



Forum

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Summer 2006

From the Executive Director 2

What is Cutaneous B-Cell Lymphoma?..... 3

Advocacy: Our Voice Heard in Washington..... 3

Top Physicians Discuss Treatment Options for CTCL..... 4

CTCL Symposium 4

Increase in CTCL Medical Meetings 4

American Academy of Dermatology Meeting..... 4

Fill These Seats: Patient Educational Forums..... 5

Patient Educational Forum Held at Fox Chase Cancer Center 5

What People Say About Patient Educational Forums..... 5

Upcoming Patient Educational Forums 5

Lymphoma Workshop in Tampa... 5

International Symposium on Cutaneous Lymphomas 6

Regional Cutaneous Lymphoma Masters Conference..... 6

Challenges in the Diagnosis and Treatment of Cutaneous Lymphomas in Children..... 7

Nitrogen Mustard Price Increase

From the phone calls, e-mails and letters we've received, we know that many of you are aware of the price increase in Mustargen® (mechlorethamine, nitrogen mustard). Both patients and physicians are concerned about how this affects patients' ability to continue on this treatment.

Merck, the former manufacturer and distributor of Mustargen® sold the rights to Ovation Pharmaceuticals, Inc., who reports that the price adjustment was necessary in order to ensure that they are able to keep the product available in the U.S. and in over eighty countries worldwide. Those of you who have used the product for a long time will remember periods in the past that it was not available due to production difficulties. It is Ovation's intention to ensure an uninterrupted supply of Mustargen®. According to Ovation, they are making substantial investments in manufacturing technologies and facilities to ensure continued availability.

Mustargen® is expensive because it is a specialty product that is difficult to manufacture and there are no economies of scale due to the small volume that is produced. Because Mustargen is used to treat patients with disorders such as mycosis fungoides, that affect a small patient population, the number of vials used is very low; therefore the cost to produce each vial is much higher.

Ovation offers a com-

prehensive patient access program to assist patients and physicians with complex reimbursement requirements. The Ovation Reimbursement Support Program provides reimbursement assistance for patients with insurance coverage issues and a Patient Assistance Program for patients with financial need. Patients and providers can obtain:

- Screening for the Patient Assistance Program
- Insurance verification
- Prior authorization
- Claims appeal assistance
- Alternate coverage research
- Referral to a charitable foundation

Patients and physicians can contact The Ovation Reimbursement Support Program by calling 866-209-7604.

If you are having difficulty finding a pharmacy that will fill your prescription, the Cutaneous Lymphoma Foundation maintains a list of mail-order pharmacies on our website.

Visit www.clfoundation.org or call 248-644-9014. *

Patient Assistance Program

The HealthWell Foundation is an independent 501(c)(3) non-profit organization that helps patients meet their cost-sharing obligations for prescription medications. The Foundation provides financial assistance to help eligible patients cover certain out-of-pocket health care costs, including prescription drug co-insurance, co-payments, and deductibles, health insurance premiums, and other selected out-of-pocket health care costs. The Foundation considers individual financial, medical, and insurance situations when determining assistance eligibility.

The HealthWell Foundation opened a Cutaneous T Cell Lymphoma fund on March 9, 2006. This fund is designed to assist patients with CTCL with their out-of-pocket costs. Applications are available on the HealthWell Foundation website (www.healthwellfoundation.org) or by calling the Foundation directly at 800-675-8416.

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 Executive Director



The Cutaneous Lymphoma Foundation has just wrapped up the busiest time of year for clinical and scientific meetings. You may wonder why we provided so much information about meetings in this newsletter. A few years ago, there were only a couple of relevant medical meetings, and they didn't include very much about cutaneous lymphomas. There has been a dramatic

increase in these meetings and workshops. This means that more doctors are aware of the disease and are learning about the most recent treatment options. Researchers are sharing information, which leads to new ideas for additional research projects.

Many people are working on how the basic research can be moved along faster to reach the patients. One of the problems that hold this back is lack of people signing up for clinical trials. We are working on a special issue on clinical trials to let you know more about them and what may be available to you.

We have chosen one meeting to highlight in this issue--the symposium in honor of Dr. Gunter Burg's retirement. I realize that most of you will scratch your heads reading this, wondering what it says, but the important points for you to get out of the article are that the topic of cutaneous lymphomas is very complicated and it is being researched around the world. Even though we have a rare disease, there are many people working to get answers.

