years scrolled in the background.

The Cutaneous Lymphoma Foundation, which began in the basement of Judy's home with a phone and a used computer as the Mycosis Fungoides Foundation, has, with her leadership, become the world's leading patient advocacy organization for this orphan cancer that afflicts over 50,000 patients around the world.

The 2009 Cutaneous Lymphoma Summit was the culmination of the efforts of a small but motivated group of people including the Cutaneous Lymphoma Foundation Board of Directors, its staff (special recognition to Amanda Kik, Director of Patient Education and Holly Priebe, Director of Operations and Finance), and the co-chairmen of the Summit. The Foundation also recognizes the wonderful corporate sponsors who provided partial funding and added immensely to the interactions with the participants during the Summit: Allos Therapeutics, Eisai Inc., Merck Oncology, Gloucester Pharmaceuticals, Therakos Photopheresis, and the Lymphoma Research Foundation (who provided funding and collaboration

for the Patient Education Forum). The CLF also wishes to thank JFK Communications for their pro bono support of the Foundation's press and communication needs at the Summit.



Leora Lowenthal, LCSW, OSW-C presents the social worker's perspective



Sue McCann MSN, RN answers questions about nursing in cutaneous lymphomas



## Lymphoma Coalition

The Cutaneous Lymphoma Foundation will be partnering with the Lymphoma Coalition to promote lymphoma awareness around the world. The Lymphoma Coalition is a partnership of over 30 patient groups worldwide that work together to share their experiences and expertise in lymphoma. They also encourage the setting up of new lymphoma patient groups around the world, especially in countries where groups are not already in existence. World Lymphoma Awareness Day will be held September 15, 2010.



## World Rare Disease Day

NORD (National Organization for Rare Diseases) is the official sponsor in the U.S. of World Rare Disease Day. We will join them to help promote awareness of this global initiative, which will take place on February 28, 2010. They will be launching a website soon where all events and activities related to Rare Disease Day in the U.S. will be posted.

## Coalition 2009 Outreach and Education Meeting for Science

The Cutaneous Lymphoma Foundation is a member of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS) Coalition. We attended the NIAMS Coalition 2009 Outreach and Education meeting on November 3rd. More than 54 organizations were represented at the meeting.

Information about the NIAMS

planning process and long-range plans and resources along with learning about the "inner workings" and grant mechanisms of the National Institutes of Health (NIH) was invaluable. The NIH has done a good job of reaching out to patient advocates as we plan to engage and collaborate in the years to come.



### Cutaneous Lymphoma Foundation Receives Partner Award

The Cutaneous Lymphoma Foundation was honored to receive an award from the Lymphoma Research Foundation and the Lymphoma Foundation Canada at this year's North American Educational Forum on Lymphoma in Brooklyn, New York.

For the last several years, the Cutaneous Lymphoma Foundation

has collaborated with the Lymphoma Research Foundation to ensure that cutaneous lymphomas are included in educational programming throughout the year and across the country, including each

Lymphoma Workshop and the North American Educational Forum on Lymphoma.

We value our ongoing relationship with the Lymphoma Research Foundation and Lymphoma Foundation Canada. Together, we can make sure that each person with cutaneous lymphoma gets the best care possible



Amanda Kik, Director of Patient Education, Cutaneous Lymphoma Foundation (left), accepts an award from Karen Van Rassel, Executive Director of Lymphoma Foundation Canada (center) and Sue Bliss, Executive Director of Lymphoma Research Foundation (right)



Steven Horwitz, MD, Memorial Sloan-Kettering Cancer Center

This is a very common question this year—and this year there are 2 “Flu shots” to consider, the seasonal flu and the H1N1 vaccine. First, what is the benefit of the flu shot? Getting the flu shot has several benefits. The most immediate is that it can prevent you from getting the flu or if you do get the flu the illness may be milder. This is an advantage both for healthy people and people who are more at risk of getting seriously ill if they get the flu—the very young, the elderly, and those with weak immune systems. The other advantage is that if most people get the flu shot it can minimize the number of outbreaks in the population. Getting the flu shot can help protect you, your family, your co-workers—and if they get the flu shot it can help protect you.

So for these reasons, I recommend getting the seasonal flu shot each year. To go further, there are a few details to remember. There are two basic kind of flu shots: the injected “shot,” which is a killed virus and is what we use for our patients with lymphoma. Because it is a killed virus, you cannot get the flu from the shot. You may feel achy or flu-like for a few days, but this is your body’s immune system reacting to the flu shot—this is not you getting the flu. The nasal mist is made with a live virus and carries some risk of causing illness in people with weak immune systems. Therefore, we do not use this vaccine for people with

lymphoma.

