

Lymphoma TODAY

Condon Family Follicular Lymphoma Research Challenge Met and Exceeded!



Tom and Christy Condon

As many of you read in the Spring 2006 issue of *Lymphoma Today*, LRF Board member Tom Condon and his family

issued a \$1 million challenge grant to the Foundation. They would pledge \$1 million for follicular lymphoma research, payable over no more than five years, if LRF could raise another \$2 million in donations or pledges by the end of December 2006. LRF is delighted to announce that the challenge goal was exceeded and that, as of December 31st, slightly more than \$5 million has been raised to fund follicular lymphoma research. A very special “thank you” is owed to the Condon family for initiating this effort. In addition, an enormous thank you is due to the Starr Foundation for its \$3 million gift that is to be given over two years and to all of the other individual donors who responded to the challenge and whose gifts were instrumental in helping the Foundation meet the challenge.

LRF is also very pleased to announce that because of the funds raised in response to the challenge, the first four follicular lymphoma research grants have already been awarded. Details of these grants will be given in the next issue of this newsletter.

Upon hearing from LRF that his family’s challenge had been met, Tom said, “On behalf of the entire Condon family, thank you to everyone who made the Condon Family Follicular Challenge a smashing success. The money raised in 2006 is already being used to fund exciting new research to fight follicular lymphoma. The Condon family is more convinced than ever that the LRF can help lead the way to a cure. We will strengthen our efforts to keep the campaign for follicular lymphoma research alive, and we hope that others touched by lymphoma will join us by supporting the LRF.”

Please Visit LRF’s New Websites!

www.lymphoma.org

LRF is pleased to announce that its main website has been redesigned! We hope that you find it more interactive, visually pleasing and informative. Thank you to all who completed the website evaluation and helped guide the development of the new website. Your feedback is welcome. Please send comments to LRF@lymphoma.org.

www.cllinfo.org

A new website for people affected by chronic lymphocytic leukemia or small lymphocytic lymphoma has been developed in partnership with the Chronic Lymphocytic Leukemia Information Group (CLIG).

Additional websites that LRF maintains include:

www.mantlecelllymphoma.org

This website is an educational resource for patients, caregivers and researchers who are battling mantle cell lymphoma.

www.lymphofacts.org

This website contains patient friendly educational materials for lymphoma patients in basic English, Spanish and Common Chinese.

TABLE OF CONTENTS

Letters	2
Clinical Trials.....	3
Research	4-7
Chapters	8-9
News	10
Development	11-12
Education	13
Advocacy	14
Support.....	15

LRF ONLINE: Register online at www.lymphoma.org to receive the e-mail edition of *Lymphoma Today* and stay informed about the latest news in lymphoma.

Lymphoma Research Foundation (LRF) is delighted to announce that it recently received a four star rating from Charity Navigator for the third year in a row.

Charity Navigator is a nonprofit organization providing analysis and ratings for over 4,000 charities with out charge. They provide objective and unbiased analytical information on some of America’s largest charitable organizations. To learn more about Charity Navigator, visit their website at

www.charitynavigator.org



LYMPHOMA RESEARCH • FOUNDATION

The quarterly newsletter of the Lymphoma Research Foundation

Content Copyright 2007 All rights reserved

FOUNDERS

Ellen Glesby Cohen

Barbara Freundlich

Jerry Freundlich

BOARD OF DIRECTORS

Errol M. Cook, *Chairman of the Board*

Michael Ditzian, *Executive Vice President*

Andrew Madoff, *Treasurer*

Evelyn Lipori, *Secretary*

Oliver Press, M.D., Ph.D.

Chairman, Scientific Advisory Board

Morton Coleman, M.D.

Chairman, Medical Affiliates Board

George Beebe

Joseph R. Bertino, M.D.

Tom Condon

Robert E. Fischer

Barbara Freundlich

Jerry Freundlich

Nancy Januszewski

Marie L. Matthews

George Ntim

Steven J. Prince

Leonard Rosen

Michael Werner

Editors: Jennifer Mills, LMSW, MPH, and Carolyn Bell, MSW

Design: H Plus Inc., Pleasantville, NY

8800 Venice Boulevard, Suite 207

Los Angeles, CA 90034

Telephone (310) 204-7040

(800) 500-9976 Fax (310) 204-7043

111 Broadway, 19th Floor

New York, NY 10006

Telephone (212) 349-2910

(800) 235-6848 Fax (212) 349-2886

Email: LRF@lymphoma.org

Website: www.lymphoma.org

Lymphoma Today is published by the Lymphoma Research Foundation for the purpose of informing and educating our readers about lymphoma and to keep them informed of ongoing work and accomplishments of the Lymphoma Research Foundation, with the ultimate goal of finding cures for lymphoma.

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 Lymphoma Today without first consulting with his or her physician.

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

Dear Friends,

We would like to begin by saying thank you to all of you who have commented on LRF's new publication, *Research In Focus*, which you should all have received in January. We are also very proud to announce that the Condon Family Follicular Challenge grant has been met!

Due to several large donors and a whole host of individuals who contributed over the past year, LRF has been able to raise \$5 million to support research focused on finding a cure for this form of lymphoma. Thank you again to all of you who helped us reach this goal. We look forward to keeping you up-to-date on the specific research projects that these funds will be supporting in future issues of this newsletter and on LRF's new website.

On page 10, you will meet the three newest members of the LRF Board of Directors and the fourteen new members of the Foundation's Scientific Advisory Board. We are

Due to several large donors and a whole host of individuals who contributed over the past year, LRF has been able to raise \$5 million to support research focused on finding a cure for this form of lymphoma.

truly thrilled to have added these distinguished new individuals, all of whom serve as volunteers, to membership on these two boards that collectively do so much work for the LRF! In addition, we are thrilled to introduce you to Amy Junge, LRF's first paid staff member of a chapter. On page 8, you can read about Amy's background and extensive experience in the nonprofit world. She joined LRF as the Executive Director of the Chicago Chapter on December 4th, 2006 and is already busy working with our wonderful Chicago chapter members on expanding their programming and fundraising activities.

We also have four new chapter presidents who took office over the past

several months. Without the countless hours of volunteer effort that go into running our chapters, we would not be as successful an organization as we have become. Sincere gratitude is due to these truly unsung heroes who make it all work at the local community level!

We also think that you will appreciate reading about the Young Adult Lymphoma Survivor survey results that starts on page 13. The analysis of the on-line survey helped LRF launch a new program specifically for young adults diagnosed with lymphoma.

We hope you enjoy this issue of the newsletter and as always, please let Sue know if there are topics that are of particular interest to you that you would like to see covered in future issues. You can e-mail her at sbliss@lymphoma.org.

All our best,



Errol Cook
Chairman of the Board



Suzanne Bliss
President



Overcoming the Threat to Clinical Trials

In November 2006, LRF’s Research Department attended *Summit X: Clinical Trials in Crisis*. This was the 10th in a series of annual conferences hosted by some of the most important organizations in the cancer clinical trials world. The message: the clinical trials system is facing a serious crisis.

A number of threats are coming together. First of all, for the first time in decades, the National Cancer Institute’s (NCI) budget has been reduced, including funding for the Cancer Cooperative Groups, which sponsor nearly half of Phase III clinical trials. At the same time, more trials are needed as advances in science make novel, potentially lifesaving treatments possible. Second, less than 7% of adult cancer patients are enrolling in trials.

So how should the cancer research community respond? Several presenters proposed lobbying for more federal dollars, but this is unlikely to be productive, given the current federal deficit of \$8.6 trillion. The idea of slowing accrual (enrolling fewer patients in trials), as the NCI recently advised, was rejected. Creating a partnership among the clinical trials groups, industry and the government would certainly help and will hopefully be pursued. Coordination among them would prevent unnecessary duplication of effort, and make it possible to focus resources on the most promising targets. However, achieving such cooperation and coordination is likely to be a long-term effort.

