DOCTOR ON CALL: RAFAT ABONOUR

Complications in Waldenström Macroglobulinemia
by Rafat Abonour, M.D.

What are the complications encountered by patients diagnosed with Waldenström macroglobulinemia? This is the question asked by all WM patients when confronting their diagnosis. Answer: there are a number of possible complications caused either by tumor infiltration in the bone marrow and/or by an abnormal level of IgM in the blood, also referred to as abnormal macroglobulinemia.

Symptoms Attributable to Tumor Infiltration

Extensive bone marrow infiltration by the abnormal Waldenström cells leads to reduction in bone marrow function and, consequently, reduced production of red blood cells. Progressive anemia is in fact the most common indication for initiation of treatment. Bone destruction, however, which is common in multiple myeloma, is very uncommon in WM.

Abnormal Waldenström cells can also infiltrate other organs, including the lymph nodes, liver, and spleen. Lymph node infiltration may be of little consequence (except that it is esthetically disturbing), or it may result in significantly enlarged nodes that cause obstruction of the bowel, blood vessels, or airways. An enlarging spleen can reduce the capacity of the stomach, and this in turn may result in a false sense of satiety. In this case one eats less, with subsequent weight loss. Other rare forms of infiltration have been reported in the lungs, bowels, stomach, head and the orbit (eye cavity). Bing-Neel syndrome is seen when long-standing, sluggish circulation causes blood vessels to leak Waldenström cells into the space surrounding the vessels. Such patients will complain of headache, vertigo, impaired hearing, ataxia (uncoordinated muscle movement), nystagmus (uncoordinated eye movement), diplopia (double vision), and, eventually, will succumb to coma.

THE LOS ANGELES FORUM
AN EXPERIENCE OF LEARNING AND FELLOWSHIP
by Tom Myers, Vice President for Research

Over 260 patients, caregivers, and doctors assembled at the Hilton Airport Hotel in Los Angeles to learn about Waldenström’s cancer and the research studies to cure this disease. A typical comment from a participant at the Forum was: “I liked the forum because of interactions with other patients, knowledge of speakers, and high quality presentations, and I am a first time attendee and look forward to attending again. The forum did not disappoint.” Another participant remarked that they liked the fact that the forum presented “cutting edge research and implications for treatment.” Finally, when another attendee said that what they liked most about the Forum was “the superb selection of researchers and physicians who are different at each forum,” their words summed up exactly the goal of the Ed Forum Committee.

This three-day conference followed the successful guidelines of past conferences. Many attendees came early to learn about immunology on Friday morning. In the afternoon simultaneous sessions were run to provide information for newly diagnosed and veteran patients alike. The newly diagnosed patients were given a basic understanding of the disease, together with recommendations on how to understand the myriad of blood tests to which we all are subjected. The veterans learned about new treatments and genetic changes.

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PRESIDENT’S CORNER
by Judith May

IWMF Patient Education Forum

The 13th IWMF Patient Education Forum was held in Los Angeles last month and attracted a good number of participants, particularly among our international members. Participants came from Greece, India, United Kingdom, Australia, Israel, and, of course, the largest group was from our neighbor to the north, Canada. An especially warm welcome was given to international members, newly diagnosed patients, and first time attendees. One of the wonderful things about coming together for the annual Ed Forum is the opportunity to meet and speak with patients who have had Waldenstrom’s macroglobulinemia for a good many years and are living well. It brings such hope to those who are attending for the first time, particularly the newly diagnosed, when they can talk with a member who has lived with Waldenstrom’s for 28 years as is the case with Emil Parente. In fact, seeing Emil there was uplifting for all of us.

If, however, you missed the Ed Forum this year, you can purchase the IWMF DVDs with all the presentations by our expert doctors and researchers. And even if you attended this year, you may well benefit by watching the presentations again in the comfort of your home. You can purchase the DVDs from our Sarasota office. For details, please see the enclosed order form.

Moreover, a comprehensive and detailed summary of this year’s presentations will be written once again by Jim Berg, Trustee and special projects writer. You will receive this bulletin in a separate mailing.

We are already at work on next year’s Ed Forum, and details will be announced as soon as we have confirmed the date, location, and hotel.

IWMF Board Notes

The IWMF Board of Trustees announces the results of its annual election for officers. The officers of the IWMF for 2008-09 are: Tom Myers, Vice President

President’s Corner, cont. on page 16
had an IgG monoclonal protein. These findings have been the familial cohort had an IgM monoclonal protein, and 2 members with a monoclonal gammopathy detected within familial B-cell disorders history. Seventeen of the 19 family members of WM patients with a history of monoclonal gammopathies (22.9% vs. 1.9%; p=0.0004) among family members of WM patients with a familial B-cell disorders. However, for family members of WM patients without such disorders. In a study submitted for publication, Dr. Treon and his colleagues examined IgA and IgG levels in 207 untreated patients and evaluated the impact of therapy and response to therapy for 93 of these patients who received treatment. Of these patients, 120/207 (58.0%), 131/207 (63.3%), and 102/196 (49.3%) had abnormally low levels of serum IgG, IgA, or both, respectively. No correlation between bone marrow involvement and immunoglobulin levels was observed.

To assess whether low IgA and IgG levels were a consequence of disease, changes in immunoglobulin levels following treatment for 93 patients were monitored. With an average follow-up of 12 months following completion of therapy, IgA and/or IgG levels remained abnormally low for 92.1% and 87.3% responding patients, respectively, including for almost all patients who achieved a complete remission. The results of these studies suggest that most patients with WM demonstrate constitutive IgG and IgA hypogammaglobulinemia despite therapeutic intervention and response.

An important consideration for these studies is that patients with WM may harbor a defect in producing normal plasma cells. Typically, B-cells mature along a lineage that includes several steps including the lymphoplasmacytic cell stage that secretes IgM followed then by the plasma cell stage that secretes IgA and IgG. WM cells are thought to be derived from lymphoplasmacytic cells. In ongoing studies, Zachary Hunter in Dr. Treon's laboratory identified mutations in a select receptor (TACI) which is essential for differentiating lymphoplasmacytic cells to plasma cells and, therefore, for causing switching from IgM to IgA and IgG production (Figure 1). Ongoing work in the Treon laboratory is focusing on more fully defining aberrations in the TACI pathway.

IWMF Research Grant, cont. on page 4
In collaboration with Drs. John Shaughnessy and Bart Barlogie at the University of Arkansas, Dr. Evdoxia Hatjiharrissi in Dr. Treon’s laboratory has spearheaded efforts to provide a detailed molecular examination of the genes expressed in WM tumor cells and the surrounding bone marrow microenvironment cells. Understanding the molecular expression of genes provides insight into which signaling pathways permit WM tumor cells to grow and survive. As part of these studies, Dr. Hatjiharrissi isolated lymphocytes and plasma cells from patients with WM and from healthy individuals and contrasted their expression of genes using advanced microarray technology in Dr. Shaughnessy’s laboratory. Such technology can detect the expression of 46,000 genes.

These studies showed significant differences in pathways which promote growth signaling and survival in WM cells. Among the down regulated genes observed to promote the growth of malignant cells were negative regulators of signaling triggered by ligands and receptors of the TNF super family, including the CD27-binding SIVA protein. The finding of SIVA down regulation is particularly interesting since it confirms work in the Treon laboratory which was presented by Dr. Sophia Adamia at the 4th International Workshop on WM at Kos, Greece. SIVA is an adaptor molecule with death-inducing signals mediated by CD70 and CD27. This signaling process may be particularly important in WM where high numbers of mast cells surrounding WM cells express CD70, possibly in hopes of triggering WM cells to die through CD27 and SIVA signaling.

A number of laboratories have shown loss of CD27 on WM cells, and the finding of lost SIVA expression represents an additional pathway by which WM cells may escape CD70 regulation. Ongoing work by Brian Ciccarelli in the Treon laboratory is focusing on mechanisms by which CD27 expression on WM cells is lost, soluble release included. (Figure 2).

Dr. Treon is Associate Professor, Harvard Medical School; Director of the WM Program, Dana Farber Cancer Institute; Member, IWMF Scientific Advisory Committee; Attending Physician for medical oncology at Dana Farber Cancer Institute and at Brigham and Women’s Hospital, Boston, MA.

Dr. Treon earned his M.D. and Ph.D. degrees from Boston University and completed an internship in medicine and a residency in internal medicine at the Boston University Medical Center. Dr. Treon’s main research interests focus on understanding the genetic basis and pathogenesis of Waldenstrom’s macroglobulinemia. With information developed in these programs his group is developing new therapies for this disease. As a result Dr. Treon has become a dominant figure in the search for better treatment and eventually a cure for WM. In his position as Director of the WM program at Dana Farber he has attracted a group of talented researchers from around the world. Their efforts have resulted in a number of new treatment regimes that are showing promise in controlling the disease. Though the disease is considered an “orphan” disease because of the small number of people who develop it, Dr. Treon has been very influential in making it known throughout the medical profession. As a result of his efforts numerous symposiums dealing specifically with the disease have been held in the last eight years, and four workshops have been organized to define the current diagnosis approaches, the characteristics of the disease, the latest treatments and the identification of the treatment results.
IWMF RESEARCH GRANT UPDATE: ESTEBAN BRAGGIO

Esteban Braggio is a postdoctoral fellow working since 2006 with Dr. Rafael Fonseca at Mayo Clinic, Scottsdale, AZ. Dr. Braggio received his Ph.D. from the Bone Marrow Transplantation Center in Rio de Janeiro City, Brazil. His research focuses on the genetics of WM, MM and MALT lymphomas using techniques that include advanced microarray methods and pattern recognition. With Dr. Fonseca as co-investigator, he was awarded an IWMF grant in 2007 to support his research directed towards understanding the genetics of WM. In the note below he describes recent results of his current research.

