



Forum

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Spring 2008

From the President..... 2

From the Executive Director 2

Cutaneous Lymphoma Foundation Welcomes New Board Member 3

Clinical Trials Update 3

Cutaneous Lymphoma Patient Educational Opportunities..... 4

Advocacy: Skin Disease Research Day 5

Raise Money with FirstGiving... 5

NIAMS Day 5

Curing Advanced CTCL Patients: The Option of Bone Marrow Transplantation 6

NCCN Practice Guidelines in Mycosis Fungoides and Sézary Syndrome Now Available



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The National Comprehensive Cancer Network (NCCN) is an alliance of 21 of the world's leading cancer centers (see map, pg. 7) dedicated to improving the quality and effectiveness of care provided to patients with cancer. NCCN institutions work together to provide physicians and patients with up-to-date

management guidelines that would lead to better care and improved quality of life for cancer patients. The development of the NCCN practice guidelines are based on available scientific evidence integrated with the experience and judgment of the clinical experts in the alliance. These cancer guidelines are utilized by clinicians worldwide and serve as an

important standard-of-care resource. The NCCN institutions' experts have pioneered and lead the concept of multidisciplinary team approach to patient care and believe that the best cancer management is the result of integration of programs in clinical care, research, and education.

For the first time in NCCN history, practice guidelines in mycosis fungoides and Sézary syndrome (MF/SS) have been developed and are available on the NCCN website. Again, the MF/SS guidelines embodies the practice patterns in the 21 expert institutions in the NCCN alliance and integrates available scientific evidence in the management of patients with MF/SS. The current

For the first time in NCCN history, a practice guideline in mycosis fungoides and Sézary syndrome has been developed and is available on the NCCN website.

guidelines have been updated this year and includes the revised staging system and updated recommendation for diagnosis and staging evaluations.

The treatment recommendations are stratified by clinical stage and other key prognostic factors. In a given clinical stage, available treatments are presented in an algorithmic fashion as primary treatment options and choices for refractory or progressive disease. This MF/SS practice guideline will serve as an important standard-of-care resource

"NCCN" continued on page 7

From the President



As I watch the flowering trees bloom, the grass turn green and the new shoots of budding plants push through the ground, I know that spring has come to Michigan. It is a time of new growth and possibilities.

I remember when we held our first patient educational forum and thinking it would be wonderful if we could do this every year. Since January, we have held seven educational forums. Before the year ends, we will have held four, maybe five more.

When I started the listserv over 10 years ago, the only people that used the internet were computer nerds. We still have some of them that are with us 10 years later. As the internet grew and became more widely available, it has opened up a new world of information and support for everyone. We have grown to over 1,000 subscribers from over 20 different countries.

We held a CTCL Teleconference in collaboration with CancerCare and the Lymphoma Research Foundation last month that attracted over 600 people. Even more will be able to listen to it by going to our website at www.clfoundation.org and clicking on "Educational Opportunities." Who could have imagined that it was possible to have that many people interested in listening to physicians discuss cutaneous lymphoma?

Our website had over 4,000 visits from 66 different countries in the month of April! When I look at the map of where these people are coming from, it is obvious that the only areas that we are not reaching patients are areas that don't have a lot of internet access. The possibility of information being so widely disseminated ten years was inconceivable.

In 1999 and 2000, the first new treatments in ten years were FDA approved for CTCL (Ontak and Targretin). It took eight years before the next treatment (Zolinza) came on the market. This year we may see another two treatments come up for approval and many others are in clinical trials. The timeline for new possible treatments has increased tremendously.

The possibilities are endless. Up to this point, we have not discussed the possibility of a cure, but with the amount of research and new discoveries in the medical community, maybe it's not outside the realm of possibilities.



From the Executive Director



Having now participated in my first two Patient Educational Forums, I can definitely say that it is great to again be involved in patient programs. As previously reported, I spent the first two months in my new position meeting numerous physicians and learning about cutaneous lymphomas.

More recently, I attended Patient Educational Forums in Chicago, Illinois and Toronto, Ontario and joined members of the Coalition of Skin Diseases in Washington, meeting with members of Congress to push for additional research funding for the National Institutes of Health (NIH). I found the Patient Educational Forums to be stimulating and the time spent talking with the patients, family members and physicians in attendance served to reinforce my understanding about the value of the work of the Cutaneous Lymphoma Foundation.