Another solution that was offered is “Adaptive Trial Design” —changing the way clinical trials are designed so as to get scientifically valid results with smaller,

Creating a partnership among the clinical trials groups, industry and the government would certainly help and will hopefully be pursued.

	Frequentist	Bayesian
Paradigm	Hypothesis Testing	Learning
Question	How likely are the trial results, given there really is no difference among treatments?	How likely is there a true difference among treatments, given the trial data?
Drug Approval	Pivotal Trial	Weight of Evidence
Trial Designs	Single Stage	Adaptive
Statistics	Traditional	Bayesian

less expensive and more patient-friendly trials. An example of how this could be accomplished was brought forward by Jane Perlmutter, Ph.D., a breast cancer survivor and patient advocate. While not a biomedical researcher, she has studied the issue and identified a strategy that is already being used with success at MD Anderson Cancer Center, and elsewhere. Many other researchers are also working adaptively, using a variety of approaches.

The key to Dr. Perlmutter’s proposed method: Bayesian statistics. All of modern science is based on statistics: the researcher makes observations on a *sample* of whatever he or she is studying, then makes inferences about the entire *population*, which she can never observe directly. In conventional trial design, the research starts with a *null hypothesis* or assumption: the study treatment is *not different* than the *control* (the standard treatment it is being compared to). In the case of a Phase III trial, the sample of patients is then randomly assigned, in equal numbers, to receive either the study or the control treatment. The experiment then proceeds until a fixed endpoint is reached. Only then are the study and control groups compared. If statistical calculation shows a *significant* difference between the two — hopefully, the patients on the study treatment did better — the researcher can conclude *that the null hypothesis was wrong*: indicating there is a difference between the two treatments.

This traditional statistical approach is called *frequentist*, and has been the gold

standard throughout the latter half of the 20th century, making possible all the tremendous advances that have been attained in medicine and other sciences. While the results are scientifically rigorous, there are also a few limitations. First, the frequentist approach generally requires large “*sample sizes*,” regardless of the prevalence of the condition being studied. Second, it does not allow for formally incorporating existing data (the results of a previous trial of the study drug in a similar condition, for example) or data collected in the course of the trial. It also takes a long time — frequently years — until a study produces results.

Given the reality of limited patient enrollment, Bayesian statistics can help address these limitations. A Bayesian approach to scientific progress focuses on continuous learning. *Probabilities* are assigned to different trial outcomes, based on prior knowledge (results of earlier trials) and continuously updated as new data are gathered, as opposed to either accepting or rejecting the null hypothesis as in the frequentists’ approach. However, only with the advent of modern computing power has it become practical to apply Bayesian statistics. (See the table for a comparison of the two approaches.)

Adaptive Trial Designs, which are receiving increasing attention, are a natural fit for the Bayesian approach. In these trials, things can be changed during the course

continued on page 7

Radioimmunotherapy Q&A

Oliver Press, M.D., Ph.D., talks about his research in radioimmunotherapy, and what the future may hold for this promising new treatment for lymphoma.

By Jo Cavallo

Radioimmunotherapy (RIT) utilizes radiation and monoclonal antibodies to treat some types of cancer. Two FDA-approved drugs, Bexxar® (Iodine 131 Tositumomab) and Zevalin® (Yttrium-90 Ibritumomab tiuxetan), use radioactively-labeled monoclonal antibodies delivered intravenously to target the CD20 antigen found on the surface of cancerous B-lymphocytes in patients with B-cell non-Hodgkin lymphoma while sparing unnecessary radiation exposure to healthy cells.

We asked Oliver Press, M.D., Ph.D., Professor of Medicine and Biological Structure at the University of Washington, member of the Fred Hutchinson Cancer Research Center in Seattle and Chair of the Lymphoma Research Foundation's Scientific Advisory Board, about his research in RIT and how it may have applications in other lymphomas.

Explain what radioimmunotherapy is and how it works.

Oliver Press, M.D., Ph.D.:

Radioimmunotherapy refers to the use of radiolabeled monoclonal antibodies for treating cancer. The greatest successes to date using radioimmunotherapy have been observed in clinical trials treating lymphomas and leukemias. The two FDA-approved products, Bexxar and Zevalin, are both radiolabeled antibodies directed against a molecule called CD20, which is present on nearly all B-cell malignancies. Both drugs use beta-emitting radioisotopes. The antibody binds to tumor cells but doesn't bind to other cells in the body (except for B-lymphocytes). The antibodies can induce some cell death by themselves but most of the cell killing derives from the beta particles that are emitted by the radioisotopes when they decay. The beta particles cause breaks in the chromosomes of the tumor cells, leading to their death.

One of the advantages of radiolabeled antibodies is that the beta particles work over many cell diameters, thereby producing a "crossfire effect" that isn't present with unlabeled antibodies. The crossfire effect allows radiolabeled antibodies to kill cells in the middle of clumps that don't

have direct access to the antibody as well as mutant tumor cells that don't express CD20.

These cells would not be killed with an unlabeled antibody.

What does the current research show about both the effectiveness of RIT and the amount of toxicity associated with the treatment?

Oliver Press, M.D., Ph.D.: The studies have consistently shown that both of these products are very effective. For example, the response rate in patients with relapsed follicular lymphoma is generally between 60% and 80%, which is very good for a single agent. The complete remission rate is 20% to 40%, which again is excellent for a single agent. Both Bexxar and Zevalin are generally very well tolerated. The main toxicity is predictable suppression of the bone marrow, which occurs somewhere between four and eight weeks after treatment.

The important thing for doctors and patients to remember is that with radioimmunotherapy, it is generally a brief one-time treatment in contrast to chemotherapy where usually six or eight cycles of therapy are administered. Consequently, with chemotherapy there are six or eight episodes of bone-marrow suppression, whereas with RIT there is just one episode of bone marrow suppression.

Why is RIT only being used in relapsing patients and not as a frontline treatment?

Oliver Press, M.D., Ph.D.: It is only FDA-approved for use in relapsing patients because the early clinical trials were done in that setting. Having said that, I think that some of the most exciting new data is in frontline treatment of patients with follicular lymphoma.

There are six studies that have tested RIT as frontline treatment and all six of them have shown outstanding results. The overall response rates in those studies have been between 90% and 100% and the complete remission rate in those studies have been anywhere from 60% to 95%.



Oliver Press, M.D., Ph.D.

The duration of responses in the studies that are mature have all been more than five years and many patients have remained in continuous complete remission without ever relapsing. I think that all six of the studies look extremely promising, but RIT is not yet approved by the FDA for that setting, so reimbursement is hard to obtain at this time for the frontline setting.

The sequencing of treatment is important to lymphoma patients. When is the optimal time in terms of benefits and risks for patients to receive radioimmunotherapy?

Oliver Press, M.D., Ph.D.: Today, the optimal time is to either receive it as the second-, third- or fourth-line treatment. If RIT were FDA approved for frontline treatment, as I mentioned, that would also be an attractive setting. However, without more data and without FDA approval I can't officially recommend it as frontline treatment yet.

Is radioimmunotherapy a treatment that could be effective in all lymphomas?

Oliver Press, M.D., Ph.D.: It is a treatment that can be used for many lymphomas. It is clearly very effective for follicular lym-

continued on page 5

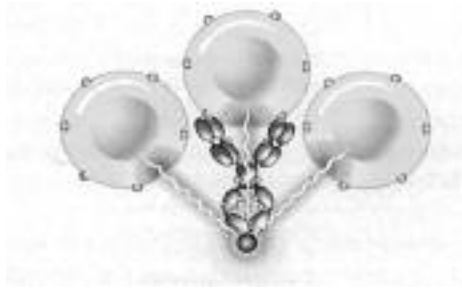
Radioimmunotherapy continued from previous page

phoma, transformed follicular lymphoma, marginal zone lymphomas and many lymphoplasmacytic lymphomas. It is less effective for small lymphocytic lymphoma, which doesn't express much CD20 on its cell surface. Studies with diffuse large B-cell lymphoma and mantle cell lymphoma show that these tumors respond to RIT but the response durations are shorter than with the indolent lymphomas.