Genome-Wide Characterization of DNA Copy Number Changes in Waldenström Macroglobulinemia

by Esteban Braggio, Ph.D.

The most recent findings of this study are the identification of inactivating mutations in two tumor suppressor genes, TRAF3 and TNFAIP3. These genes are part of a cellular pathway called nuclear factor kappa B (NF-kB), which regulates the transcription of hundreds of genes involved in several cellular processes. These processes include inflammation, innate immunity, cell growth and cell death. Both genes are described as “negative regulators” of the NF-kB, because they play key roles in the regulation of this pathway. Regulatory controls of the NFkB pathways are lost when these genes are inactivated by mutations, resulting in several implications regarding immune response, cell growth, and cell death dysregulation. These findings may also have therapeutic implications.

Bortezomib (Velcade), a first-in-class proteasome inhibitor, has demonstrated anti-tumor activity in refractory and relapsed multiple myeloma (MM) and more recently in both untreated and relapsed Waldenström macroglobulinemia (WM). Inhibition of the NF-kB pathways is thought to be a principle mechanism of action by bortezomib. Our group has previously shown an association between TRAF3 inactivation and good response to bortezomib in MM patients. The identification of TRAF3 mutations highlights the role of NF-kB pathway in WM and possibly identifies a subset of patients who might benefit from a treatment based on proteasome inhibitors.

Doctor on Call, cont. from page 1

Symptoms Attributable to Circulating IgM

In general, patients with WM bleed more easily either because IgM interferes with clotting factors or because IgM has the effect of coating the platelets, consequently making them less effective.

Hyperviscosity results from the increased level of IgM in the blood stream. Because IgM is a large protein, an increased amount of monoclonal IgM leads to greater vascular resistance, higher viscosity, and slower blood flow to vital organs. Symptoms of hyperviscosity are evident in only 10% to 30% of patients with WM. The most common complaints are fatigue, bleeding from the gums and nose, and retinal bleeds which can lead to blurred vision or even loss of vision. In more advanced cases, patients may experience headache, vertigo, nystagmus, dizziness, sudden deafness, diplopia, or ataxia. Untreated advanced hyperviscosity can lead to confusion, dementia, stupor, stroke, or coma.

Symptoms of hyperviscosity usually appear when the normal serum viscosity of 1.4 to 1.8 cP (centi-Poise) reaches 4 to 6 cP (corresponding to a serum IgM level of at least 3 g/dL). There are huge variations in the threshold from an asymptomatic status to one showing the effects due to hyperviscosity. Some patients with a large amount of IgM (approaching 5-7 g/dl) remain symptom-free, while others exhibit symptoms at much lower levels.

Cryoglobulinemia, the formation of cryoglobulins in the blood, is another complication related to IgM. Cryoglobulins are serum proteins or protein complexes of IgM that undergo reversible precipitation at low temperatures. While this complication may be detected in 20% of WM patients, fewer than 5% present with symptoms from cryoglobulinemia such as Raynaud syndrome (blue and painful finger tips in cold weather), joint pain, purpura (purple or red spots under the skin), skin ulcers, or kidney damage.

Finally, IgM can bind to red blood cells at cold temperatures and produce a condition called cold agglutinin disease. This happens in about 10% of WM patients and leads to chronic red blood cell destruction, resulting in various degrees of anemia.

Symptoms Attributable to Tissue Deposition of IgM

IgM deposition can occur in the kidneys presenting as excess protein leakage by the kidneys, in the intestine leading to diarrhea, and in skin seen as rash or nodules.

Symptoms Attributable to Autoantibody Activity of IgM

Although IgM is intended to be our first line of defense against bacteria and other foreign insults, in WM the serum IgM most often has no specific target. In rare cases IgM can react with the patient’s own normal protein, leading to
THE IWMF PATIENT DATABASE

by
Joe Burke, Peter DeNardis, Ronald Dratz, Sue Herms, Tom Hoffmann

The long-awaited IWMF Patient Database is finally emerging. A team of member-volunteers has been at work for more than two years (and still continuing) to develop this repository of information about WM. Its value to present and future WM patients will be incalculable. The Database Coordinators are now ready to unveil the database and reveal its organization and capacity, although some of its sections are not yet in a final form. The following brief introduction explains the organization of the database, its targeted audience, and what it is expected to teach us about WM.

What is this patient database?

The patient database will contain the collective knowledge of historical facts and test results about Waldenstrom patients who are members of the IWMF. It will contain a great deal of information that is derived from a series of questions and selectable answers asked of each patient who registers and contributes his or her experience and test results to this knowledge base of data about WM. These questions and answers are organized in a series of Topical Modules listed below:

**Patient History:** Questions include usual physical data plus prior disease and family history that may show links to other lymphomas and cancers. This module will also collect data on longevity of patients versus age at diagnosis and other test parameters.

**Test Results:** This contains questions about CBC results (complete blood counts), immunoglobulins (IgM, IgG, IgA by nephelometry and electrophoresis), SV, comprehensive chemical panel, bone marrow biopsy, and scans data (X-ray, CT, MRI, etc.).

**Treatments & Drugs:** Questions include the types of treatments and medications used to control WM, along with treatment doses and protocols, side effects, allergies, response to treatments and drugs, and the duration of remission.

**Symptoms & Conditions:** Questions refer to problems related to WM such as pain, vision problems, unsteadiness, joint aches, mental fog, etc.

**Personal Data and Graphs:** Based on personal data entered in the Test Results Module this module provides tabular and graphical displays showing the status of WM and the benefits of treatments. Members will no longer have to sort through sheets of test results since this data will be available in chronological tables and/or graphs that can be viewed and printed.

**Glossary:** An on-line glossary is keyed to terms that appear in the questions and selectable answers found in the Topical Modules. The glossary will be an aid to unfamiliar terms so that questions or the selectable answers are better understood. This reference tool will also serve as a mini-tutorial about WM.

**What will we learn from the database?**

WM, like many orphan diseases, remains a poorly understood lymphoma to many clinical oncologists and hematologists who may encounter very few patients in their practice. Most information concerning WM comes from the observations of clinical research trials and the work of those research doctors who devote time to studying WM. While information from research studies and key workshops continues to provide essential and valuable guidance to clinicians, that information is not always seen or pursued by our doctors. Since WM is a rare orphan disease, the time that a clinician can devote to understanding all the varied signs and symptoms of WM is extremely limited, in contrast to the time devoted to those cancers encountered with much greater frequency.

Following diagnosis, doctor and patient alike have similar questions. Should this case of WM be treated aggressively? Or not at all? Which treatment was better for someone who had not had prior treatment and which for those patients who had many prior treatments? What were the outcomes of those treatments? How many developed peripheral neuropathy from treatment and from which drugs and at what doses?

Where will our doctors get this information? The potential answer is: directly from the IWMF Patient Database or from the information we bring to them from that database.

None of the drugs we use was developed for WM. We are the off-label beneficiaries of drugs developed for other lymphomas and cancers. How do the data from those developmental trials apply to us? The answer lies in our collective experience. And the collective experience of all IWMF members is not public knowledge available to our doctors or to us at present. This will continue to be the case until our database comes to fulfillment through the participation of IWMF members. The variations that occur among WM patients require that we enlist the help and participation of all IWMF members.

Those who use IWMF-Talk are well aware of the diversity of response we patients have to various drugs and treatments and also of the diversity of symptoms that at times seem linked to WM and test results. At times each of us seems an island of differing symptoms, conditions, and degree of wellness that have no apparent relationship to other WM patients or our test results. Is that true, or is it because we have not collected data from enough patients to find common ground within a group? Will that common ground point to the need and the way to treat and overcome those symptoms that impact our quality of life?

The IWMF Database, cont. on page 7
Very few of us participate in clinical trials devoted just to WM patients. Very few WM patients participate in new drug trials that target other lymphomas. Most of our data rest in the files of our personal hematologists and never are shared with other doctors because of the strict medical and governmental rules that prevent sharing such information among doctors and other medical professionals. Our database can break that restriction and form the foundation of a detailed history of our struggles and successes with WM for our individual and collective benefit.

Why does this database have to be on-line?

There are several reasons for putting this database on-line. The first and foremost reason is that a paper form database remains stuck in time. That is, the information presented is not something that can be readily updated without continuously sending periodic questionnaires to members. An on-line database can and should be updated whenever a member has new data to enter – test results, treatment outcomes, symptoms, etc. Those entries can be made at any time convenient for the member, hopefully soon after such information becomes available to him or her.