During my career I have been involved with numerous patient programs including cardiac surgery, bone marrow transplant, hemodialysis, trauma centers and many community based primary care programs. I neither observed in those programs the kind of candid two way dialogue between physicians and patients that I experienced at the Cutaneous Lymphoma Patient Educational Forums, nor have I encountered groups of patients as well informed about their disease or as supportive of one another and willing to share information and experiences as the patients attending the forums and those interacting with one another using the Foundation's various communication channels.

Less exciting but equally important was the time spent in Washington meeting with members of Congress and their staffs to discuss government funding levels for research. Specifically, the discussions focused on increasing dollars for the National Institutes of Health (NIH) whose funding (after accounting for inflation) has essentially been flat for a number of years. The good news is that both members of the House and Senate have put forth bills that would mean a real increase in funding for NIH. Although the President has indicated his opposition to such an increase, the outcome will depend on the ultimate conclusion of what appears to be a difficult federal budget process.



Forum

The newsletter of the Cutaneous Lymphoma Foundation
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Forum is published by the
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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.

Cutaneous Lymphoma Foundation Welcomes New Board Member

The Cutaneous Lymphoma Foundation welcomes a new leader to the Board of Directors.

A native of Philadelphia, Susan Thornton has been in the health care information technology field for the last 24 years in various consulting, sales and marketing positions, and is currently working for Draeger Medical as the IT Solutions Marketing Manager for their anesthesia and intensive care software solutions. In addition to her professional career in health care technology, Susan has been active in many non-profit organizations in the Philadelphia region, holding Board positions at the Eastern Pennsylvania Chapter of the Sierra Club, The Leukemia & Lymphoma Society Eastern PA Chapter and was one of the original members of the Tristate Multisport Association. Susan's love of sports, in particular triathlons, has given her the opportunity to coach with the local Team in Training triathlon teams, become Race Director for the Patriot's Triathlon and mentor many beginning triathletes. Susan holds a Marketing/Management degree from the University of Pennsylvania's Wharton School and recently completed the Fundraising Certification Program at the University of Pennsylvania. *



Clinical Trials Update

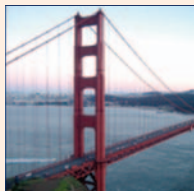
You may find clinical trials listed on www.clfoundation.org (click on "Clinical trials"). The three listed here are recent updates:

The first is open for patients of all stages of disease. The drug consists of a diphtheria toxin which is attached to an antibody that can specifically target cancerous T-cells. This trial is currently only available in Texas, but enrolled patients will receive full supportive stay (including travel and lodging). For more information about this trial, call Dr. Arthur Frankel, 254-724-4469.

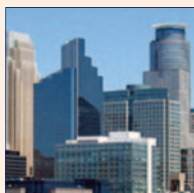
The second trial is a stem cell transplant study for patients with advanced disease, and is being conducted at the National Institutes of Health (NIH). To obtain more information and to find out if you qualify, call 1-800-411-1222.

The third is evaluating the effectiveness of topical romidepsin (depsipeptide) in patients with early-stage CTCL. Romidepsin has already shown to be effective in treating CTCL in some patients with later stages of the disease. For additional information, contact Susan L. Booher, R.N. at NCI, 301-402-1474.

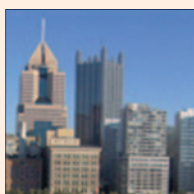
Cutaneous Lymphoma Patient Educational Opportunities



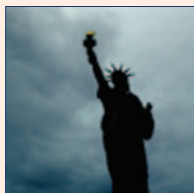
September 26, 2008: San Francisco
North American Educational Forum on Lymphoma, presented in partnership with the Lymphoma Research Foundation.



October 18: Minneapolis, MN
Lymphoma Workshop, presented in partnership with the Lymphoma Research Foundation



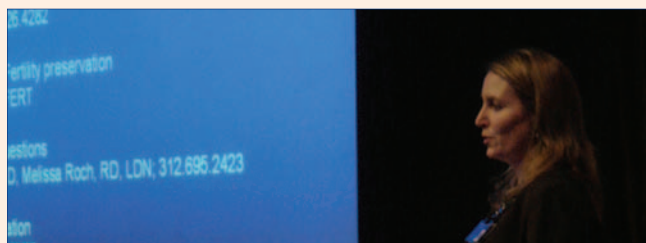
October 25: Pittsburgh, PA
11th Annual Brian V. Jegasothy Support Group for CTCL, presented in partnership with the University of Pittsburgh Medical Center



November 8: Brooklyn, NY
Lymphoma Workshop, presented in partnership with the Lymphoma Research Foundation



Dr. Steven Rosen and Dr. Christiane Querfeld at the Chicago Cutaneous Lymphoma Patient Educational Forum.