Does using RIT preclude other treatments in the future?

Oliver Press, M.D., Ph.D.: I think this is a big misconception that a lot of patients and doctors have. Radioimmunotherapy does have some impact on the bone marrow reserve but it is probably no greater than giving a course of chemotherapy. Two published studies have looked at the ability to give subsequent therapies in patients who previously received RIT. These studies found that it is quite feasible to tolerate further chemotherapy or collect stem cells for autologous stem cell transplantation in nearly all the patients where it has been attempted.

I think that there should not be a lot more concern about giving RIT than there is about giving another course of chemotherapy. Having said that, virtually all of our treatments with the exception of rituximab (Rituxan®) do have some impact on bone marrow stem cell reserve and the more treatments a patient receives the more likely it is that the



Radiolabeled antibody killing cancer cells

patient will have low blood counts or infections.

What are some of the financial and practical issues for patients receiving the treatment from their local oncologist?

Oliver Press, M.D., Ph.D.: I have found that patients who receive RIT are generally extremely happy with the convenience of the treatment because they come into a treatment center for a test dose one week and a treatment dose the next week and then they are done.

However, physicians often don't feel RIT is as convenient as the patients do because the hematologist or oncologist needs to coordinate treatment with a nuclear medicine physician. These logistic considerations have resulted in RIT being underutilized. There are also billing and reimbursement issues. The hematologist or oncologist can't bill for the radiolabeled antibody treatment administered by the nuclear medicine physician so there is a

financial disincentive for referring patients for this treatment.

There is also concern by some physicians that they'll lose control over their patients. In addition, like any new treatment, RIT is expensive but it is no more expensive than getting a full course of treatment using other new agents.

What are some of the questions still needing answers through clinical trials about RIT?

Oliver Press, M.D., Ph.D.: Validating the use of RIT as frontline treatment is an important question. There is currently a major national study comparing R-CHOP chemotherapy versus CHOP Bexxar to see if there is an advantage in terms of progression-free survival and overall survival for patients getting upfront RIT. Other trials are looking at R-CHOP followed by a radiolabeled antibody and rituximab maintenance.

You talked about some of the misconceptions of RIT, are there others?

Oliver Press, M.D., Ph.D.: There is a pretty widespread radiation phobia among both patients and physicians. RIT is not a modality that is in the comfort zone of many people and there are some unrealistic concerns about how dangerous it is. There is also a lot of misinformation suggesting that RIT is more damaging to the bone marrow than it really is.

Radioimmunotherapy Clinical Trial Spotlight

A Phase III national, multi-center clinical study, sponsored by the National Cancer Institute and its oncology cooperative groups, is enrolling patients with previously untreated follicular lymphoma.

Patients will be assigned to treatment with CHOP chemotherapy, plus Rituxan® (rituximab) monoclonal antibody treatment or CHOP chemotherapy, plus Bexxar® (tositumomab) radioimmunotherapy. The purpose of the study is to see how well these treatments work when given together for previously untreated patients with follicular NHL. It is not yet known which combination of treatments is more effective. Hundreds of lymphoma patients will be enrolled in this study at numerous medical centers throughout the United States.

Contact the LRF Helpline and Clinical Trials Information Service at 800-500-9976 or helpline@lymphoma.org if you would like additional information about eligibility and a referral to a medical center in your area that is participating in this study.

RIT Teleconference for Patients and Loved Ones

May 18, 2007 - 1:30-2:30pm EST

LRF will be hosting a telephone education workshop for patients and loved ones. Drs. Zelenetz and Vose will present the latest on RIT research and clinical trials and will be available to answer your questions during this hour-long program. This program is free of charge, but registration is required. Please call our Helpline at 800-500-9976 or visit our website at www.lymphoma.org for more information.

Highlights from the American Society of Hematology Meeting

Data from 153 abstracts on lymphoma studies were presented at the 2006 American Society of Hematology Conference held in Orlando, Florida, last December. Below is a review of some of the study findings, which may lead to new directions in the staging and treatment of the various lymphomas.

Anaplastic Large Cell Lymphoma

- A report from the International T-Cell Lymphoma Project about 186 cases of anaplastic large cell lymphoma (ALCL), found that 60% of systemic ALCL patients express the anaplastic lymphoma kinase ALK protein (ALK-positive) and have a higher survival rate than ALK-negative patients. Contrary to previous reports, ALK-negative ALCL patients had a superior outcome compared to unspecified peripheral T-cell lymphoma patients.

Diffuse Large B-Cell Lymphoma

- Last year, the U.S. Food and Drug Administration (FDA) approved the addition of Rituxan® (rituximab) to CHOP (cyclophosphamide, adriamycin, vincristine and prednisone) chemotherapy. In the RICOVER-60 trial, elderly patients with diffuse large-B-cell lymphoma (DLBCL) were treated either every 14 days or every 21 days with six to eight cycles of CHOP or R-CHOP. The results showed that patients given six cycles of R-CHOP-14 resulted in a three-year overall survival rate of 78%.
- Reports from the Dutch-Belgian Hematology-Oncology Cooperative Group showed that the addition of six doses of Rituxan to CHOP-14 for eight cycles improved both the overall survival rate and the failure-free survival rate in elderly patients.
- Data was presented on the prognostic and risk factors of DLBCL. In a study of DLBCL patients, the presence or absence of bone marrow disease had clinical significance. For example, 41 of the 488 patients who had concordant DLBCL in the bone marrow had the worst outcome. Twenty-eight had discordant histology with predominantly

small B-cells, and 11 had atypical lymphoid infiltrates. The study also found that patients with the discordant low-grade B-cell lymphoma had a poorer prognosis than patients who had no marrow involvement.

- Although primary DLBCL of the testis has been linked with poor long-term survival, a Phase II study of 45 patients by the International Extranodal Lymphoma Study Group 10 found that the overall survival rate of Stage I patients treated with R-CHOP, intrathecal methotrexate and prophylactic scrotal radiotherapy and Stage II patients treated with loco-regional radiotherapy, was 88% and the event-free survival rate was 78%.
- Two new oral targeted agents, Revlimid® (lanalidomide) and Zarnestra® (tipifarnib), are showing promising results in relapsed and refractory DLBCL patients.

Follicular Lymphoma

- The results from several randomized clinical trials using Rituxan in different chemotherapy regimens including CVP (cyclophosphamide, vincristine and prednisone), CHOP (cyclophosphamide, adriamycin, vincristine and prednisone), MCP (mitoxantrone, chlorambucil and prednisolone) and as a single therapy were updated and showed that the overall survival rate is significant. In a study of 321 patients with a median age of 53, the estimated four-year disease-free survival rate was 54% for patients receiving R-CVP compared with 17% for CVP alone. Patients receiving R-CVP had a significant improvement in overall survival compared to CVP. The German Low Grade Lymphoma Study Group (GLGLSG) reported that the time to treatment failure in patients older than age 60 with R-CHOP was five years versus just 2.1 years for CHOP. More importantly, the R-CHOP regimen prolonged the overall survival rate in elderly patients by 90% compared to 81% treated with CHOP chemotherapy regimen.

- Data from two GLGLSG studies of 1,332 patients showed that CHOP versus MCP and CHOP versus R-CHOP trial showed that Rituxan was responsible for the differences in the time to treatment failure. Regarding overall survival, after adjusting for Rituxan as the most relevant determinant, the differences between the study groups remained significant. The conclusion by the GLGLSG is that Rituxan is the essential treatment modality responsible for the improvement in the short- and long-term outcome of patients with advanced stage follicular lymphoma.