A second reason is the sheer volume of information that would have to be keyed into the database by a very limited number of volunteers. The information you supply to this database is intended to remain confidential. The way to keep that information confidential is to limit your data to just a very few people who serve as gatekeepers to the database. These few gatekeepers are the only members who are able to register you to participate in the database, and they must be able to verify that you are a member of the IWMF. No one else is allowed to know your identity as a WM patient or be able to link your information to you, unless you share that information with a caregiver or other privileged person. It would be impossible for those few gatekeepers to enter your data for you in a timely manner even if they would be willing to attempt such a task.

How secure are my data and identity?

Whenever someone uses the Internet to enter data the issue of privacy and security of information becomes a significant concern, especially when it involves the identity of a patient and that patient’s medical data. This concern has been of primary focus during the development of this database exactly because it had been decided from the beginning that the database would be on-line.

This database is not restricted by or required to follow HIPAA guidelines or those of other countries regarding a patient’s medical data. However, a substantial effort has been, and will continue to be, made to ensure your privacy and the privacy of your data.
These simple questions do not begin to tap the almost unlimited number we can pose to the database. A fair follow-on question is, “Who poses these questions and provides the answers?” The quick reply is **you, indirectly and directly**. The bulk of many questions will come from IWMF-Talk. You will also be able to present questions of personal interest directly to the database gatekeepers. Those questions and answers will comprise the **Reports Module**. The **Reports Module** will have an index to topics for questions on treatments, symptoms, longevity, and many others. One will simply go to a section of this module and review those questions and answers. This module will eventually contain a keyword search capability that will aid in finding answers of interest. If that answer is not found, it may motivate you to submit questions that will be answered.

There will be instructions in the **Reports Module** telling you how to submit your questions. The answers will be sent to you directly. Your questions with answers derived from the database may then be included in the **Reports Module** if applicable to the interests of others. So, when you want to know if some symptom is common to WM, ask us and we’ll see how many patients report a similar symptom. We will also be able to provide an indication of severity, duration and, if you ask, relationship to other conditions or treatments.

**How good or accurate are these results? That is, can we rely on them?**

The data you and others enter into the database will be as good as your records. We certainly expect that they will be comparable to the history you give to your doctors. The test results are those you will enter directly from the sheets you get from your doctor or lab, and they will be as accurate as what the lab provides. We even have a way to check the results you enter to be sure no gross error is made, such as forgetting to insert a decimal point.

You will need to have your test results from your lab and doctor. Many patients ask for these results at the time tests are performed. If you do not, it should be relatively easy to get past results from your doctor who keeps all that data. Your doctor’s office will usually supply these copies to you at no or minimal cost, but do give them time to gather and copy those records. Now or during your next visit will be a good time to ask. Once you place those results in the database, they will remain there for you.

We will be offering tips from time to time on how to keep other records, for example symptoms-related information. We are not proposing that you immediately devote a lot of time to getting or keeping records. Rather, we hope you will gather this information gradually and periodically will enter your data as time permits. The goal is to eventually have you enter all your data. The more data you enter, the more reliable will be the answers to each question. The database will then become the permanent archive of your records. You will not only be able to see your records for your own needs but will also be able to share them with your current or new doctors who need that information to treat you. And all the rest of us will benefit, too.

**Okay, sign me up! How do I register to become a participant in this database?**

It’s pretty simple and requires only a few things.

1. You must be a member of the IWMF to participate, enter data, view results, or pose questions from the database. The only non-members who will be invited to see group results are licensed doctors and their staff. They will not be able to see your individual results unless you allow them to do so.

2. You must have a computer or access to one. In most instances you will be notified via e-mail of your membership verification and successful registration for the database within 4 to 24 hours of completing the application form on the database. It is possible to use a public computer such as those available in libraries. In that case you can check back in a day to confirm that you are registered. The next step is to enter your username and password to start the process of entering data or looking at results.

3. The Internet address you will need to type into your web browser to enter the database to register is: **http://iwmfdatabase.com**

That’s all it takes.

**A few closing comments**

This database is a labor of love and interest in the welfare of all WM patients by the 30+ volunteers who have spent many hours developing the database. You will be introduced to many of these volunteers in succeeding articles on the database when we cover a topic which they helped to develop. The database is not yet complete and, therefore, neither is the work of these volunteers. But enough is complete that you can begin entering your data for the **Patient History** and much of the **Test Results Modules**.

The **Treatments and Drugs, Symptoms and Conditions, and Personal Data and Graphs Modules** will be under development by the time you register. We hope to finish these very important modules by the end of this year.
The IWMF Database, cont. from page 8

The Glossary Module will also be released later this year, probably in concert with the release of the Treatments and Drugs Module.

The Reports Module will not be opened for viewing answers to questions until we have data from at least 50 members. The applicability of the results presented in the Reports Module depends on the number of patients who have entered data. That applicability of results will continue to change and improve in proportion to the number of members who share their data.

If you’ve ever been tweaked about prospecting, just remember, when mining for gold or precious gems, the work can be very hard, but the result of that effort may be priceless. The reward of your efforts in participating in the IWMF Patient Database may be priceless to your quality of life and that of your fellow IWMF members.

INTERNATIONAL NEWS AND HAPPENINGS
by Roy C. Parker

International Attendance at the Forum and the International Breakfast

International members attending from as far away as Australia, Greece, India, Israel, the United Kingdom, and, of course, from our northern neighbor, Canada, all enjoyed breakfast together on Sunday morning at the Forum. It was a chance for these members to meet each other and to also meet personally with the officers and members of the Board of Trustees of the foundation. It was also an opportunity for our international members to tell the foundation what they need for their support groups overseas and to find out what the foundation can offer to them.

Growth in Overseas Support Groups and Contact Persons

The IWMF has enjoyed an increasing presence overseas as evidenced by the growing number of new international support groups and individual contact persons. You will find the names of the international contacts and international support groups published in this issue of the Torch. At the same time, inquiries from abroad are increasing monthly, and our overseas membership continues to grow at a steady pace. To support our international members the IWMF continues to selectively expand its publication of booklets and pamphlets translated into French, German, Italian, and Spanish.

5th International Workshop on Waldenstrom’s Macroglobulinemia

The Fifth International Workshop on Waldenstrom’s Macroglobulinemia is scheduled to take place in Stockholm, Sweden, October 15-18, 2008. These biennial workshops bring together WM specialists from across the globe to discuss the most recent breakthroughs in clinical and laboratory studies. In the past workshop papers have been published in special editions of Seminars in Oncology.

The Fifth International Workshop on Waldenström’s Macroglobulinemia will celebrate a ten-year milestone in the advancement, through the efforts of many international investigators, of knowledge directed toward better treatments and a cure for this B-cell malignancy. The location of the 5th International Workshop is especially significant as Stockholm was the home of Dr. Jan Waldenström, discoverer and pioneer researcher of the disease that bears his name.

The workshop is designed to be a collaborative and comprehensive meeting on an international level for both seasoned and new scientists of the Waldenstrom B-cell malignancy. WM patients are not invited to attend the workshop.

For fuller details visit the website of the International Workshops on Waldenstrom’s Macroglobulinemia: www.wmworkshop.org/wmworkshop/Stockholm/Stockholm08.html

IWMF Stockholm Patient Seminar:
October 19, 2008

In Stockholm, Sweden, on Sunday, October 19, the IWMF is organizing a one-day seminar of medical and research presentations open to all WM patients and their family members. While there is no cost to attend the one-day seminar, participants are expected to make travel and housing arrangements at their own expense.

Scheduled for the morning session of the seminar are presentations by faculty members from the 5th International Workshop on Waldenstrom’s Macroglobulinemia. Four physicians well known to the readers of the Torch have already agreed to participate. These doctors, who are volunteering their time, are:

Eva Kimby, M.D., Ph.D., Huddinge University Hospital, Karolinska University Hospital, Stockholm, Sweden

International News, cont. on page 19
New Statistics on NHL Incidence and Survival Rate – The American Cancer Society recently published Cancer Facts & Figures 2008. It reports that an estimated 66,120 new cases of non-Hodgkin’s lymphoma (NHL) will be diagnosed in 2008. Since the early 1970’s incidence rates for NHL have nearly doubled. Although some of this increase is due to AIDS-related NHL, for the most part the rise is unexplained. Since 1991 increasing NHL incidence has been confined to women. The five-year survival rate for NHL for all races increased, from 48% for patients diagnosed between 1975-77 to 64% for patients diagnosed between 1996-2003.

TRU-016 Targets CD37 Antigen on B-Cells – Trubion Pharmaceuticals has announced a Phase 1/2 clinical trial of its TRU-016 drug which targets the CD37 antigen present on B-cells. The trial is to include patients with chronic lymphocytic leukemia (CLL) and non-Hodgkin’s lymphoma. TRU-16 has demonstrated potent anti-tumor activity in preclinical evaluation and may provide patients with additional treatment options when used alone or in combination with chemotherapy or CD20-directed therapies.

Tandem Drugs Sorafenib and RAD001 in New Mayo Clinic Trial – Sorafenib and RAD001 are two drugs that block some of the main switch pathways in cancer cells from working properly. When combined, it is hoped that they may prevent the cells from growing or initiate their death. They are being tested in combination in a Phase 1/2 study at the Mayo Clinic in Rochester, MN, in patients with relapsed NHL, Hodgkin’s lymphoma, and multiple myeloma. The study should be completed in three years.