We are really excited about the positive response to our educational forums. If you have never been to one before, I encourage you to attend. This is a chance to hear doctors talk about the disease, meet people who live with and face the same challenges as you. We have been able to expand the number this year thanks to educational grants from Therakos, Ligand, and Ovation. We have been able to collaborate with the Lymphoma Research Foundation to include cutaneous lymphomas in their programs.

We will soon have new publications available for patients thanks to a generous educational grant from Merck. Shortly there will be a guidebook for people with CTCL, how the disease and treatments affect your life and a treatment tracker, so you can keep track of your own health history.

If you are receiving the newsletter and have not joined your Foundation, do it now! The Foundation's accomplishments would not be possible without the generosity of our members, friends, and corporate partners. Every cent counts, so please continue to support our important work.

What is Cutaneous B-Cell Lymphoma?



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

Cutaneous B-cell lymphoma is a type of lymphoma that is detected on the skin in which the cancerous cells are B-lymphocytes or B-cells.

Lymphocytes are the white blood cells that circulate in our blood. They are a part of our immune system and primarily serve in our body's defense against infections. Lymphocytes are concentrated in large numbers in our lymph nodes (or glands) that are distributed throughout our body. Lymphocytes travel from lymph nodes into the blood and enter into all tissues and organs in the body, including the skin.

Lymphocytes are categorized into two main types: B-cells and T-cells. B-cells are lymphocytes that make antibodies for fighting infections. T-cells are lymphocytes that recognize foreign proteins. B-cells and T-cells work together to ensure that our immune system maintains its full function.

Lymphoma is a cancer of lymphocytes. Lymphomas are typically systemic in nature and develop in lymph nodes throughout the body. The exception are cutaneous lymphomas that develop on the skin and do not involve other organs. There are no known causes of cutaneous

lymphomas and there are no inherited genes identified with lymphoma development.

Cutaneous B-cell lymphomas typically develop as a "bump" on the skin. It will often start out as a small area of redness, the size of a pencil eraser, and may enlarge to the size of a grape or larger. The head and neck are the most common areas affected. Usually one red to purplish nodule develops but multiple lesions can appear. Sometimes they can be itchy or tender but usually they are painless. The initial impression of patients is that they have a "bite" or "pimple", but the areas persist which leads to their evaluation.

The diagnosis of cutaneous B-cell lymphoma is confirmed by a skin biopsy since other non-cancerous skin conditions can look like cutaneous B-cell lymphoma. These include skin reactions to bug bites or certain medications and produce inflammatory changes in the skin termed "cutaneous lymphoid hyperplasia" or "pseudo-lymphoma."

The skin biopsy is evaluated for features that are characteristic of lymphoma. Multiple tests are often performed on the skin biopsy to help identify cancerous B-cells. Special staining using monoclonal antibodies and DNA testing are commonly used. It is recommended that the diagnosis be established by a dermatopathologist (skin pathologist) with experience in evaluating cutaneous B-cell lymphoma skin biopsies.

Once the diagnosis of cutaneous

B-cell lymphoma is established by skin biopsy, staging tests are required to ensure that the lymphoma is confined to the skin and no other organs are involved. In addition to a complete medical history and physical examination, blood tests and imaging studies (chest x-ray and/or CAT scan of the chest, abdomen and pelvis) are obtained. Detection of abnormally enlarged lymph nodes requires a lymph node biopsy.

The goal of treatment of cutaneous B-cell lymphoma is complete clearing of all skin lesions. Once clear, patients are followed for recurrences which can occur in 25% to 68% of patients. Recurrences are often treated in a similar manner as the initial skin lesions. The vast majority (greater than 90%) of cutaneous B-cell lymphomas never progresses to systemic lymphomas and is considered to have an excellent prognosis. Some types of cutaneous B-cell lymphomas, such as those involving the legs, however, tend to be more aggressive with association of progression to lymph node involvement.

Treatment of cutaneous B-cell lymphomas consists of radiation therapy, surgery or a combination of both. Choice of treatment depends on factors such as the size, location and number of lesions involved. Aggressive treatments, such as systemic chemotherapy, have not been shown to improve outcomes or prevent relapses. Treatment options are best discussed with a physician who has experience with evaluating and treating cutaneous B-cell lymphoma. *

Advocacy: Our Voice Heard in Washington

Skin Research Day is an event in which representatives from the American Academy of Dermatologists, the Society of Investigative Dermatologists and the Coalition of Skin Diseases meet in Washington to meet with members of Congress. Chris Shipp, a Cutaneous Lymphoma Foundation Board Member, and Amanda Kik, part of our contract staff, joined these groups in April to make

over 50 visits to members of the House and Senate to ask for a 5% increase in funding for the National Institutes of Health (NIH) in fiscal year 2007. This comes after the 2006 NIH budget was reduced, for the first time in decades.