Lynne Wagner, PhD speaks at the Chicago Cutaneous Lymphoma Patient Educational Forum.



A panel of experts speak at the Toronto 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 or call (248)644-9014

These educational opportunities are made possible by generous unrestricted educational grants from:
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Advocacy: Skin Disease Research Day

April 10, 2008 was a beautiful day in the nation's capital with the cherry blossoms in full bloom as representatives from the American Academy of Dermatology, the Society for Investigative Dermatology and the Coalition of Skin Diseases met with members of Congress to discuss increased funding for the National Institutes of Health (NIH) and the cumulative impact of five consecutive years of inadequate budgetary support. This situation impacts current research, threatening advances in medicine and putting the US at risk of losing both an entire generation of young researchers and its global competitive edge. The Cutaneous Lymphoma Foundation was represented by Executive Director Gary Ross and Amanda Kik, Director of Education.

Due to prolonged budget constraints, the NIH currently approves only one in four original research applications it receives. This practice has two negative effects. First is a tendency to fund conservative research applications over more innovative proposals that might achieve breakthroughs in combating diseases. Second is the fact that a growing backlog of failed applications (NIH

only approved 24 percent of applications received in 2007) has pushed the average age of a researcher receiving his or her first grant from 39 years of age in 1999 to 43 in 2007. This kind of obstacle will ultimately result in fewer students pursuing medical research as a career.

This year there is some reason for optimism regarding research funding as both the Senate and the House are proposing increases for NIH in the pending federal budget. The Senate approved a Budget Resolution which contains a \$3 billion, or 10.3% increase in funding to the NIH in fiscal year 2009, and an overwhelming number (179) of Representatives are supporting a 6.5% increase in funding. The message that the advocates took to the legislators on April 10 was to support at least a \$1.9 billion or 6.6 percent increase in funding to the NIH. Based on a Bureau of Economic Analysis evaluation, this amount would restore NIH's purchasing power and provide for a real 3% increase in available dollars. A proportional share of these dollars would be allocated to skin disease research as part of the programs of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS). *

Raise Money with FirstGiving

Raise money for the Cutaneous Lymphoma Foundation, the only organization that supports patients with mycosis fungoides, Sézary syndrome and all forms of cutaneous lymphomas.

firstgiving

Are you having a birthday? Running a race? Celebrating a marriage? Would you like to honor someone? Use FirstGiving to utilize these important life events to raise funds for the important work of the Cutaneous Lymphoma Foundation.

It is quick and easy to get started. Simply visit www.firstgiving.com/CLF, and create a personalized page. You can input your story and upload photos. Then, just send an email to your friends and family and watch the funding roll in!

NIAMS Day

In March, the NIAMS Coalition gathered in Washington, DC to submit testimony to the House Committee on Appropriations in support of the National Institute of Arthritis and Musculoskeletal and Skin Diseases (NIAMS).

The NIAMS Coalition is comprised of more than 70 organizations (medical, patient advocacy and research based) dedicated to advancing the critical research funded at NIAMS.

The Cutaneous Lymphoma Foundation (represented by Judy Jones, President) and the Coalition of Skin Diseases urged Congress to support an increase in funding for the National Institutes of Health (NIH) and NIAMS.

If NIAMS does not get consistent funding, the nation risks losing the promising research that is so important to finding cures and providing more effective, lower cost therapies and treatments. Because cutaneous lymphomas are a rare disease, this is especially important for our patients, caregivers and medical professionals.



Curing Advanced CTCL Patients: The Option of Bone Marrow Transplantation



Dr. Madeleine Duvic is Professor and Deputy Chair of the Department of Dermatology at the University of Texas MD Anderson Cancer Center. She has been a pioneer

in cutaneous T-cell lymphoma research and sits on the Cutaneous Lymphoma Medical Advisory Board.

Stem cell transplants are being used for a variety of medical conditions from heart failure to cancer. During the International Society for Cutaneous Lymphomas (ISCL) meeting held in February, we discussed the pros and cons of bone marrow transplantation for CTCL patients. Dr. Fred LeMaistre runs a transplant center in San Antonio and gave the keynote address. Other speakers summarized their results at other CTCL centers including Northwestern, Ohio State, Stanford, and MD Anderson.

Hematopoietic stem cells (HSC) are present in both the bone marrow and the blood stream. HSC can be collected from either source, but obviously the blood is more accessible with less discomfort. Bone marrow transplant refers to using HSC collected from the bone marrow while peripheral SC are from blood. HSC are most commonly used therapeutically for treating patients with leukemia and lymphomas but autoimmune diseases and even heart failure may respond.