Hodgkin Lymphoma

- Results by the German Hodgkin Lymphoma Study Group of its HD12 trial showed that escalated doses of BEACOPP X 8 chemotherapy improved the failure-free survival and the overall survival compared to COPP/ABVD X 8 and baseline BEACOPP X 8. The HD12 trial involved 1,661 patients and compared escalated doses of BEACOPP X 8 with escalated BEACOPP X 4 followed by baseline BEACOPP X 4 with or without radiation therapy to initial and bulky disease. Of those 1,661 patients, 93% achieved a complete remission, 2.2% progressed early, 4.6% relapsed, 8.2% died with 3.2 percent of the deaths related to acute toxicity at a median follow-up of 48 months. Second neoplasms were observed in 3.2% of patients.

Mantle Cell Lymphoma

- There were updates from 34 clinical trials in mantle cell lymphoma (MCL), which included studies from all stages of the disease from newly diagnosed patients to those who were already treated and had relapsed or had recurrent disease. In a Phase II trial of 11 relapsed MCL patients at Cornell Medical Center using a combination of RT-PEPC (the addition of rituximab and thalidomide to prednisone, etoposide, procarbazine and cyclophosphamide), 82% responded to the treatment and the majority did not show disease pro-

continued on page 7

ASH Meeting

cont. from previous page

gression within the first 10 months of follow-up. In addition, researchers are studying what role the combination therapy may have in targeting angiogenesis.

Peripheral T-Cell Lymphoma

Two studies showed the benefits of incorporating autologous stem cell transplantation into the initial treatment of peripheral T-cell lymphoma.

- The Nordic Lymphoma Group reported Phase II study results of using CHOEP (cyclophosphamide, doxorubicin, vincristine, etoposide and prednisone) chemotherapy followed by an autologous stem cell transplant. Of the 77 patients in the study, 58 patients had the transplant and one-year post transplant, 30 of 39 patients were in complete remission.
- In a review of 89 patients with unspecified peripheral T-cell lymphoma, there was an improved overall survival rate and disease-free survival rate in patients receiving a stem cell transplant, either at the time of first response or at the time of relapse.

Clinical Trials continued from page 3

of the trial, based on the accumulating data, as long as the “adaptation rules” are established prior to starting the trial. For example, if one of the treatments appears to be superior, a greater proportion of patients can be assigned to that treatment, although they are still assigned randomly. The advantages: smaller samples are generally required and more of the patients receive the better treatment. In short: the trial is more efficient, and better for the patients. And when done correctly (which can be more difficult than traditional trials), the results are just as rigorous and valid.

So why isn't everybody doing it this way? For one, FDA requirements favor the tried and true frequentist approach. For another, software development for Bayesian statistics has been slow, but is catching up. Bayesian approaches are in use, however, especially for Phase I and II trials. Donald Berry, bio-statistician at MD Anderson, has pioneered their use, and some pharmaceutical companies are in the vanguard too. As the advantages of Bayesian methods become evident, more researchers will use them. Also encouraging is that the FDA is working on guidance documents that will help researchers

understand appropriate applications of Adaptive Trial Designs and other innovations.

Another important theme at the conference was enhanced communication — both with patients, and with the community oncologists who treat them (many of whom hesitate to refer their patients to large trials). Summit working groups have been assembling web-based materials designed to help researchers in both these areas. With regard to patients, materials are offered both on education about trials, and on creating patient-friendly trial documentation. For more information on this, see the Summit's website at: http://www.cancersummit.org/work_groups.htm.

For more information on Bayesian statistics and Adaptive Trial Design, see Dr. Perlmutter's webpage at: http://www.gemini-grp.com/index_files/Bayesian.htm.

Thanks to Dr. Perlmutter, for her help in writing this article and to the Summit, for their kind permission to use her material. Dr. Berry's article: Bayesian clinical trials, Nature Reviews, January 2006, was also extremely useful.

2006 Educational Forum Presented the Latest on Lymphoma

The 2006 North American Educational Forum on Lymphoma took place on October 27 – 29, 2006 in Los Angeles, California. This year's program marked the third year of collaboration between Lymphoma Research Foundation (LRF) and Lymphoma Foundation Canada (LFC) and LRF's first year of collaboration with the International Waldenstrom's Macroglobulinemia Foundation (IWWMF) and the Chronic Lymphocytic Leukemia Information Group (CLIG). With nearly 500 lymphoma patients and caregivers in attendance, the 2006 Ed Forum was truly a remarkable and unique experience for program attendees. This comprehensive in-person educational program is the largest gathering of lymphoma patients, caregivers, and healthcare professionals in North America.

Program chairs, Bruce D. Cheson, M.D., F.A.C.P. (Georgetown University Hospital and Lombardi Comprehensive Cancer Center) and Randy Gascoyne, M.D. (British Columbia Cancer Agency) assembled more than twenty of the world's leading lymphoma experts and patient sup-

port specialists to provide Ed Forum attendees with a unique opportunity to learn about their individual type of lymphoma and to network with other program attendees. Highlights from this year's program included nine disease-specific breakout sessions, a panel discussion on new research into lymphoma therapy, epidemiology of lymphoma, advanced concepts of lymphoma, patient support topics, and more than fifteen disease-specific facilitated networking groups.

LRF is pleased to announce that some of the 2006 presentations are available on the website www.lymphoma.org/webcasts.

LRF would like to thank the sponsors of the 2006 North American Educational Forum on Lymphoma for their continued support. Presenting Sponsors: Genentech BioOncology and Biogen Idec; Platinum Sponsor: Merck Oncology; Silver Sponsors: Millennium Pharmaceuticals and Ortho Biotech; Bronze Sponsors: Berlex, Berlex Canada, Cephalon Oncology, Eli Lilly, Favril, Incorporated, Genitope Corporation, GlaxoSmithKline, Hoffman-La Roche Canada, Sigma-tau Pharmaceuticals, and SuperGen.

Passing The Torch

LRF would like to welcome the following new Chapter Presidents, Lisa Lill of Southern California, Pat Riordan of Dallas, Debbie Roscoe of Minnesota and Michael Yudell of the Philadelphia/Delaware Valley region. As we celebrate the past and look to the future, we would also like to express our deep appreciation to past presidents Barry Apfel (South Florida), Leigh Olson (Dallas), Pat Embree (Massachusetts) and Heidi Dieter (Minnesota) for building a strong foundation for the LRF chapter network.

Lisa Lill, Southern California Chapter President, became involved with the chapter by joining the 2006 *Lymphomathon* Committee. Lisa's father is a non-Hodgkin lymphoma survivor and has been in remission since 1998. Lisa is dedicated to growing the Southern California Chapter and making a difference.

Pat Riordan, Dallas Chapter President, and his wife Judy have been involved with the chapter for over three years. Prior to this position, Pat served as the Chapter Treasurer. Pat has enjoyed working with Leigh Olson who has truly done a remarkable job as the first president of the Dallas Chapter. Under Leigh, the chapter raised almost \$300,000, and Pat is eager to grow the Dallas *Lymphomathon* as well as provide outreach in the community.



Heidi Dieter, Minnesota Chapter Immediate Past President, turns over the gavel and position to Debbie Roscoe, Minnesota Chapter President, at the chapter's annual Holiday party.

Debbie Roscoe, Minnesota Chapter President and a non-Hodgkin lymphoma survivor, has been involved with the Minnesota Chapter since its inception. Debbie explains that there was "no question when LRF came to Minnesota three years ago to start a chapter that I would definitely be a part of it." Over the last three years Debbie has enjoyed her involvement with the chapter and is excited for her new role as President. "Heidi Dieter has done an incredible job as our first President and I hope to continue to grow the chapter through educational programs and



Featured above are Geoffrey Williams, San Francisco Bay Area Chapter President, and Southern California's new Chapter President Lisa Lill. At the 2006 Chapter Leadership Conference in Los Angeles, Lisa had the opportunity to meet many of our chapter leaders.

chapter development," says Debbie.