Subcutaneous Veltuzumab Will Be Evaluated for NHL and CLL – A new clinical trial will be evaluating a low-dose subcutaneous formulation of veltuzumab in patients with NHL and CLL. Veltuzumab, developed by Immunomedics Inc., is a humanized anti-CD20 monoclonal antibody. It has some biochemical differences with rituximab and appears to have a higher binding potency to lymphoma cells. Veltuzumab is completing its initial intravenous dose-finding trials, where it was found that doses as low as 80 mg/m2, administered weekly over four weeks, had substantial complete responses (24%), with infusions being well tolerated.

R788 Oral Drug in B-Cell Lymphoma Studies – Rigel Pharmaceuticals’ R788 drug candidate is currently in early-to-mid stage studies for B-cell lymphoma. R788 is an oral SYK kinase inhibitor that blocks the activation of mast cells, macrophages and B-cells. Research has shown that R788 effectively interrupts the growth of B-cells and signaling proteins that contribute to the survival of B-cell tumors.

Lenalidomide (Revlimid) Promising for NHL but Has Some Risk Factors – Lenalidomide (marketed as Revlimid) has recently been reported to make a major impact in the treatment of B-cell malignancies. A more potent analog of thalidomide, lenalidomide was developed to enhance its anti-tumor properties with an improved safety profile. Dr. Treon et al. initiated a small Phase 2 clinical trial of lenalidomide in combination with rituximab for WM patients. One important adverse effect in Dr. Treon’s study was an acute decrease in hematocrit within the first two weeks of therapy. Further studies are anticipated to optimize the dosing schedule. Another risk factor for lenalidomide use has been an increased incidence of venous thromboembolism (blood clotting) in multiple myeloma patients receiving the drug in combination with dexamethasone or certain chemotherapies. Additional studies have suggested that aspirin, heparin, or warfarin be given concurrently to patients receiving this drug.

The Role of Infections in Development of NHL – An article recently published in the Annals of Oncology suggests that individuals with advanced NHL who also have certain infections at diagnosis may be able to delay treatment for their cancer if their infection is treated first. Growing evidence indicates that infection with certain viruses or bacteria may play a role in the development of some lymphomas. For example, treatment of H. pylori (a bacterium) in gastric MALT lymphoma can result in complete disappearance of the cancer. Anti-cancer responses have also occurred in lymphoma patients with hepatitis C following treatment for their infection. Researchers are concluding that identification and treatment of associated infections may be a first step in developing therapies for certain NHLs and that the biology of these NHLs may actually be different from NHLs without associated infections.

New Therapy Uses Metronomic Strategy – Many patients with recurrent lymphoma are unable to tolerate intensive therapies or have disease that is refractory to treatment. Cornell Medical College and New York Presbyterian Hospital have developed a metronomic chemotherapy strategy (defined as continuous or frequent treatment with low doses and with no prolonged drug-free breaks) that is less toxic but still effective. They treated 75 lymphoma patients with a daily low-dose oral PEP-C regimen (prednisone, etoposide, procarbazine, and cyclophosphamide) at certain specific times of the day for continuous, prolonged periods. This metronomic therapy achieved a 69% objective response rate and was generally well tolerated.

New Drug Targeting BCL2 Gene Regulation Proceeds to Phase 1 Study – ProNAi Therapeutics Inc. has received clearance from the U.S. Food and Drug Administration (FDA) to proceed to Phase 1 clinical trials with its drug PNT2258. This nucleic acid drug targets a DNA sequence upstream
of the BCL2 gene, which regulates apoptosis (death) in cancer cells.

GlaxoSmithKline Purchases New Anti IL-6 Drug – GlaxoSmithKline has agreed to purchase worldwide rights from EUSA Pharma Inc. for its pre-clinical antibody aimed at treating lymphoma and rheumatoid arthritis. The human antibody, called OP-R003, targets a protein called interleukin-6, which is up-regulated in many lymphoma types, including WM.

TREANDA Application Accepted by FDA – The FDA has accepted Cephalon Inc.’s application for TREANDA (bendamustine HCl) for injection in the treatment of patients with indolent NHL who have progressed during or following treatment with rituximab or a rituximab-containing regimen. TREANDA is a hybrid of a purine analog and an alkylating agent. The FDA is expected to announce its decision on the application by October 31, 2008.

Carfilzomib Receives Orphan Drug Designation – Proteolix Inc. announced that the FDA has granted orphan drug designation to carfilzomib, a selective blocker of proteasome activity similar to bortezomib (Velcade). The designation encompasses all subsets of multiple myeloma and WM. Carfilzomib is currently in Phase 2 clinical studies. Proteolix is developing a pipeline of next-generation proteasome inhibitors, including an oral agent.

New CD20 Antibody Improves Binding with Immune Effector Cells – New clinical data from the University of Alabama at Birmingham shows that patients with recurrent lymphoma benefited from an experimental drug called AME-133v. AME-133v is a humanized anti-CD20 monoclonal antibody but differs from rituximab in that it binds much more effectively to the receptor site of the patient’s immune effector cells, even in patients resistant to rituximab. Patients are currently being enrolled in a Phase 2 study of the drug.

B-Cell Precursors Derived from Epidermal (Skin) Stem Cells – The University of Iowa Carver College of Medicine presented evidence for the use of epidermal (skin) stem cells modified to differentiate into B-cell precursors. When the isolated epidermal stem cells were co-cultured with S17 bone marrow stromal cells in a special supplemental medium, they changed their surface marker profile and gene expression pattern to one characteristic of B-cell precursors. Such cells underwent variable, diversity and joining rearrangement at the immunoglobulin heavy-chain locus. These are genetic changes unique to lymphocytes.

New Research Proposes Using Cytotoxic T-Cells for B-Cell Lymphoma Therapy – The Fred Hutchinson Cancer Research Center is working on a new therapy for B-cell lymphoma based on the use of cytotoxic T-cells. Since most patients with indolent lymphoma relapse after monoclonal anti-CD20 therapy, these researchers have proposed harvesting a patient’s cytotoxic T-cells, genetically modifying them with a mouse T-cell receptor targeted at the CD20 molecule, cloning the modified T-cells in therapeutically significant numbers, and re-introducing the modified T-cells to the patient. These modified T-cells would then attack the patient’s CD20 positive B-cells, including tumor cells. The researchers are proposing a Phase 1 clinical trial for this novel type of therapy.

Recent Congressional Actions on Genetic Testing and Cancer Clinical Trials – Congress recently passed the “Genetic Information Nondiscrimination Act” that provides federal protections against the misuse of genetic information by employers and health insurers. Specifically, the law prohibits the use of genetic information to deny employment or insurance coverage, ensures that genetic test results are kept private, and prevents insurers from basing eligibility or premiums on genetic information. As of press time, the bill was sent to President Bush, who has indicated that he will sign it into law. In other action, Senator Sherrod Brown of Ohio and Representative Deborah Pryce of Ohio have introduced the “Access to Cancer Clinical Trials Act” to Congress. This bill would require health insurers and health plans to pay for routine care costs when a cancer patient enrolls in a clinical trial. It would not require health insurers and health plans to pay for clinical trial costs, including the actual drug or device being tested and the research-related costs.

FDA to Add More Employees to Review and Approve Drug Applications – Under pressure from Congress, the FDA has announced plans to hire 1,300 employees within the next six months. Nearly two-thirds of the positions are allocated to the Center for Drug Evaluation and Research, which is responsible for review and approval of drug applications.

The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, Gareth Evans, Daniel, Howard Prestwich, and Bert Visheau in disseminating news of interest to the WM community.
IWMF President Judith May extended a special welcome to the founding members of the Ben Rude Heritage Society at the May 17 appreciation luncheon held during the Educational Forum in Los Angeles. Ben Rude was the second president of our foundation. Although he passed away in early January 2005, his gift of inspiring leadership carries on, in part, through the Ben Rude Heritage Society. Recently established by the Board of Trustees, the Society honors Ben and all those generous individuals who have followed his example by making “planned” or “deferred” gifts to the IWMF, including bequests, gift annuities, trust arrangements, insurance policies, or similar planned gifts.

The Society was inaugurated with gifts totaling over one quarter of a million dollars, given by eleven individuals representing eight families. One family of founding benefactors comes from England, one from Canada, and, representing the USA, there is one family from the east coast, two from the middle of the country, and three from the west. We truly have an international effort.

Leading the list of founding members is Laurie Rude, the spouse of the Society’s namesake. Laurie has not only remembered the IWMF through a trust but has also agreed to serve as the chairperson of the Society. Laurie recalled that Ben wanted it known that his experience with cancer enriched his life (and Laurie’s too, she adds) “because of the people it brought us in contact with--and the foundation he served which educated him about his disease.”

The second donor on the list is Ivy Cooper from Lymm, Cheshire, England, who is the mother of a Waldenstrom’s patient. Mrs. Cooper included the IWMF in her will as a tribute to her son, C.D. Potter, a pharmaceutical products salesman who has had WM for about four years.

George Knipelberg is the name of our Canadian benefactor who provided for the IWMF through a bequest. George was born in Saskatchewan, in a small town of less than 1,000. He played semi-professional hockey in the US for several years but eventually retired to pursue a career with Carling O’Keefe Breweries. George held various positions at Carling’s for over 27 years, including that of provincial sales manager. In the early 1990’s George was diagnosed with WM, but he lived with the disease for fifteen years until his death on August 8, 2007.