According to the 2005 Burden of Skin Disease Report, skin diseases currently account for \$38.6 billion in costs per year in medical services and lost productivity. One out of every three

people in the United States suffers from a skin disease.

Many current research projects have the potential to help both CTCL and other related skin disease patients. It is necessary to continue the funding of these projects.



Top Physicians Discuss Treatment Options for CTCL

On April 7-9, 2006 Therakos convened an advisory board meeting in Boston, MA, bringing together 20 leading physicians from the US and Europe who research cutaneous T cell lymphoma and its treatment. The participants discussed treatment options and ways to optimize therapy for the treatment of all stages of CTCL. Active research is underway at various centers looking at different treatment combinations. There are also several centers currently investigating the use of photopheresis in the treatment of early stage CTCL. Additionally, physicians reviewed the recently published guidelines for treating CTCL put forth by the European Organization for Research and Treatment of Cancer (EORTC). This is an attempt to make the approach to treatments uniform, no matter who is prescribing the treatment. Finally, all of the physicians in attendance heard an enlightening talk from Judy Jones, Executive Director of the Cutaneous Lymphoma Foundation, reminding them to consider the patient's perspective and actively involve each person in determining the best treatment for each person on an individual basis. Bringing together top minds to discuss CTCL is a step forward and helps patients receive better care.

CTCL Symposium

The Cutaneous Lymphoma Foundation and the International Society for Cutaneous Lymphomas (ISCL) sponsored a CTCL Symposium at the Society of



Left to right: Dr. Stuart Lessin, Dr. Christiane Querfeld, Judy Jones

Investigative Dermatology meeting in May. There were fourteen presentations on the following topics: Clinical Trials, Gene Expression and Biomarkers, Apoptosis, Immunobiology and Immunotherapy. Christiane Querfeld of Northwestern University received the Cutaneous Lymphoma Foundation Young Investigator Award for 2006.

Increase in CTCL Medical Meetings

National Cancer Institute (NCI) Workshop: The NCI sponsored a workshop titled "Immunobiology and Immunotherapy of CTCL" on May 6-7 in Philadelphia,



Left to right: Dr. Thomas Waldmann, Dr. Sam Hwang, Judy Jones (at the NCI Workshop)

PA. Attendees from many countries shared presentations and discussions over the two days. Information gained from conferences like these move research in the field forward at a faster rate. Thanks to Dr. Sam T. Hwang for organizing this important workshop.

International Society of Cutaneous Lymphomas (ISCL): The ISCL held a day long T-and B-cell Cutaneous Lymphomas Workshop in San Francisco this March under the leadership of Dr. Elise Olsen. More than 80 physicians and researchers attended these presentations and discussions.

Dermatology Nurses Association (DNA): The DNA held its first-ever sold out Annual Convention in March for a crowd of over 1150 nurses and dermatologic health care professionals under the leadership of conference chairperson, Marianne C. Tawa. Dr. Marie-France Demierre gave the presentation Cutaneous Lymphomas: CTCL and Cutaneous B-Cell. Judy Jones gave a talk on the role of advocacy organizations in dermatology.

Society of Investigative Dermatology (SID): Health professionals numbering 1,511 gathered in Philadelphia to discuss and exchange scientific information on skin health and disease. Besides the meetings and presentations, there were over twenty poster sessions directly related to cutaneous lymphomas.

Pathogenesis of CTCL—Insights from the Skin Cancer SPORE

Community: This CME course, under the direction of Dr. Thomas Kupper at Dana-Farber Cancer Institute, provided advanced educational information for clinical dermatologists, and an opportunity for interaction of physicians and scientists working on this group of diseases.

American Academy of Dermatology Meeting

The American Academy of Dermatology (AAD) annual meeting is the largest professional meeting of dermatologists in the United States. This meeting gives us the opportunity to talk with the medical community and share knowledge about the latest CTCL research.