An autologous (auto) stem cell transplant (auto-SCT) uses the patient's own stem cells, expands them in culture, and they are reinfused when the patient receives high dose chemotherapy.

Allogeneic SCT (allo-SCT) are with stem cells from another person who is called a matched donor. Cells all have marker proteins (called HLA or MHC antigens) that tell the body they belong. If you give any kind of transplant that is not matched it will be rejected immediately unless high doses of immunosuppressive therapies are given. The best match, of course, is an identical twin. Brothers or sisters can also be identical to one another and close matches for HLA antigens. In the event a related donor is not available, unrelated donors who are willing to help are sought from the national donor database. Failing that, cord blood stem cells can be used and harvested from the

The point of having a stem cell transplant is to allow patients to receive very high dose chemotherapy to get rid of the cancer and knock out their own bone marrow function.

umbilical cord.

The point of having a SCT is to allow patients to receive very high dose chemotherapy to get rid of the cancer and knock out their own bone marrow function. Without the transplant, a patient is at greater risk for a deadly infection or other complication. In the past decade, non-ablative SCTs have been modified. The dose of chemotherapy is lower and the graft (donor stem cells) is allowed to slowly take over the patient's marrow (called chimerism - because the patient and donor co-exist together for a while). This process is not as dangerous but the price is a side effect called graft vs host disease (GVHD). Donor T-cells can attack the skin, GI tract, liver, lungs, and eyes and if this is severe can be even worse than having CTCL in its most severe form.. Luckily, there are immunosuppressive

drugs that can suppress GVHD but again make the patient more susceptible to infections. GVHD has a beneficial effect of killing off some of the tumor cells.

Having a SCT actually only takes about 5 minutes. It is exactly like getting a blood transfusion through a vein. It is a rescue tool given just following a week of high dose chemotherapy in the hospital. SCT rescues the patient's immune system. Since CTCL is a disease of the immune system, replacing it with another's system makes good sense whereas an auto-SCT does not do as much, although it may improve the disease for a while.

Which CTCL patients should

consider having a SCT and what kind? The risk of death from infection or graft vs host disease are real risks, so SCT should only be discussed when the CTCL is aggressive or has progressed to the point that high dose

chemotherapy is needed. First, we know that auto-SCT can improve but not cure CTCL patients and the disease will come back sooner rather than later. Secondly, allo-SCT have the potential to cure CTCL but require a 10/10 HLA matched donor and a relatively healthy patient who is able to tolerate high dose chemotherapy and has a good care-giver support team. The ideal patient is young, has at least stage IIB with large cell transformation soon after diagnosis or has blood, node or internal disease such that their median survival estimate is only 2-3 years. Sézary patients who are miserable from their disease may also be appropriate to transplant earlier rather than later. Since the risk from transplant procedure includes death from infection and chronic GVHD, only for a patient whose CTCL requires chemotherapy

and has a good chance of succumbing to the disease within the next 2-3 years should be considered for an allo-SCT at this time.

At our center we have found that total body skin electron beam radiation, given just prior to the allo-transplant, decreases tumor burden and may have immunosuppressive effects on the GVHD. Electron beam treatment takes 8-9 weeks with a rest period. It is followed by 2-3 weeks of in patient chemotherapy, then the transplant. After the patient's counts recover, they are transferred to outpatient and make daily clinic visits for the next 100 days, until the risk of acute GVHD

is past. Immunosuppressive therapy or photopheresis is given to prevent GVHD. Drugs to prevent viral, fungal, and bacterial infections are administered intravenously. Around the time of the transplant and following it the patient is at risk for sepsis from their lines and poor immune systems. They often are kept in isolation and wear masks. CTCL may come right back after the SCT. In this case, donor lymphocyte infusions are used to supplement the transplant. SCT have a graft vs tumor effect if the disease relapses early, before the graft has fully taken. It is also possible to wind up with both GVHD and recurrent MF after transplant, which is a difficult situation

but may respond to photopheresis or denileukin diftitox.