Michel Yudell, Delaware Valley/Philadelphia Chapter President, began his tenure in 2006. In just a few short months, despite the challenges of undergoing treatment, Mike has already begun to build the chapter and plan activities of interest to the local lymphoma community. "I look forward to raising money for lymphoma research, providing support for lymphoma patients and their families, and educating the public about the disease. I believe that together we will do extraordinary things in the coming months, years, and decades," says Mike.

Pat Embree completed her term as Massachusetts Chapter President in December 2006. Under Pat's leadership the chapter raised over \$110,000 in the Falmouth Road Race, held educational programs, provided outreach and participated in local events. In the interim, Pat is continuing to lead the chapter and plans are underway for a *Lymphoma Workshop* and the Inaugural Massachusetts *Lymphomathon* in the spring.

Barry Apfel completed his term as South Florida Chapter President in August 2006. Barry describes his connection to LRF as serendipitous and stemming from the late Joey Ramone. When Joey Ramone died of lymphoma, Barry made a donation in his memory and was put on LRF's mailing list and was later diagnosed with lymphoma. In 2003, he received a letter announcing the opening of the South Florida Chapter and decided to get involved. Barry was very proud to serve as the first South Florida Chapter President. While LRF is currently searching for a new President in South Florida, Sharon Barash and Donna & Jerry Kaplan have graciously assumed the role of leading the chapter.

LRF takes great pride in the many accomplishments of our chapters and would like to congratulate them for their success in

increasing awareness, providing education and outreach in their communities and for raising over \$1.4 million in 2006. The chapters' leadership and membership are integral to enabling LRF to achieve our mission to eradicate lymphoma and serve those touched by this disease.

Arizona Chapter



Joan Bald, Arizona Chapter President, and Wendy Harpham, M.D., Dallas Chapter Member, at a recent survivorship program in Scottsdale, AZ.

Chapter Office Opens in Chicago

LRF is pleased to announce the opening of the first chapter office in Chicago, IL. Amy Junge, Executive Director for the Chicago Chapter, joined the LRF staff in December 2006. Amy is an accomplished nonprofit executive with fourteen years of experience in volunteer leadership and fundraising. The majority of her career has been spent with the American Heart Association of Metropolitan Chicago as Division Manager, working with local board members and the cardiology community of North Cook County; and with St. Jude Children's Research Hospital as Regional Director, managing three offices and growing regional fundraising from \$3 million to over \$7 million in six years. Amy's experience also includes leading a \$4.5 million capital campaign for St. Francis de Sales Parish and serving *SuperSibs!*, an organization that supports siblings of children with cancer, as Director of Development. Amy and her husband, Nick, live in Lake Zurich, IL and have two kids. To contact Amy, e-mail her at: ajunge@lymphoma.org

Dallas Chapter

Chapter members Leigh Olson and Wendy Harpham, M.D. collaborated with the Labyrinth Theater to promote a production of *The Sisters Rosensweig*. The play was written by acclaimed playwright Wendy

Wasserstein. The theatre chose to honor Ms. Wasserstein's life by donating 25% of the proceeds from the play and a related silent auction to the Dallas Chapter.

On November 8th, the chapter held an educational program at the Gilda's Club of North Texas. Wenru Song, M.D. presented on *A New Immune Therapy for Lymphoma*.

The chapter is very excited for the upcoming Lymphomathon on April 28th. If you are interested in participating in the Lymphomathon or getting involved with the Dallas Chapter please e-mail Dallas@lymphoma.org or visit www.lymphomathon.org/DallasFtWorth2007.

Minnesota Chapter

On November 11th, more than 165 patients and caregivers convened in Minneapolis, MN for a full-day educational program entitled, *Lymphoma Workshop: Understanding Lymphoma Basics and Current Treatment Options*. Under the direction of Thomas Habermann, M.D., Professor of Medicine at Mayo Clinic College of Medicine and a member of LRF's Scientific Advisory Board, the Minnesota Chapter developed a comprehensive agenda with disease and treatment specific breakout sessions, as well as patient support topics. The program faculty included more than ten lymphoma physicians and patient support specialists from Mayo Clinic and University of Minnesota Cancer Center. During the networking lunch, a mother and daughter lymphoma survivor team encouraged attendees with their personal story. The afternoon included breakout sessions on nutrition, spirituality, stress management and caregiver support. The program concluded with a presentation to the entire group on clinical trials.

Presented in collaboration with Cutaneous Lymphoma Foundation, Mayo Clinic, and University of Minnesota Cancer Center, the 2006 Minnesota *Lymphoma Workshop* was supported through unrestricted educational grants from Biogen Idec, Genentech BioOncology, and Millennium Pharmaceuticals.

In January the Minnesota Chapter was selected as one of 36 charities to participate in the Allianz Charity Fair. Allianz employees will be voting on which four charities to support for 2007. Chapter President Debbie Roscoe, Ben Haines and Cathy Bergin attended to share information on LRF and the Minnesota Chapter.

The chapter is looking forward to their upcoming Lymphomathon on June 9th at Lake Nokomis. If you are interested in learning more about the chapter or the walk please e-mail Minnesota@lymphoma.org or visit www.lymphomathon.org/Minnesota2007.

South Florida Chapter

On December 12th over thirty volunteers and chapter members gathered at the home of Donna & Jerry Kaplan for a holiday wine and cheese reception. Sharon Barash and the Kaplans thanked everyone for their efforts in planning the Lymphomathon.



On January 18th the South Florida Chapter hosted an educational program entitled, *Ask the Doctor About Lymphoma*. Humberto Caldera, M.D. spoke about innovations in lymphoma therapy and then answered questions for program attendees. The chapter honored past President Barry Apfel for his three years of service.

The South Florida Lymphomathon took place on February 24th at The Polo Club of Boca Raton. The event raised over \$65,000 and 300 walkers participated. A good time was had by all. If you are interested in learning more about the South Florida Chapter, please e-mail SouthFlorida@lymphoma.org.

Utah Chapter



On February 7th the Utah Chapter invited Mohamed Salama, M.D. to speak at their chapter meeting. Dr. Mohamed Salama, a hematopathologist from the University of Utah School of Medicine described how physicians distinguish and diagnose different lymphomas, focusing on the most common types of B-cell lymphomas. If you would like to find out more about the Utah Chapter please e-mail Utah@lymphoma.org

Lymphomathons

In 2006, the Lymphomathon program grew to 17 walks nationwide, welcoming over 6,000 participants and raising almost \$1.3 million dollars for lymphoma research and programs. The success of this grassroots program depends almost entirely on the volunteer leaders around the country who work tirelessly to bring in corporate sponsors, recruit teams and put together a fantastic community event to honor and support those whose lives are affected by lymphoma.



The 2006 Arizona Lymphomathon at the Phoenix Zoo raised \$100,000 with more than 1,000 people participating. Congratulations Arizona!

Volunteers are already gearing up for the 2007 season, which will feature inaugural Lymphomathons in New York City (May 5th), Boston (May 12th) and Philadelphia (September 15th) as well as the return of successful Lymphomathons in Arizona, Chicago, New Jersey, Michigan, and San Francisco, just to name a few. Our walk leaders have exciting plans to make each and every walk even more successful this year.

If you are interested in finding out more about a Lymphomathon or a chapter in your area, visit www.lymphomathon.org or e-mail the LRF Development Department at events@lymphoma.org.



The Los Angeles office staff showed some team spirit participating in their first walk.