William O. Bresnick and Ellen Kaner Bresnick come from Potomac, MD. Both have provided an IWMF legacy through their wills. Bill is the caregiver at home; away from home he is an attorney specializing in environmental and energy issues. Ellen, who was an English teacher for 36 years and retired only last year, was diagnosed with WM two years ago and recently started treatment in the clinical trial that Dr. Ghobrial is conducting at Dana Farber. The Bresnicks have two daughters and three young grandchildren.

Anne and Peter Mitro, who live near Cleveland, OH, have also included the foundation in their estate plans. The Mitros are no strangers to IWMF as Peter, who speaks several languages and has had a long career in the field of finance, served on the Board of Trustees from 2002 – 2005, following Anne’s diagnosis in 2002.

Reuben Tross remembered the foundation in his will before he passed away in April, 2007, after serving for many years as an officer of the juvenile system of Cook County in the Chicago area. His nephew, Nate, acted as his uncle’s trustee and facilitated contact with the IWMF.

Also honored at the luncheon were Vivian and Robert Boas who currently live in Henderson, NV, near Las Vegas. Both worked with Lockheed Aircraft for over 30 years, Vivian in the office and Bob eventually as a supervisor of the famous “skunk works” in a top security division of Lockheed. Vivian was diagnosed a few years ago with Waldenstrom’s, and soon after that she decided to incorporate the IWMF in their estate planning through a will because of her deep-felt appreciation for the services given by the foundation. She made her bequest with the hope that the proceeds would “truly help someone in the future.”

The final honoree is no stranger to WMers. Elinor Howenstine became a Trustee in 2004 after being diagnosed with WM in November of 2000. Elinor was graduated from Ohio State University and later took additional courses in economics and business. She went on to work for the foreign affairs agency of the U.S. Department of State. She was subsequently assigned to the U.S. delegation to NATO in Paris. After returning from Europe she moved to San Francisco and entered the world of finance as a stockbroker, investment manager, and vice president/portfolio manager until retiring in 1998. Elinor, who loves art, theatre, ballet, cooking, and hiking, serves as a surrogate mother for three nieces.

Laurie concluded the ceremony by expressing gratitude for “these founding members of the Society--named after my late husband and second president of this great organization--who placed their treasure in our hands. It is members such as these who are the key to the future legacy of this foundation.”

If you, too, have the IWMF in mind as you consider estate planning, please complete the Ben Rude Heritage Society inquiry form on page 28 of this newsletter. Join these founding members at next year’s appreciation luncheon!
AN INTERNATIONAL PERSPECTIVE
Living with Cancer in the UK
by Fionna Eden-Bushell

Fionna Eden-Bushell is a name familiar to subscribers of IWMF-Talk as she frequently posts from Glasgow, Scotland, where she now resides. After a childhood spent on the remote Island of Mull off Scotland’s West Coast, Fionna headed for London where she began her working life as a fashion model. Several decades and several career-changes later—including a period of full-time care for her three daughters—Fionna qualified as a Scottish Tourist Guide, the profession she still practices with relish fifteen years later. Already a cancer survivor when diagnosed with WM, she is today both active and optimistic after living for ten years with our disease.

“It’s low grade and indolent.” The doctor was quietly spoken, his words carefully chosen, as he stepped through the verbal minefield of telling the patient the truth. I was the patient, and his words sounded comforting. But there was a sting in the tail. “Low grade means slow to develop, but indolent means incurable.”

This was not what I wanted to hear, but it could have been worse. Incurable it may be, but terminal it isn’t, and with care it can be controlled.

In the UK we make payments into the National Health Service throughout our working lives. In return, with certain exceptions, we receive free medical treatment at the point of need thus removing one major anxiety – how to pay for ill health. The NHS is organized and funded separately in Scotland, where I live. As in England and Wales, there are many different Health Boards, some delivering better services than others, resulting in the notorious “post-code lottery” (zip code), but, in my experience of cancer care, Glasgow, Scotland’s largest city, is second to none.

In 1998 my good health record suffered a downturn after three months of daily nose bleeds, blurry vision, and fuzzy brain culminated in a sudden high fever. My trusty GP (General Practitioner) ordered a set of blood tests and within days the laboratory reported the identity of a disease so rare that my doctor could not restrain his excitement! He spelled the name letter by letter, and I spent the next few days learning to pronounce it. Waldenstrom’s macroglobulinaemia (UK spelling) does not trip easily off the tongue. A week in hospital, with further tests including a bone marrow biopsy, confirmed the diagnosis.

I was determined to find out about WM, and I soon discovered the IWMF on the Internet. The information pack I was sent provided the basis of all later knowledge about WM while the related IWMF-Talk produced a steady flow of e-mails which to this day continue to demonstrate the extraordinary range of problems and treatments that fellow WMers endure. Determined not to become self absorbed and introspective, I rationed my research, allowing myself to wallow in WM only when each clinic visit approached—which at that time was every two weeks.

There are private hospitals in Scotland, but Glasgow is renowned for its University Faculty of Medicine. My GP referred me to the care of a Consultant Haematologist, Dr. Edward Fitzsimons, Senior Lecturer and dedicated Physician at a large teaching hospital. With such a small population base (five million in the whole of Scotland) I could not expect to find an expert in WM. Yet despite the pressures of work in an over-burdened and under-funded NHS, Dr. Fitz is not only able to communicate, he is willing to consider my contributions—often taken from IWMF-Talk. Above all, he is caring and never stints on time. What is more, I just jump on my bike and cycle from home to attend his clinic at the glossy new Beatson Cancer Centre!

Plasmapheresis provided the instant fix I needed before launching into long-term treatment. I was amazed by the improvement. My dysfunctional brain re-engaged and clarity returned to my eyes. This was dramatic, unexpected and very reassuring, even though the effects were transient. I underwent several further PP sessions over the next few months, enjoying the banter, tea, and biscuits that accompanied each two-hour session throughout the summer. I continued to work, arranging days off to see Dr. Fitz at regular intervals to discuss treatment options. He dismissed any suggestion that expensive chemotherapy agents would not be available to me. We finally settled on cladribine (2CdA), and I entered hospital as an in-patient for a week of chemotherapy. I became the passive participant in a process which I expected should make some impact on my body. I watched with curious detachment as the clear but toxic substance dripped relentlessly into my blood stream for a full week 23/7 (one hour off daily for a shower!) I anticipated nausea, faintness, trembling--some sensation at the very least. But there was nothing. The substance entering my blood stream could have been clear water.

Water it clearly wasn’t! It worked! A temporary loss of taste and an episode of shingles proved something was happening. I watched my blood numbers carefully, paying particular attention to IgM which declined from 50(00) at diagnosis to 30(00). I was in partial remission. But remission is not a cure.

Within three years the numbers were moving in the wrong direction again, and I underwent a course of Rituxan. I did not respond. A rethink of treatment options resulted the following year in a course of seven rounds of fludarabine, to which was added cyclophosphamide (Cytoxan) for the last
Dr. Rafat Abonour, Associate Professor of Hematology/Oncology, is Director of the Plasma Cells Disorders Program at Indiana University. The author of numerous articles, his clinical and research activities are focused on translational research in the areas of hematologic malignancies and bone marrow/stem cell transplantation. His work on gene transfer into hematopoietic stem cells in the setting of stem cell transplantation gained national interest when the efficient transfer of the multi-drug resistant gene-1 into autologous CD34+ cells was established.

Dr. Abonour’s current efforts are disease-focused and centered on incorporating novel therapy in the management of rare plasma cell disorders such as Waldenström macroglobulinemia and amyloidosis. As an active member of the Eastern Cooperative Oncology Group, Dr. Abonour is the chair of a study looking at rituximab in combination with chemotherapy in the treatment of Waldenström macroglobulinemia.

An avid runner, Dr. Abonour practices what he advocates when he urges cancer patients to combat fatigue by embracing a regular exercise program.

**The Los Angeles Forum, cont. from page 1**

that occur with the disease. They also learned that it will probably be many years before vaccines are available for WM. All attendees assembled at the end of the afternoon to hear the exciting news about the new patient database that will be available to IWMF members in early summer.

The Friday reception and dinner allowed patients and caregivers to network with old friends and make new acquaintances. Harriet Fulbright, wife of former Senator Fulbright, kept the dinner crowd on edge with her inspirational account of her battle with our disease. She made a personal plea for more funds for Waldenstrom’s research and then presented her annual donation to Judith May, President of IWMF.

Everyone met together for Saturday’s sessions and learned about the effectiveness of newer therapies as well as conventional treatments. A surprise finding was disclosed when microarray analyses showed that there may be several different forms of Waldenström’s. Treatment of the side effects of WM was discussed, followed by an interesting report on IWMF-supported research at Mayo Clinic. The afternoon session was capped off by an exciting presentation on the research initiatives underway at the Bing Center of the Dana Farber Cancer Institute.

On Sunday morning at the popular Ask the Doctor session more questions were raised than time allowed for answers. The conference concluded after the IWMF business meeting. One attendee observed that “the conference was very well organized. I am a first-timer and I appreciated the opportunity to meet others with the same disease while gaining so much information. I plan to return each year.”