This year, Nikki Thomason from the Lymphomatoid Papulosis group joined us in the exhibit hall as we shared CTCL information with physicians.



Left to right: Nikki Thomason (Lymphomatoid Papulosis Support Group), Dr. Paul Bergstresser (University of Texas Southwestern), Judy Jones (Cutaneous Lymphoma Foundation), Dr. Steve Katz (Director of National Institute of Arthritis and Musculoskeletal and Skin Diseases), Malinda Heuring (National Foundation for Ectodermal Dysplasias)



Fill These Seats

Cutaneous Lymphoma Patient Educational Forums

9th Annual Brian V. Jegasothy Support Group for CTCL
 University of Pittsburgh Medical Center
 Pittsburgh, PA
 October 14, 2006

Cutaneous Lymphoma Patient Educational Forum
 New York, NY
 October 7, 2006

North American Educational Forum on Lymphoma, held by the Lymphoma Research Foundation and Lymphoma Foundation Canada
 Los Angeles, CA
 October 27-29, 2006

2nd Annual CTCL Educational Symposium
 Robert H. Lurie Comprehensive Cancer Center of Northwestern University
 Chicago, IL
 November 1, 2006

Cutaneous Lymphoma Patient Educational Forum
 Toronto, Ontario
 November 4, 2006

More information about educational forums is available online at www.clfoundation.org or by phone at (248)644-9014.

Patient Educational Forum Held at Fox Chase Cancer Center

Each person who attended the free Patient Educational Forum at Fox Chase Cancer Center in Philadelphia, PA in May walked away with a new understanding of this disease.

Dr. Stuart Lessin, Director of Dermatology at Fox Chase Cancer Center, provided attendees with an overview of CTCL, including common myths and facts. The presentation was clear and free of jargon, so it was easy for all to understand.

Dr. Frank Strobl followed up with a concise explanation of how photopheresis, a common treatment for CTCL, works, right down to what patients do when they sit in the chair (watch TV or read a book).

Presenting information on new therapies in CTCL, including exciting new research in clinical trials, was Dr. Ellen Kim, Assistant Professor of Dermatology at University of Pennsylvania Health System.

The final speaker, Judy Jones, Executive Director of the Cutaneous Lymphoma Foundation, talked about her experience as a patient. Like many people with CTCL, it was a long time before Judy received a correct diagnosis, and she went through several therapies before finding one that worked.

After a question and answer session and a lunch break, there were two breakout sessions. The patient and caregiver breakout sessions allowed people to talk about their personal experiences with this disease.

The Cutaneous Lymphoma Foundation thanks each of the speakers for volunteering their time and knowledge for the benefit of people with cutaneous lymphoma and those that care about them.



Pictured from left to right: Dr. Stuart Lessin, Dr. Ellen Kim, Judy Jones, Dr. Frank Strobl

What People Say About Patient Educational Forums

Thank you for the opportunity to meet other patients and to hear about other options.
 -Marta

The breakout sessions were great. It is comforting to know others in similar circumstances.
 -Pat

This opened my eyes about the disease. I was diagnosed eleven years ago but this gave me a new perspective.
 -Jeff

Great information! It was presented so we understood even the most complicated information. This gave me confidence in dealing with this diagnosis.
 -Claire

Lymphoma Workshop in Tampa

In collaboration with the Lymphoma Research Foundation, the Cutaneous Lymphoma Foundation had two breakout sessions on CTCL at the Lymphoma Workshop in April in Tampa, Florida. Dr. Sokol gave an overview of CTCL and Dr. Glass (both from Moffitt Cancer Center) discussed treatment options.



Dr. Glass (left) and Dr. Sokol (right)

International Symposium on Cutaneous Lymphomas

On February 16, 2006 an international symposium *Cutaneous Lymphomas: A Challenge for the Pathologist and the Clinician* took place at the University Hospital of Zurich in honour of Professor Dr. Günter Burg, who is retiring. This event drew many prominent experts in the field of primary cutaneous lymphomas from all over the world.