New Board Members

At its December 2006 meeting, the LRF Board of Directors accepted with true regret the resignations of Barbara (Bobbi) Warren, Lew Taffer and Marcia Greenberg. Both Bobbi and Lew had come to the end of their most recent three-year terms on the Board and felt it necessary to leave the board at this time. Marcia, an ex-officio member of the Board, due to her position as Chair of the Chapter Development Committee, is leaving the Board since she will no longer be serving as Chair of that committee, although she will remain a member of it. Fellow board members and all the LRF staff wish to thank Bobbi and Lew for their many years of service and for their hard work on the many committees on which they have also served over the years. Thanks is also due Marcia for her year of distinguished service as the first ever, Chair of the Chapter Development Committee and therefore also the first official "chapter representative" on the national Board of Directors. All will be missed!

Nancy Januszewski

Nancy Januszewski is a six-year survivor of non-Hodgkin lymphoma, who lives in New Jersey with her husband, John. They have three grown children and one grandchild. Nancy graduated with a BS/Computer Science degree from Rutgers University. She worked for nine years for IBM and then six years as a Project Manager for a consulting firm that developed custom business software systems.

Nancy and John attended LRF's Blood Cancer Advocacy Days in 2003 and have both become active, tireless volunteers for the organization since that time! In 2003, Nancy established the Central New Jersey Chapter and has served as its President since its inception. She has also chaired three *Lymphomathons* that have raised nearly \$300,000. She is a member of the Public Policy and Advocacy Committee and on January 1st assumed the Chairmanship of the National Chapter Development Committee. By virtue of this latter position, she also concurrently becomes a member of the LRF Board of Directors for a one-year term.

LRF is very fortunate to have all of Nancy's business and organizational skills, as well as a personality that endears her to all that meet her. Welcome to the Board, Nancy!

Michael Werner

Michael Werner currently resides in Chicago with his wife and three children. Michael earned his bachelor's and master's degrees at Stanford University. He has an interest in international relations, speaks Mandarin and during his college years spent time in Taiwan and Bangkok. He began his business career in the New York M & A group at Goldman, Sachs & Co., then went on to Pacific Holding Company in Los Angeles where he served as VP of Mergers, Acquisitions and Investments. In 1988, Michael joined his family's business where he moved rapidly through the ranks of Werner Ladder Co., ultimately becoming President. After selling Werner Ladder, he became President & CEO of Globe Union Group, Inc., an international manufacturer and distributor of both branded and private label kitchen and bath and commercial plumbing products. Michael is also an avid road and mountain bike rider and skier.

Michael was diagnosed with indolent follicular non-Hodgkin lymphoma in January 2006 and through the LRF's Chicago Chapter became interested in the Foundation. Again, the board is very pleased to have him as a new member where his interests in strategy, marketing, fundraising and governance will be put to good use throughout his three-year term. Welcome, Michael!

Steven Prince

Steven Prince was born and raised in New York City and then earned his bachelor's of science degree in economics from the Wharton School of the University of Pennsylvania. After spending eight years in banking, he began a career in commodities at J. Aron and Company, moved on to Drexel Burnham Lambert Trading Corporation and eventually with colleagues from Drexel, formed AIG Trading Corporation. In 1994, Steven became co-head of AIGTC's energy business and in 1997 that business was sold to Sempra Energy, where he currently holds the title of Chairman & CEO of Sempra Commodities.

On a personal note, he is married and the father of three children. He is active in several nonprofit organizations and the LRF is honored that he has chosen to join LRF's Board for a term of three years.

New SAB Members

The Foundation is pleased to announce that the following lymphoma experts have joined the LRF Scientific Advisory Board in 2007. We are privileged and grateful to have their time and talents to help LRF fulfill its mission!

John Byrd, MD

Director of Hematological Malignancies for the Division of Hematology/Oncology, Ohio State University School of Medicine and Public Health

John Chan, MD

Co-Director, Center for Lymphoma & Leukemia Research, University of Nebraska Medical Center

Martin Dreyling, PD, MD

Attending Physician & Assistant Professor, University of Munich, Grosshadern

Kojo S. J. Elenitoba-Johnson, MD, PhD

Associate Professor, Director, Division of Translational Pathology, University of Michigan Medical School

Jonathan Friedberg, MD

Assistant Professor of Hematology and Oncology, University of Rochester/Wilmot Cancer Center

Randy Gascoyne, MD

Clinical Professor, Department of Pathology, British Columbia Cancer Agency

Leo I. Gordon, MD

Professor, Division of Hematology/Oncology, Northwestern University Medical Center

John G. Gribben, MD, DSc, FRCP, FRCPath

Professor of Cancer Immunotherapy/Director of Stem Cell Transplantation, Barts and The London School of Medicine

Neil Kay, MD

Professor of Medicine, Mayo Clinic

Larry W. Kwak, MD, PhD

Chair, Lymphoma/Myeloma & Professor, Lymphoma/Myeloma, MD Anderson Cancer Center

Ari Melnick, MD

Assistant Professor, Department of Developmental & Molecular Biology, Assistant Professor, Department of Medicine (Oncology), The Diane and Arthur B. Belfur Faculty Scholar in Cancer Research, Albert Einstein College of Medicine

Owen O'Connor, MD, PhD

Head, Laboratory of Experimental Therapeutics for Lymphoproliferative Malignancies, Memorial Sloan-Kettering Cancer Center

Kanti R. Rai, MB, BS

Chief of Hematology/Oncology, Long Island Jewish Medical Center

Lou Staudt, MD, PhD

Chief, Lymphoid Malignancies Section, National Cancer Institute

The 2006 Annual Gala Was A Captivating Evening, Taking Guests Back to the Glamour of Old New York



Gala Co-Chairs – Geoffrey Williams, San Francisco Bay Area Chapter President; Gladys Cook & Errol Cook, Chairman & CEO

LRF's Annual Gala—A Night On Broadway—was held Monday, October 16th at the New York Marriott Marquis and raised almost \$800,000! The event honored LRF's finest leaders and volunteers, and offered guests a fun and exciting evening. The theme of the Gala was Old New York and included silent and live auctions, Raise it for Research, and live entertainment provided by the New York University Jazz Band. 500 people attended, with a mixed group of doctors, survivors, business professionals, company leaders, and celebrities such as Mariano Rivera, John Starks and Herb Williams. The Gala was co-chaired by Errol Cook, LRF's Chairman of the Board, and his wife Gladys. Geoffrey Williams, President of LRF's San Francisco Bay Area Chapter was the Gala Design Chair.

Genentech BioOncology was the recipient of the 2006 Freundlich Leadership Award. This award was named after Barbara and Jerry Freundlich, LRF co-founders, and was established to honor an outstanding leader in the corporate community who has supported the mission of the LRF. Thank you to Genentech for making a big difference in the lives of those touched by lymphoma.

The Ellen Glesby Cohen Leadership Award was established by a grant given by Biogen Idec and was created to honor the memory of LRF co-founder Ellen

Glesby Cohen. LRF was honored to present this award to Joanne DeVries, Lill Mikelman, Rochelle and Charles Shotland, Renee Nalitt and Albert Spielman, and Lisa Warren. Each of these individuals have been involved as volunteers with LRF and its predecessors, Cure for Lymphoma Foundation (CFL) and Lymphoma Research Foundation of America (LRFA), for many years. They have spent countless hours in the LRF New York and Los Angeles offices helping with a wide range of projects. These individuals have served as unpaid staff for years for the Foundation. Without their steadfast commitment to LRF, much of the service and information that we offer patients and their families would not be possible. Thank you to our Ellen Glesby Cohen Leadership Award recipients!

All of the wine, champagne, water and chocolate for the evening were donated to LRF thanks to Samantha Shanken and her team at Wine Spectator. Thank you to the following donors: Chandon Etoile Sparkling Wine, Fiji Natural Artesian Water, Ghirardelli Chocolate, Mouton Cadet, Sebastiani, and St. Francis.