If you were not able to attend the Forum you still have the opportunity to listen to and watch all the key presentations in detail. Those presentations were taped and are being put into a set of DVDs that should be available mid-summer. For your convenience, an order form is included with this issue of the Torch.
President's Corner, cont. from page 2

for Research; Roy Parker, Vice President for Administration; Bill Paul, Treasurer; Jim Bunton, Secretary; and Judith May, President. I am honored to continue as President and look forward to working with this talented group of people for another year.

The following Trustees were re-elected to 3-year terms: Jim Bunton, Tom Myers, Ron Yee, Dave Lively, and Don Lindemann. The Board said farewell to two departing Trustees, Karen Pindzola (PA) and Dr. Guy Sherwood (IN), and welcomed three new Trustees, Cindy Furst (CO), Don Brown (IL), and Peter DeNardis (PA). I’m sure these names are already very familiar to many of you.

The IWMF Trustees are all volunteers, working through a committee structure to accomplish the work of the foundation. We are also happy to have the help and support of many volunteers from the membership. At the Ed Forum we were delighted to recruit more volunteers for outreach to new patients (the Awareness Project) and to have more volunteers join the fundraising efforts of the IWMF.

We are happy to introduce Alice Riginos, a special volunteer from Washington, D.C. Alice has been the Assistant Editor of the Torch this past year, working with Don Lindemann. Now the Torch has been officially passed to Alice, the new Editor. Don, our excellent Editor for the past three years, will continue to stay involved and assist the new Torch team.

An upcoming article will review the backgrounds of our new trustees and new editor.

I conclude this review of Board activities with a special appeal. There is a very urgent need to find two more people with skills and experience using audio-visual equipment who would be willing to help at next year’s Ed Forum. We currently have two people who spend the entire Ed Forum running cameras, handling sound and lighting, and moving equipment around to the various rooms where it is needed. Often sessions run simultaneously. The A/V volunteers barely have time to eat and cannot take breaks. The time frame for the Ed Forum has increased to include pre-meetings for support group leaders and early bird sessions for the newly diagnosed, first timers, and treatment veterans. The Forum has grown into a Thursday to Sunday conference for many of us. We need to be sharing the A/V work among at least four people. The IWMF owns quality A/V equipment, and, with volunteers, we are able to save $2,500-$3,000 a day in Ed Forum hotel costs.

Telephone Education Workshop – July 31, 2008

Please take note of the upcoming CancerCare telephone workshop on July 31: “Managing Treatment Side Effects: Supportive Care.” This workshop will focus on many of the side effects that are discussed on IWMF-Talk, i.e., fatigue, mouth sores, peripheral neuropathy, and quality of life concerns.

Date and time: Thursday, July 31, 2008, from 1:30-2:30 Eastern Time.

CancerCare workshops are free – no phone charges apply – but pre-registration is required. To register simply go to the CancerCare website, www.cancercare.org

IWMF Patient Database

After more than two years of intensive development, the IWMF Patient Database will be open for IWMF member registration before the fall issue of the Torch is in circulation. I urge you to read carefully the article in this issue by the Database Coordinators that outlines the organization of the database and encourages members to be ready to enter their personal data just as soon as registration is open. This is a major undertaking by member-volunteers, and the efforts of Database Coordinators Joe Burke, Peter DeNardis, Ron Draftz, Sue Herms and Tom Hoffmann will greatly expand our understanding of WM.

Have a wonderful summer, and Stay Well.

Judith

ONE MORE TIME: ROW-BOB-ROW

by Dick Weiland and Bob Lynch

In 1995 at the age of 47, Bob Lynch was diagnosed with WM and was given a prognosis of 3-7 years if he started chemotherapy immediately. He and his wife Sue were thrilled when he successfully finished 18 months of treatment. Then they started wondering what good can come out of this experience.

In 1998 they decided to take rowing, a pastime Bob loves, and turn it into a unique effort to raise money to find a cure for WM. Over the last eight years Bob has completed four rows and raised $130,000 for cancer research. In addition to the money raised, Bob and Sue have also raised awareness of WM. They have shared their story of hope with thousands of people, resulting in over three dozen published articles, six TV news stories, and two film documentaries.

Despite a nerve disorder producing tingling and pain in his feet, Bob will be doing a special row this year—which may be his last. He is calling it the “Florida Panhandle Peace Row.” Bob will cover 175 miles of the Floridian coast, from Pensacola to Carrabelle, in early November.

Once again, funds raised will go to IWMF to support research studies. So make checks payable to IWMF, use the IWMF contribution envelope provided in this issue, and note Row-Boar-Row on your check. Or contribute online at www.iwmf.com.

Let’s help Bob make this last trip another winner!
Cook's Happy Hour

by Penni Wisner and Nancy Lambert

Summer is here and with it the hope, if not the actuality, of real, garden-ripe tomatoes. The kind grown for flavor not shipability. These are not the tomatoes called “vine-ripe” on their label in the supermarket. The ones that look so attractive still attached to their stems.

Instead, this column is about tomatoes grown carefully by small farmers for their flavor. The ones sold in season at farmers’ markets and roadside stands. With the rediscovery of heirloom varieties, tomatoes’ shape, color, and flavor have expanded exponentially. They can be smooth or deeply lobed, round or oval, fat or small, and colored red, of course, but also orange, yellow, purple black, and striped orange and green.

Nancy and I have been waiting for this season to describe perhaps our favorite healthy snack: bruschetta smeared with tomato. And what are bruschetta? Toast. An open-face sandwich. Bruschetta are toasts topped with anything from sardines, to bean purees, to eggplant caponata, to sliced, crushed, or chopped tomato.

So here is the easy way to make what we hope will soon be your favorite summer snack or appetizer: chop a couple of ripe tomatoes. Don’t bother peeling them. Press in a clove of garlic, season with salt and pepper to taste, add some chopped herbs such as chives, basil, oregano, thyme or a mixture of herbs (tomato is one of those foods that goes with just about any and every herb and spice), a small splash of balsamic vinegar, and a larger splash of extra-virgin olive oil. (I have just been to a two-day olive oil tasting workshop but will not climb onto my olive oil soapbox just now) Mix this together gently, cover loosely if you need to protect it from flies or drifting cat and dog hair (as is the case in my kitchen). Let the tomatoes sit at room temperature to develop flavor. They can sit several hours. This reminds me: never refrigerate a tomato. That will kill its flavor. Even if you return the tomato to room temperature, it will not have the flavor it did before chilling.

When you are ready to eat, slice good, crusty bread such as baguette (you want something with real texture since it needs to support the tomato topping.). Brush the slices with olive oil on both sides and toast them. Or, hopefully, since it is summer, you have the grill going and can grill the bread which gives it an irresistible flavor. Then simply spoon the marinated tomatoes onto your toast. Voila! Tomato bruschetta.

Our motto: Eat Well to Stay Well

Penni (penniw@pacbell.net) and Nancy (llnc3@aol.com) look forward to hearing your suggestions for healthy, fast, and easy snacks.

Administrative Matters

by Roy C. Parker, Vice President for Administration

Los Angeles Forum Video Recordings

As in past years, our outstanding videography volunteers have filmed (and are now in the process of producing in DVD format) video recordings of the recent Education Forum held in May in Los Angeles. The DVDs of the sessions contain all the outstanding presentations by our various speakers, including the complete recording of the Ask the Doctor session.

Now you can see and hear these presentations in their entirety in the comfort of your home, sitting in your comfortable lounge chair, and cradling your trusty medical dictionary. Unlike the experience at the Forum, you can push the pause button or go back and review a particular presentation or parts thereof. This feature is useful to both attendees and those of you, dear readers, who rely on the Forum DVDs to be informed and kept up to date.

If you would like to purchase a set, please complete the enclosed form and return it to the business office.

Forum Registration Woes

A very small percentage of registrants to the Forum (this writer included) discovered that, while their electronically submitted registration was received and acknowledged by the IWMF Office, the credit card information went missing into some technological black hole with the result that their registration was not recorded. This malfunction was caught in time before it became a problem upon arrival at the hotel. Rest assured that our technical wizards have identified what went wrong and that this software flaw is being corrected.

Be Green: Receive the IWMF Torch on the Web

Another reason to opt in to receive the quarterly Torch electronically. New members may not be aware that the Torch is posted on the IWMF web site (www.iwmf.com) just prior to being mailed to members. An increasing number of members are choosing to opt in. This not only saves the IWMF printing and mailing costs but, at the same time, allows you to receive the Torch in a much faster time frame than postal service delivery. Going with electronic delivery is an extra bonus for the planet and our environment while it saves the IWMF a considerable amount of money. Send an e-mail to the IWMF office at info@iwmf.com advising that you do not wish to receive a paper copy of the Torch via the mail system. If you need copies you can always download them from our web site.
FROM IWMF-TALK

by Rob Selden

Many concerns were voiced by participants of IWMF-Talk over the past months, ranging from dental health and questions about insurance and job change to treatment tips and wine consumption.

Mireille Toutant raised several questions about autologous stem cell transplant. She’s already had her stem cells harvested but it seems to be the best time to proceed with the transplant. After a few exchanges with members both on- and off-list, Mireille explained more of her medical history and said that she was considering doing a transplant this summer.