The same is true for the H1N1 (so called swine flu), which is just a different strain of Influenza, this year. The “shot” for H1N1, while relatively new, is a killed virus and should be safe for people with lymphoma. The main issue for the H1N1 vaccine is availability. To date, my hospital has only received 200 doses so there is not much to go around. I’ve been telling my patients, “you can get it-if you can get it,” meaning if you can find it somewhere, it’s OK to get it, we just don’t have it available yet. We are told the supplies will increase as time goes on.

A few exceptions to above—if you have an egg allergy or history of a nervous system disease called gullian-barre, the flu shot may be contraindicated for you. In addition, if you are on immunosuppressive treatments such as rituxan or campath, the flu shot will probably be ineffective because your body cannot make a new immune response due to the therapy you are receiving.

Another question we get is about the shingles vaccine. Shingles also called varicella zoster is a reactivation of the chicken pox virus that most of us have living dormant in our bodies. This is tempting to get for people with cutaneous lymphomas as when those people get shingles it can sometimes be more severe. However, this vaccine is a live virus and could cause illness in someone with a weak immune system. As such, we currently have no experience to say this is safe in people with leukemia or lymphoma so we don’t give it to our patients. There are studies underway to see if this is safe but until we have safety data we do not give it to our patients.

### Shortage of Oxсорalen-Ultra for PUVA

Valeant Pharmaceuticals, suppliers of Oxсорalen-Ultra, have their product on back order in the United States until March, 2010 and in Canada until October, 2010. Patients and physicians are just discovering this when they are not able to fill their prescriptions.

We have asked members of our Medical Advisory Board what they would recommend for patients unable to get Oxсорalen-Ultra. If you are currently receiving PUVA treatments and unable to continue, you should discuss with your doctor if it would be appropriate for you to switch to an alternate form of phototherapy (alone or in combination with other treatments, e.g., oral retinoids) or change to another type of treatment.

We are researching this issue and will post updates on the CTCL-MF listserv and our website at [www.clfoundation.org](http://www.clfoundation.org) as information becomes available.

### FDA Approves Two New Drugs for CTCL

The Food and Drug Administration (FDA) has approved pralatrexate (Folotyn) for the treatment of relapsed or refractory peripheral T-cell lymphoma (PTCL), a type non-Hodgkin's lymphoma that can affect the skin. Folotyn is a folate analogue metabolic inhibitor, and targets the same pathway as methotrexate. It is given as an intravenous infusion. More information about Folotyn may be found at: [www.folotyn.com](http://www.folotyn.com). Information about PTCL may be found at: [www.focusonptcl.com](http://www.focusonptcl.com).

Romidepsin (Istodax) has been FDA approved for the treatment of cutaneous T-cell lymphoma (CTCL) in patients who have received at least one prior systemic therapy. It is a histone deacetylase (HDAC) inhibitor, similar to Vorinostat (Zolinza). Istodax is given as an intravenous infusion. More information about Istodax may be found at: [www.istodax.com](http://www.istodax.com).

More approved drugs for CTCL and T-cell lymphomas mean more treatment options for patients and potentially easier access to medications. We look forward to more clinical research to refine these new drugs role in the treatment of advanced stage disease.

### Cutaneous Lymphoma Foundation Jerseys Make Great Gifts!

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.



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



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.

**Triathlete Exceeds Fundraising Goal in Memory of His Father**

Cliff Grable was training for a triathlon in Savannah and decided to raise money in memory of his father, Jim Grable who died from cutaneous T-cell lymphoma (CTCL) in January. He was surprised and frustrated with how little seems to be known about the diagnosis and treatment of this skin/blood cancer so he decided to take this opportunity to raise some money for research and support of this disease.

Thanks so much to Cliff, his family and friends who have made a difference in the lives of others who have this disease.



**Bike/Kayak Trip for CTCL**

A three person team consisting of Kieran O'Kane, Bob Wells and Brace Krag conducted a campaign to raise awareness about cutaneous T-cell lymphoma. During the first week of June, O'Kane (via kayak) and Wells and Krag (via bike) paddled/rode in parallel from Plattsburgh in Upstate New York's Adirondack region to Manhattan. Their average mileage was between 55 to 75 a day. Prior to the ride, a notice was sent to hospitals in the towns along the route from the Cutaneous Lymphoma Foundation.

This was a unique way to raise awareness of our disease. These three became interested in promoting awareness for CTCL when they saw patients that had difficulty getting an early diagnosis. They knew that early intervention can alter the course of this disease.



## Cutaneous Lymphoma Patient Educational Opportunities

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.

**March 6, 2010**  
**Scottsdale, Arizona**  
Lymphoma Workshop, presented in collaboration with the Lymphoma Research Foundation



**April 17, 2010**  
**Boston, Massachusetts**  
Lymphoma Workshop, presented in collaboration with the Lymphoma Research Foundation



**April 24, 2010**  
**Toronto, Ontario**  
Cutaneous Lymphoma Patient Educational Forum



**May 22, 2010**  
**Chicago, Illinois**  
Lymphoma Workshop, presented in collaboration with the Lymphoma Research Foundation



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