In summary, transplantation is the most extreme option for treating CTCL patients but does offer the chance of cure. It is safer if done at a center with experience in CTCL and in transplantation where the mortality rate is 10-20% or better. Newer drugs for treatment of CTCL are being developed as are better ways to treat and prevent CTCL. Therefore, patients who get transplanted have often tried other treatment options first and are willing to take the risk of having complications of GVHD, relapsed disease, infections and even death. *

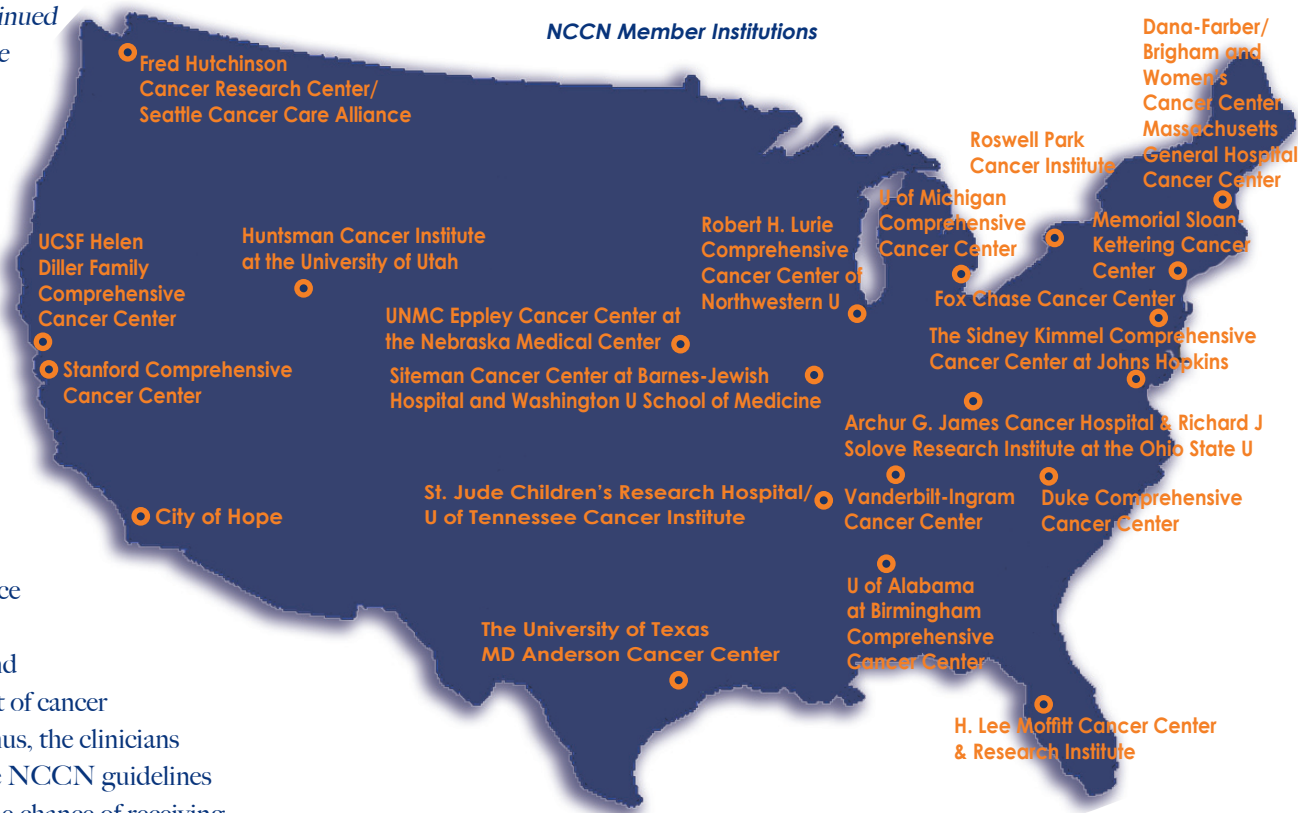
"NCCN" continued from front page

not only for clinicians and patients, but also for medicare and other health insurance providers. Medicare and insurance carriers refer to the NCCN practice guidelines for approval and reimbursement of cancer treatments. Thus, the clinicians who follow the NCCN guidelines will increase the chance of receiving authorization and reimbursement for treatments in the care of our patients with MF/SS. The MF/SS guidelines will be updated as new treatments and scientific evidence are available that justify incorporating the information in clinical practice.

The next skin topic that will be

addressed by the NCCN NHL panel is to develop a clinical practice guideline for primary cutaneous B-cell lymphomas. Practice guidelines for other cutaneous T-cell lymphomas will follow in the coming years including the CD30+ lymphoproliferative disorders. Please

visit the official NCCN website at "nccn.org" for more information about NCCN and its resources and activities. For MF/SS practice guidelines, please go to the "NCCN Clinical Practice Guidelines," then click on "Non-Hodgkin's Lymphomas." *



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