Sandhya Jain Patel from Christie's auction house performed the Live Auction and Raise It for Research portion of the

evening. Our live auction included a New York Yankees Experience tour including a meeting with Robinson Cano, a surf trip to Brazil led by Nexus Surf, a New York Giants VIP experience, a commissioned painting from artist Ronald Suchiu, and a trip for two to Hawaii with airfare, hotel and a set visit for two to the hit TV show LOST. Thank you to all of our live auction donors and bidders and a huge thank you to our Raise it for Research donors!

"I want to thank everyone who participated in the Gala. Whether you supported through a sponsorship, purchased a ticket, were in-kind donors, made a contribution, purchased a journal ad, volunteered your time, or were honored that evening, you helped make the Gala a success. Your support and graciousness is very much appreciated and enables LRF to continue its mission to eradicate lymphoma and serve those touched by this disease," said Errol Cook.

A HUGE thank you to Mike Stengel, Bill Fink, George Ntim and all of the staff at the New York Marriott Marquis for their tireless dedication and support to our Gala.

SAVE THE DATE: This year's gala will be held on Monday, October 22, 2007 at the New York Marriott Marquis!



Ellen Glesby Cohen Leadership Award Recipients (Lill Mikelman not pictured)

Making A Difference

The development team at LRF frequently receives calls from individuals asking what they can do to make a difference. Here are a few ways that you can help:

Donations Outright gifts at any level make a difference. You can contribute cash or appreciated stock. If your employer has an employee giving program, you can contribute through your workplace. You can inquire whether your company participates in a matching gift program or is interested in supporting one of LRF's events. Making a gift through a bequest is a lasting tribute to your belief in the mission and activities of the Foundation.

Your gift can either support our entire mission or can be directed to a specific program. Some people have an interest in supporting a particular area of **research**. Donations to LRF's **patient aid grant** program, which awards grants to support the

quality of life of lymphoma patients and enables them to get the treatment they need, are always welcome. To donate to a specific program, please indicate your interest either on your check or in an accompanying note.

Chapters There are other ways to support LRF's work. Get involved in your local LRF chapter by participating in a chapter *Lymphomathon* or other chapter event. More information on LRF chapters and events can be found at www.lymphoma.org.

Regardless of how you choose to support LRF, your dollars and your efforts will make a difference. For more information on how you can support the Foundation's mission, contact Joan Mistrough, Vice President of Development, at 1-800-235-6848 or jmistrough@lymphoma.org.

Save the Date for LRF's Annual East Coast Golf Classic!

The Lymphoma Research Foundation will host its annual East Coast Golf Classic on Monday, August 6 at Sleepy Hollow Country Club in Scarborough, NY. The day will include brunch, golf, cocktails, buffet dinner, raffle, "Top Tees" drawing and much more! For more information, please contact Tanya Gleeson at 800.235.6848 or tgleeson@lymphoma.org.

Mark Your Calendar

Condon Family & Friends Charity Golf Tournament Benefiting the Lymphoma Research Foundation

Saturday, April 21
Glen Annie Country Club
Santa Barbara, CA

The **Condon Family & Friends Charity Tournament** will include:

- Happy Hour
- Family Dinner
- Prizes & Raffle

If you aren't able to join us to golf, please join us for the dinner portion of the evening.

Please bring your family and friends!

Contact Tanya Gleeson at 800.235.6848 x360 for pricing and information

Survey Findings Influence New Young Adult Lymphoma Survivorship Webcasts

Thank you to all who participated in the young adult on-line survey last spring and to those of you who participated in one of the focus groups. 645 lymphoma patients and survivors initiated the survey (403 diagnosed with Hodgkin lymphoma and 242 diagnosed with non-Hodgkin lymphoma). 510 people between the ages of 18-39 completed the survey between March 15th and June 15th. The average age was 31 and the majority of participants had already completed treatment. Based on the findings of both the on-line survey and the focus groups, LRF is delighted to announce the development of a new young adult lymphoma survivorship program in 2007.

The following activities are being designed specifically for people affected by lymphoma between the ages of 15-39 from the point of diagnosis through long-term survivorship:

All of these new webcasts and materials will be available via our website at www.lymphoma.org/youngadults.

- 5 new webcasts and segmented “podcasts” focusing on:
 - Information for young adults newly diagnosed with lymphoma
 - Relationships (families, friends, colleagues)
 - Practical information (e.g., work, school, health information)
 - Health maintenance (e.g., transitioning to primary care after treatment, fertility)
 - Emotional/Psychosocial issues
 - Existential concerns (e.g., keeping hopes and dreams alive and how to cope with fears of recurrence)
- Topic-specific on-line material

Healthcare professionals providing care to young adults diagnosed with lymphoma are critical to increasing quality of life and better disease management. LRF will be creating a CME/CEU accredited webcast for healthcare professionals and hosting a program for nurses at the 2007 Pan Pacific Lymphoma conference.

All of these new webcasts and materials will be available via our website at www.lymphoma.org/youngadults. If you do not have internet access, please contact the LRF Helpline at 800-500-9976.

This project is supported by Grant/ Cooperative Agreement #U58/CCU224305 from the Centers for Disease Control and Prevention. Its contents do not necessarily represent the views of the Centers for Disease Control and Prevention.

2007 North American Educational Forum on Lymphoma

This annual event provides people with lymphoma and their families with critical information about making the best decisions on treatment options, patient support issues, and the latest in lymphoma research.

New York Marriott at the Brooklyn Bridge
October 12-14, 2007

Conference Co-Chairs:

John Leonard, M.D. (New York Presbyterian Hospital-Weill Cornell Medical Center)

Ralph Meyer, M.D. (National Cancer Institute of Canada and Kingston General Hospital and Cancer Centre of Southeastern Ontario)

Owen O'Connor, M.D., Ph.D (Memorial Sloan-Kettering Cancer Center)

For more information, please visit www.lymphoma.org/edforum2007

Lymphoma Workshop: Understanding Lymphoma Basics and Current Treatment Options

These full-day educational programs are designed to bring patients and their families the latest information about lymphoma and treatment options. Seminars are held in collaboration with academic medical institutions around the United States. A lymphoma specialist chairs each program and guides the content and speaker selection.

Upcoming Locations and Dates:

Princeton, NJ
April 28, 2007

Needham, MA
June 16, 2007

San Francisco, CA
September 15, 2007

Minneapolis, MN
November 3, 2007

www.lymphoma.org/lymphomaworkshops

Ask the Doctor About Lymphoma

Ask the Doctor is a national series of two-hour, topic-specific community-based programs that combine a presentation by a leading lymphoma specialist with an extensive question and answer session.

Upcoming Locations and Dates:

Duluth, MN
April 19, 2007

Omaha, NE
May 19, 2007

www.lymphoma.org/askthedoctor

Public Policy on our NEW website



With the launch of LRF's new website, you will find a new and improved section devoted to public policy and advocacy. First, based on important feedback, we renamed the "Advocacy" section "Public Policy." Here, you will find information on our public policy priorities, which are to: 1. Increase federal funding for lymphoma research and education; and, 2. Ensure access to high quality cancer care. These priorities are outlined on the new "Public Policy" landing page. In addition, **TAKING ACTION** on behalf of the lymphoma community – **LymphomADVOCACY** – is now easier and requires fewer steps to submit a letter to your Members of Congress. The Public Policy Department hopes that you find this full of user-friendly information. In addition, with links to Patient Education, Chapters, the Lymphoma Support Network, and 2007 Lymphomathons, you are just one click away from learning about other ways to get, and stay involved with LRF. Please feel free to send any comments or suggestions about this section of the website or any other public policy matters to advocacy@lymphoma.org. We are always interested in hearing from you!

What Happened to Appropriations for Fiscal Year 2007?

As you may know, the 109th Congress did not enact appropriations in the FY 2007 appropriations cycle for most agencies/activities, including the Labor, Health and Human Services and Education Appropriations bill.