The topic of dental health during treatment was raised when Don Nolan inquired whether anyone had noted any negative effects on their teeth following Rituxan-Cytoxan-prednisone therapy. Several members replied that there shouldn’t be any effect. But yours truly chimed in that, whether from treatment or disease, those with low white counts are susceptible to gum infection, which can lead to gum recession and bone loss. Sue mentioned that certain chemotherapies cause temporary reduction of saliva, which is one of our natural protectants against tooth decay; a high-fluoride toothpaste may help in such dry mouth situations.

The issue of bleeding gums was raised by Rosalba Buontempo, who communicates with IWMF-Talk for her father. His prior IgM count was 5500, and she wondered if his bleeding gums might be similar to other nosebleeds caused by blood vessel damage. Colin Perrott described the complexities involved in our platelets and clotting systems and how in WM this can cause clot-resistant nose and gum bleeds. Tom Hoffmann offered that the most important thing is for her dad to be checked by his dentist; factors other than WM effects might be causing these bleeds.

Pete DeNardis cited an article in the Financial Times about research into the anti-cancer effects of red wine. University of Rochester researchers have found that resveratrol (found in grape skins and red wine) helps destroy mitochondria in pancreatic cancer cells and makes tumor cells more sensitive to radiotherapy. Paul Okunieff, chief of radiation oncology at the university’s medical center, acknowledged that this hasn’t been well studied but that wine consumption is not prohibited during radiotherapy. Our Jerry Fleming noted that Dr. Irene Ghobrial of Dana-Farber is studying resveratrol as a treatment for WM. Even though therapeutic levels of resveratrol aren’t possible with average wine drinking, nevertheless several members posted that they were perfectly willing to try “natural” resveratrol (aka wine) in the meantime. It should be noted that we should consult our doctors first, since alcohol may be contraindicated during treatment.

As her husband was about to embark on Cytoxan/Fludara therapy, Cici Menchen asked for suggestions to discuss with their doctor, especially concerning drugs to minimize side effects as well as foods and drinks to add or avoid. Numerous members chimed in with suggestions for lots of fluids, small and frequent meals, mild smelling foods with little fat to minimize the chance of nausea. Regarding drugs, Ativan can minimize anxiety and help with nausea. Various anti-emetics can be prescribed; responses to them vary, and they’re known to cause constipation as their own side effect.

Great news was reported by Penni Wisner after her annual visit to the oncologist. Eight years after completing therapy with 5 cycles of Cytoxan/Fludara plus 4 doses of Rituxan, she has no M-spike and an IgM count of only 42. Questioning her oncologist whether this represents complete response or complete remission, he answered that remission is historical - if the disease doesn’t come back, then she’s had a complete remission. Eight years, and counting!

Ray Patti asked to hear about solo Rituxan success stories. Numerous members reported on their response duration. Joan Kopernik noted 32 months followed by 3 maintenance infusions, with a recent IgM of only 950. Arno Muller, one of our longest diagnosed members (1986), only needed treatment in December 2003 (pheresis and Rituxan) and his IgM was still dropping in January four years after the R-solo treatment. Laura has had at least a 4-year remission with solo-R. Her current IgM is 344. Lori Mancuso’s solo-R treatments began in 2000 with IgM starting at 6800; now in 2008 her most recent count is just about 350.

More than 650 members responded to the website survey distributed in February. In the coming months, the IWMF

FROM IWMF-Talk, cont. on page 19

HOW TO JOIN THE IWMF-TALK

Here are two ways to join:

1. Send a blank e-mail to: iwmf-talk-subscribe-request@lists.psu.edu
   Make sure to enter the word subscribe as your subject, and do not sign or put anything in the message area (make sure you do not have any signature information in there). Also, do not put a “period” after “edu” or it will reject. Once approved you can post by sending e-mail to iwmf-talk@lists.psu.edu

2. Contact Peter DeNardis at pdenardis@comcast.net and provide your full name
website committee will be compiling the results to develop improvements for the website.

Mike asked about the complicated issue of job change and insurance coverage. Obviously, we’re not talking about the highly charged issue of universal insurance coverage and portability but the hit-the-ground-running issue of dealing with the insurance one has and preserving maximum benefits in this equation. Responses ranged from looking into various state programs that can offer insurance after COBRA expires to creating a small business that could then purchase group insurance.

Judith May advised us about the Leukemia & Lymphoma Society’s co-pay and financial assistance programs. They’ve recently increased the maximum assistance amount, and it will be retroactive to January 1, 2008. You can visit their website at www.lls.org to see what assistance is available.

Bertha Henriques delivered the sad news that her father, Joe, a member of IWMF-Talk since 2000, died on March 1 of viral pneumonia. He had WM for more than 15 years with minimal treatment of only Leukeran in the past few years.

How to manage and negotiate with our doctors for our care is the interesting issue that Nancy Herring articulated. Colin Perrott offered some interesting ideas, notably giving the doctor advance notice of substantial issues you wish to talk about so she/he can set aside sufficient time. Bob Reeber reminded us that it’s up to the patient to learn as much as possible about our disease to be able to ask reasonable questions about the doctor’s recommendations and alternatives. And, of course, there is frequently the possibility of a second opinion, depending on one’s insurance coverage.

Sandi Banks inquired about a pain under her ribs on the left side. Several members responded that this may be due to spleen enlargement. She was due to have a CT scan and then an upper GI to investigate further, as she had responded well to 5 infusions of Rituxan, yielding an IgM in the 600s.

This spring was a busy time for new members posting to the list, including Orit Gilad, John Nall, Frank Klosik and Joann Zloklikovits. They range from being diagnosed less than two weeks prior to posting to being diagnosed four years ago and currently in treatment. Joann’s story was particularly arresting. Within days of being diagnosed with WM and still recoiling from the initial shock, Joann (a nurse by profession and a caregiver to both son and husband at home) had located the IWMF and quickly learned of and attended a support group meeting in New York. At the meeting she was helped by an IWMF member, whose full name she never learned, offering guidance to a newly diagnosed patient. All of this reflects so well on the outreach of the IWMF and its welcoming ways. But after Joann’s shock and reaction, she got a second opinion and was told that she does not have WM. However, Joann now knows that only a bone marrow biopsy can confirm the presence of WM, and she plans to have a biopsy and confirm the diagnosis either way. She certainly experienced quite a lot in the month of May. Joann’s was not the only voice on IWMF-Talk to express gratitude for the kindness and concern shown to a new member. All of these new members apparently received many messages of support off-list as well as on, and are thankful for the support and resources available through IWMF-Talk and the IWMF.

Welcome aboard!

Rob Selden, guest TalkList Correspondent for this issue, frequently posts on IWMF-Talk.

International News, cont. from page 9

Robert A. Kyle, M.D., Mayo Clinic, Rochester, MN, USA
Veronique Leblond, M.D., Hôpital Pitíé Salpêtrière, Paris, France
Steven P. Treon, M.D, Ph.D., Dana Farber Cancer Institute, Boston, MA, USA

Sunday afternoon will be devoted to an Ask the Doctor session.

It is expected that attendees will be coming from a number of countries in Europe and elsewhere. Pre-seminar tourist options are available for Saturday, October 18.

A brochure for the IWMF Stockholm Patient Seminar containing further information and registration instructions is available upon request from the IWMF office. Request your copy by e-mail: info@iwmf.com.

Information regarding the Stockholm Patient Seminar is also posted on the IWMF website www.iwmf.com under ‘events calendar.’

IWMF To Participate in European Symposium

The IWMF will participate in the international European symposium “No Policy Without Patients” to be held on October 30, in Maastricht, the Netherlands. Sponsored by the European Myeloma Platform (EMP) and the MM & WM Patient Association of the Netherlands (CKP is their acronym), the symposium is held in honor of the celebration of the 25th anniversary of the CKP.

The aim of the symposium is to demonstrate the influence of patient associations on the formulation of health policies at national and European levels. Recommendations for the future role of patient associations will be formulated.

More information at: www.kahler.nl/ckp/symposium/symposiumen/
Support Group News, cont. on page 21

This list is only for support group leaders to use in communicating with each other about support group issues. It is used by the leaders to share their experiences and ideas for facilitating our IWMF support groups. Please e-mail Support Group Coordinator Arlene Hinchcliffe at wmfc@noco.ca if you would like to participate.

CALIFORNIA
Sacramento and Bay Area

Thanks to the Sacramento office of the Leukemia & Lymphoma Society (LLS), John Haluck, Attorney at Law, spoke to the group about cancer and the law. A CLL patient himself, he is intimately familiar with the many ways cancer may affect a patient’s legal, employment, and insurance status. Lawyer Haluck gave many good resources and a clearer understanding of patients’ rights. For example, it was news to many in the group that, under California law, approved clinical trials are not “experimental,” thus insurers must pay their full share. All four phases are covered though payments may be restricted to services provided in California.

Dr. Steven Treon will be the speaker at the group’s next meeting on September 21, held in conjunction with the LRF’s Annual Patient Education Forum in San Francisco.

GEORGIA

The Georgia support group will be holding two meetings in the fall with speakers from the Dana Farber Cancer Institute. At our September 13, meeting we will be hosting Dr. Steven Treon, and on October 25, Dr. Irene Ghobrial will be presenting. The South Carolina support group is invited to attend. Details of the meetings will be announced in late July. If you are interested in attending these meetings from outside of Georgia, Alabama or South Carolina, please contact Mal Roseman.