Following are the highlights from this meeting:

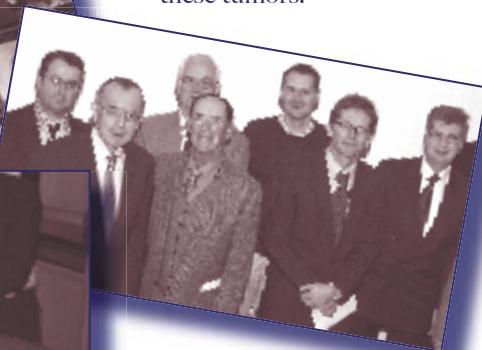
The scientific component of the symposium began with a lecture by Professor Burg's long-time friend and lymphoma specialist Professor H. Kerl from Graz (Austria). Professor Kerl underlined the enormous contribution of Professor Burg to the development of lymphoma research. Further, Professor Kerl addressed important problems in early diagnosis of primary cutaneous B-cell lymphomas, the interactions of

lymphoma cells with their micro-environment and the prognosis of diffuse large cell lymphomas.

Professor N. Pimpinelli from Florence (Italy) spoke next about new aspects in the biology of cutaneous B-cell lymphomas.

Professor M. Kadin from Boston (USA) spoke about the associations of lymphomatoid papulosis (LyP) with different kinds of lymphomas such as mycosis fungoides, Hodgkin's disease and anaplastic large cell lymphoma.

The afternoon session opened with the lecture of Professor R. Willemze from Leiden (Netherlands) on the development of the modern WHO/EORTC - classification of these tumors.



The next lecture was held by Professor E. Vonderheid from Baltimore (USA), who spoke about the difficulties

in differentiating erythrodermic cutaneous T-cell lymphoma from inflammatory erythroderma.

Professor R. Panizzon from Lausanne (Switzerland) spoke about various irradiation therapy possibilities for treating cutaneous lymphomas.

Professor B. Dreno from Nantes (France) discussed standard and new treatments of cutaneous B-cell lymphomas (CBCL).

Professor Dummer from Zürich (Switzerland) addressed the topic of standard and experimental therapies in cutaneous T-cell lymphomas.

In the final lecture of the symposium Dr. W. Kempf from Zürich (Switzerland) reported on the development of dermatopathology in Zürich over the last few years and underlined the important contributions of Günter Burg.

Several interesting and instructive clinical presentations also found their places in the program. These were presented by members of the staff of the Department of Dermatology in Zürich. This symposium was certainly one of the most interesting events in 2006 for specialists dedicated to cutaneous lymphoma research. *

Regional Cutaneous Lymphoma Masters Conference

The Cutaneous Lymphoma Foundation participated in a Regional Cutaneous Lymphoma Masters Conference held at Dana-Farber Cancer Institute in Boston on April 5, 2006. The purpose of this regional meeting was to provide a comprehensive overview of current therapies and best practices in the management of cutaneous lymphoma and to showcase some of the important work ongoing at the Dana-Farber Cancer Institute. Approximately 60 clinicians from the Massachusetts, Maine, and Connecticut area attended and heard presentations from the co-chairs, David Fisher, MD and Thomas Kupper, MD and faculty including Madeleine Duvic, MD, Jennifer Jones, MD, Alain Rook, MD, Linda Wang, MD, JD, Lynn Wilson, MD and Judy Jones. This meeting was underwritten through an educational grant from Ligand Pharmaceuticals Inc. Ligand plans a series of these useful regional meetings at other centers of excellence around the US this year.



The Faculty of the Dana-Farber Regional Cutaneous Lymphoma Masters Conference (L to R): Linda Wang, MD, JD, Madeleine Duvic, MD, Lynn Wilson, MD, Thomas Kupper, MD, Judy Jones, Alain Rook, MD, Jennifer Jones, MD, David Fisher, MD.

Challenges in the Diagnosis and Treatment of Cutaneous Lymphoma in

Children by *Narin Apisarnthanarax, M.D., Joan Tamburro, D.O., Kevin D. Cooper, M.D. from Case Western Reserve*

While primary cutaneous lymphomas such as mycosis fungoides (MF), other cutaneous T-cell lymphomas (CTCLs), and primary cutaneous B-cell lymphomas (PCBCL) are predominantly cancers of middle-aged and elderly adults, these diseases do occur in the pediatric population, affecting children of all ages from infants to adolescents, and on to young adulthood. The challenges of diagnosing and treating such complex and often ambiguous diseases are magnified by parents' concerns, expectations, and the child's own level of understanding. It has only been in the last several years that investigators have truly begun to understand the characteristics of pediatric CTCL as more data have become available in larger studies.