When the 110th Congress convened in January, the new congressional leadership announced that it would address the unfinished appropriations work of the previous Congress by passing a full-year Continuing Resolution with funding set at 2006 levels. U.S. House Appropriations Chair David Obey (D-WI) and U.S. Senate Appropriations Chair Robert C. Byrd (D-WV) also pledged to make some adjustments in funding levels "to address the nation's most important policy concerns."

Lymphoma advocates raised their voices in concert with other activists and successfully influenced Congressional action

regarding adjustments in the full-year FY 2007 Continuing Resolution to reflect vital priorities of the cancer community.

The FY 2007 Continuing Resolution as passed by the U.S. House resulted in a \$619.5 million increase for the National Institutes of Health (for a total of \$ 28.9 billion). This includes an increase of approximately \$43 million for the National Cancer Institute (as compared to FY 2006 levels and including statutory obligations such as taps for the Common Fund, etc.). This moderate increase reverses the projected decline in funding for the National Institutes of Health (NIH) and will increase research project awards and grants, as well as expand funding for high risk and high impact research. While this increase is certainly better than the expected decrease in funding for NIH and NCI, we must do a better job at funding biomedical research. The U.S. Senate had not yet acted on this bill as we finalized this edition of the newsletter. For an update, please go to the Public Policy section of the website.

LRF discussed FY 2007 appropriations, in addition to the Comprehensive Cancer Care Improvement Act on its teleconference last fall. To listen to the archive of the teleconference, go to www.lymphoma.org and click on the "Archives" section. **THANK YOU** to all who sent letters to their Members of Congress in support of additional funds for health and education in the FY 2007 Continuing Resolution. Your **ACTIONS** do make a difference!

Appropriations for Fiscal Year 2008

As indicated above, with a change in leadership and majority party in both the House and the Senate, there are new opportunities to press for increased biomedical research funding and for making lymphoma research a national health priority.

How can you get involved?

1. We are growing our grassroots efforts! Join us by registering to receive our Action E-Alerts. Go to www.lymphoma.org and click on the "REGISTER" icon in the left navigation section of our homepage. Check the Public Policy interest box to receive the alerts. If you are already a registered user, update your profile by checking on this box.
2. When you receive an Alert – TAKE ACTION
3. Recruit your friends to raise their voices. Click on "Reach out to a Friend" and insert their names and e-mail addresses. They will receive an e-mail from you prompting them to also TAKE ACTION.
4. Visit the Public Policy section of the website to be informed. We will continue to post briefing materials and talking points to keep you apprised of issues important to the lymphoma community and to aid in your communications with your Members of Congress.
5. Participate in our public policy and advocacy teleconferences. LRF will hold three national teleconferences. Join us for these important programs – All are welcome!

Patient Aid Spotlight

LRF receives many Patient Aid Grant applications each month from people who are struggling with the financial burden of lymphoma treatment. In this column, we have spotlighted a recent grant recipient.

We would like to thank the generous individuals who donate to LRF's Patient Aid Program.

Brian's* family applied for financial assistance when Brian was diagnosed with T-Cell lymphoma at the age of 6. When

Brian was admitted to the hospital for over a month, the family drove close to 100 miles a day to be with him. The high price of gasoline really added up with so many trips so they applied for a Patient Aid Grant to help cover their gasoline bills. Brian's father had to quit his job to care for his ill son. His wife continued to work, so they asked a family member to come care for their younger child, who is a pediatric cancer survivor too. Their health insurance didn't begin to cover all of their medical expenses, and with very little income, the family became overwhelmed with bills. Brian's family was very grateful for the assistance LRF gave this patient and we were happy we could help a family in need.

If you would like to donate to this program, please visit the Patient Aid section of LRF's online donation page, write Patient Aid in the notes section on your check, or include a letter with your donation.

*Patient's name has been changed.

Stories of Hope

Lymphoma Research Foundation has been compiling stories and photos of lymphoma survivors, all inspiring individuals, who with courage and the right support were able to find the strength to battle their disease. These stories and photos are available to view on the LRF website at www.lymphoma.org.

LRF would like to continue to expand this area of the website to offer encouragement and understanding to lymphoma patients and their caregivers.

If you or a loved one has managed some of the challenges of living with lymphoma, the Foundation invites you to submit your Story of Hope and photo, easily through the LRF website, to help inspire others living with the disease. Each person's experiences with lymphoma is unique, so all stories are welcome!

Helpline and Clinical Trials Information Service is here to Help!

LRF's Helpline team is available to answer questions about your diagnosis, treatments, provide referrals to resources for financial assistance and support, and to conduct personalized clinical trial searches upon request. Helpline staff speak English and Spanish. The Language Line interpreter service is available for people speaking Chinese or other languages. Call 800-500-9976 Monday through Friday from 8am-5pm PST or e-mail helpline@lymphoma.org.

Join the Lymphoma Support Network!

If you are interested in volunteering to provide support and encouragement to other patients or survivors, please consider joining LRF's nationwide one-to-one peer support program. The Lymphoma Support Network Coordinator matches patients or caregivers with volunteers who have had similar lymphoma related experiences. You can fill out and submit a questionnaire through the LRF website or call 800-500-9976 to request one be mailed to you.

www.lymphoma.org

2007 CALENDAR OF EVENTS

ASK THE DOCTOR ABOUT LYMPHOMA

April 19, 2007—Duluth, MN

CONDON FAMILY AND FRIENDS GOLF CLASSIC

April 21, 2007—Santa Barbara, CA, Glen Annie Country Club

LYMPHOMA WORKSHOP

April 28, 2007—Princeton, NJ

LYMPHOMATHON

April 28, 2007—Dallas/Ft Worth, Fair Park

LYMPHOMATHON

April 28, 2007—Michigan, Lower Huron Metro Park

LYMPHOMATHON

May 5, 2007—NYC, South Street Seaport

LYMPHOMATHON

May 6, 2007—Central New Jersey, Mercer County Park

LYMPHOMATHON

May 12, 2007—Boston, Artesani Park

RIT TELECONFERENCE

May 18, 2007 1:30-2:30pm EST

ASK THE DOCTOR ABOUT LYMPHOMA

May 19, 2007—Omaha, NE

LYMPHOMATHON

June 9, 2007—Minnesota, Lake Nokomis

LYMPHOMATHON

June 10, 2007—San Francisco, Golden Gate Park

LYMPHOMA WORKSHOP

June 16, 2007—Needham, MA

LRF'S ANNUAL EAST COAST GOLF CLASSIC

August 6, 2007—Scarborough, NY, Sleepy Hollow Country Club

LYMPHOMATHON

August 26, 2007—Chicago, Montrose Harbor

LYMPHOMA WORKSHOP

September 15, 2007—San Francisco, CA

LYMPHOMATHON

September 15, 2007—Philadelphia, Fairmount Park

LYMPHOMATHON

October 6, 2007—Connecticut, Rocky Neck State Park

NORTH AMERICAN EDUCATIONAL FORUM ON LYMPHOMA

October 12-14, 2007—New York City, Marriott at the Brooklyn Bridge

LYMPHOMA WORKSHOP

November 3, 2007—Minneapolis, MN

LYMPHOMATHON

November TBD—San Diego, Orange County, CA, Arizona, Georgia, Los Angeles

LYMPHOMA
RESEARCH • FOUNDATION

Lymphoma Research Foundation
111 Broadway, 19th Floor
New York, NY 10006

RETURN SERVICE REQUESTED

This issue of Lymphoma Today is supported, in part, through an unrestricted educational grant from GlaxoSmithKline.

NONPROFIT
ORGANIZATION
US POSTAGE
PAID
NEW YORK, NY
PERMIT # 370

If you received more than one copy of Lymphoma Today, kindly notify us at (800) 235-6848.