Primary cutaneous lymphomas are relatively uncommon malignancies in adults, but they occur even less frequently in the pediatric population. For example, pediatric MF makes up only as much as 5% of all MF cases. It is thought that cases of pediatric MF are under-reported, since they may be even more difficult to diagnose than in adults. Pediatric MF is often mimicked by common benign skin conditions such as atopic dermatitis ("eczema"), psoriasis, pityriasis rosea, and tinea corporis. Similarly, hypopigmented MF, in which usually red MF lesions present as white patches, may be confused with vitiligo, idiopathic guttate hypomelanosis, and pityriasis alba and other post-inflammatory hypopigmentation. Additionally, physicians may generally be less inclined to perform skin biopsies on children presenting with a rash than on adults. When skin biopsies are performed, the results in early MF lesions are often not diagnostic of the disease. Given these

difficulties, the diagnosis of pediatric MF often cannot be made until an average of 5-8 years from the time that skin lesions first appear. Consequently, a rash that begins on a child often can not be diagnosed as MF until they are a young adult.



Pediatric primary cutaneous lymphomas are generally similar to those that occur in adults. All manifestations of PCBCL and CTCL that are seen in adults are also seen in the pediatric population, including follicular center lymphoma, marginal zone B-cell lymphoma, and the advanced stages of disease such as tumor-stage MF, Sezary Syndrome, erythrodermic MF, anaplastic large cell lymphoma, and subcutaneous panniculitis-like T-cell lymphoma. Early stages of disease (Stage IA-IIA MF) are the most common presentation, and the prognosis in these stages appears to be as good as in adults.

A few differences may exist between adult and pediatric cutaneous lymphomas. The hypopigmented variant of MF is a very common manifestation in pediatric patients, occurring in nearly 25% of all pediatric MF cases. Fortunately, hypopigmented MF has a relatively good prognosis. There is also evidence that cytotoxic CTCL is more common in pediatric patients. In adults, cytotoxic CTCLs are CD8+ cutaneous lymphomas (as opposed to CD4+ in classic MF) that usually behave very aggressively and have a worse prognosis. In children, however, CD8+ cytotoxic CTCLs usually pursue a non-aggressive course. The reasons for these differences are currently unknown. Primary cutaneous CD30+ anaplastic large cell lymphoma (PCALCL) may be less common in pediatric patients than adults. As in adults, however, pediatric patients

with localized PCALCL should be treated conservatively without systemic chemotherapy.

Treatment of CTCLs in pediatric patients is distinctly challenging. All treatment options that are available to adults are also available to pediatric patients, although rigorous safety testing in pediatric CTCL has generally not been performed. Treatments typically begin with topical therapies such as corticosteroids, nitrogen mustard, BCNU, phototherapy, and local radiation therapy. Therapy for more advanced disease includes interferon, oral retinoids, oral low-dose methotrexate, total skin electron beam therapy, and systemic chemotherapies. The more recently FDA-approved medications bexarotene (Targretin®) and denileukin difitox (ONTAK®) have not been studied in pediatric patients.

Generally, treatment decisions for pediatric patients are difficult to make because younger patients are more sensitive to the adverse effects of certain therapies. Of particular concern, is that given their young age, pediatric patients have more time to develop and experience the long-term adverse effects of anti-cancer therapies. When treated with oral/topical psoralen plus ultraviolet A (PUVA) or narrowband UVB phototherapy, local radiation therapy, or total-skin electron beam therapy, younger patients are inherently subject to greater risk for developing skin cancers because they have a longer expected lifetime ahead of them. Similarly, pediatric patients in need of systemic chemotherapy may develop leukemia later on in life, and patients taking retinoids such as isotretinoin (Accutane®) are at risk of premature stunting of bone growth. Topical corticosteroids and nitrogen mustard may be among the safer treatments for early-stage disease with less cancer risk. In the end, proper treatment for pediatric CTCL is individualized to the unique situation and needs of each patient, and should be carefully discussed and planned with consideration of risks and benefits with a cutaneous lymphoma specialist. *

Mark Your Calendar

**Cutaneous Lymphoma Patient
Educational Forum**
New York, NY
October 7, 2006

**9th Annual Brian V. Jegasothy Support
Group for CTCL**
University of Pittsburgh Medical Center
Pittsburgh, PA
October 14, 2006

**North American Educational Forum on
Lymphoma**, held by the Lymphoma
Research Foundation and Lymphoma
Foundation Canada
Los Angeles, CA
October 27-29, 2006

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Educational Forum**
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November 4, 2006



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