ILLINOIS

The Chicago Area support group is very happy to report that Dr. Morie Gertz spent a wonderful two hours with us on May 3, exceeding his planned 90 minute presentation. We experienced a live performance of his famous “Weeds in the Garden” presentation, followed by Q & A about some WM fundamentals. We also were the first to hear his newly prepared presentation on treatments that he was soon to give at the IWMF Education Forum in Los Angeles. His talk was followed by an extended general Q & A period covering 15 prepared questions and a number of additional questions from the attendees. It was clear that we all heard some very encouraging new information about treatments. We thank the Mayo Clinic for allowing us a room at the Sheraton Chicago during their “Living with Blood Cancer” conference where Dr. Gertz was also a participant. Our next meeting will host another well-known WM specialist, Dr. Steven Treon, on the afternoon of Saturday, August 16. Contact Don Brown if you would like a summary of the meeting with Dr. Gertz or more details on Dr. Treon’s August 16 visit.

MICHIGAN

The Michigan support group met on Saturday, May 3, at Beaumont Hospital in Royal Oak. Cassandra Wolanin, an oncology certified nurse, spoke to the group about the different kinds of chemo and bio therapies available to treat Waldenstrom’s. She also informed the group about the types of drugs given during treatment that prevent unpleasant side effects when the chemical or biological therapies are administered. Although the group was small at this meeting, the discussion was rich and very much appreciated by those attending. The food for the potluck was also excellent.

MINNESOTA & WESTERN WISCONSIN

The Minnesota and western Wisconsin support group met on Saturday, May 17. Our guest speaker was Alice Shapiro, Ph.D., from Park Nicollet Institute. She helped us understand the role of nutrition in reducing the harmful side effects of cancer therapies. It was very informative and we all appreciated Dr. Shapiro’s spending some time with us on what turned out to be a beautiful, sunny Saturday afternoon. Such afternoons are far and few between in Minnesota this year, so her sacrifice did not go unrecognized. We’re planning our second annual summer potluck picnic: we plan to get together on Saturday, July 12, for an afternoon of feasting and fun. Out next scheduled support group meeting is September 20, when we’ll be joined by Dr. Irene Gobrial. We’re all looking forward to this.

WESTERN OHIO, EASTERN INDIANA, & NORTHERN KENTUCKY

The western Ohio, eastern Indiana, northern Kentucky support group met for its quarterly gathering at Upper Valley Medical Center, Troy, Ohio. In our “leader’s” absence, Lori N. did a great job of standing-in as master of ceremonies. As our own group member, Dr. Guy Sherwood, was our speaker, the mc’s task was an easy one. Dr. Sherwood gave us a preview of the immunology paper he was scheduled to present at the IWMF Education Forum in Los Angeles. As all have come to expect, Dr. Sherwood’s presentation was superb in...
style and content. We were especially glad to welcome new participants into our group, which is now seven and a half years old. We next meet in northern Cincinnati at the office of the LLS on July 19, 2008, at 10 am. This LLS office has been most welcoming in hosting our gatherings in alternate quarters of the year, even providing us with lunch! With the geography of our group covering such a wide multi-state area, our two-site meeting locations at opposite ends of our territory really help to accommodate those driving long distances.

OREGON/SOUTHWEST WASHINGTON

On May 3 Dr. Steven Treon spoke at the quarterly support group meeting. Dr. Treon’s research and clinical studies focus on developing therapies for the treatment of multiple myeloma and Waldenstrom’s macroglobulinemia. He answered questions about WM from patients, family members, and friends in attendance. We received very positive feedback from attendees. Our previous record attendance was 26; 49 were present to hear Dr. Treon. Our support group is a joint effort of the IWMF and the LLS; the LLS provides our meeting location and a free lunch (an RSVP is required, however!). Tentative dates for future WM support group meetings are the fourth Saturdays of January, April, July and October. We will meet July 26 and October 25, 2008, at Fairfield Inn and Suites, Lake Oswego (near Portland, Oregon). Tentative dates for 2009 are 1/24, 4/25, 7/25 and 10/24. We encourage you to mark your calendars. Visitors from across the US and Canada (and from international locations) are welcome to join us if you are in the area on business or vacation. When scheduling trips to the beautiful Pacific northwest, check with the support group leaders in this region to verify dates of meetings.

PENNSYLVANIA

Harrisburg

Our summer meeting will be our annual picnic on August 10. Kate and Don Wolgemuth have offered to host this event at their home.

Philadelphia

The Philadelphia area group meets every other month on Sunday afternoons. We sometimes have a speaker or a tape and sometimes we just share our WM experiences with each other. Our April meeting was of the sharing variety, and what a terrific meeting it turned out to be. One member brought up the topic of “should you or should you not tell people that you have WM.” Several people had reasons for not telling children or elderly parents and relatives. Others described not telling people at work; some had no problem with this. A new patient and his wife talked about her mother having had WM 40 years ago and how different it was at that time. We were happy to be able to assure her that things have changed quite a bit, and a discussion ensued about how it was then

and now. We’ve come a long way, baby! The Pindzolas’ little dog, Heidi, wandered about looking for scratches and pats on the head.

SOUTH CAROLINA

The South Carolina WM support group met in early April in Aiken, SC. While we had a relatively small group this time (8 people), we had a very informative discussion about our respective experiences, comparing notes on treatments, symptoms, and doctors. Some of the veteran WMers were able to offer insight to a relatively new WMer. In the fall we have two opportunities to join forces with the Georgia support group in Atlanta: September 13 for a presentation by Dr. Steven Treon and October 25 for a presentation by Dr. Irene Ghobrial. Drs. Treon and Ghobrial will bring us up to date on the latest research at the Dana Farber Cancer Institute and on available treatments for WM. For more information, contact the SC support group coordinators, John and Paula Austin.

TEXAS

Dallas & Northern Texas

The northern Texas WM support group meeting in March featured Bonnie Lucio, a physical therapist at Baylor University Medical Center, who spoke about peripheral neuropathy, which many of us WMers suffer from. Jerry Fleming, the group facilitator, will report on the 2008 IWMF Education Forum at the May 31 support group meeting. On August 23, Dr. Steven Treon will present an “Update on Multiple Myeloma and Waldenstrom’s Macroglobulinemia.” Marvin Stone, M.D., Baylor University Medical Center, will also make a presentation. The north Texas myeloma support group and the LLS will be participating with us for this meeting. The presentations will be in the Folsom Room on 17 Roberts, Baylor University Medical Center in Dallas. Registration will be at 10:00 am. Following the presentation, we will have lunch and a WM Support Group meeting.

Houston

Dr. Maria Scouros, CEO and medical director of the Houston Cancer Institute, spoke at our April meeting. The meeting was co-sponsored with the LLS. Dr. Scouros, a hematology oncologist, has satellite offices, in addition to her Houston Blalock office, in Sugarland and the Woodlands. John and I credit her conservative and thoughtful practice with keeping John so well for so many years! The next Houston support group meeting will be on Sunday, August 24, at 2 PM. For more information, contact Barbara and John Manousso.
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three rounds, both taken orally, so no need for hospital visits. It was not entirely plain sailing, but the results are impressive. Three years on, and nearly ten years since diagnosis, I am feeling as good as it gets. My IgM reduced steadily over many months following treatment and now remains stable at around 12(00). I am not on any regular medication and see Dr. Fitz only three times a year.

So if I still have cancer, and further treatment is inevitable, why am I so sure I can live with it?

Twenty years ago my excellent non-smoking, low-fat health record was brought to an abrupt end. I was forty-eight when my GP – the same one – first ascribed the big “C” to my name. If cancer can ever be considered glamorous, then blood is at the pretty end, while bowel, by its very nature, is not. Bowel cancer patients are considered cured if they survive five years post operatively. Fifty-five per cent do not but I was one of the lucky ones. A skilled and kindly surgeon -- at the same hospital I attend now -- performed a resection of the sigmoid colon, cutting out the diseased S-bend-like destroying dry rot.

Our three daughters, encouraged by their parents to travel, had already left home. Into the breach stepped my husband, not only caring for me during my recuperation but, in addition, also taking on the tasks of cooking and catering and general household management, tasks he has never relinquished. This allowed me to embark on a new career as a tourist guide, a profession that inevitably involves travel where one is often cooped up in contained spaces and subject to coughs and sneezes and obscure diseases. I have not always escaped the consequences, but, thanks to the NHS, I carry antibiotics to cover most eventualities. I use heparin injections to avoid DVT (deep vein thrombosis) on one or two transatlantic flights each year to visit the USA where our travelling daughters settled and married, providing us with eight gorgeous grandchildren.

Cancer is not always a life sentence. I may be living on borrowed time but I have at least eight good reasons to keep going!

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**HAVE YOUR SAY**

The *Torch* welcomes letters, articles or suggestions for articles.

If you have something you’d like to share with your fellow WMers, please contact Alice Riginos at 202-342-1069 or ariginos@sy-thetis.org

*THE LIFELINE*

*June 17, 2008*

If you can’t get to a local support meeting, use our IWMF Telephone Lifeline to call a WM veteran.

The lifeline is seeking volunteers who speak a language other than English. If you would like to volunteer, please contact the IWMF business office at 941-927-4963 or info@iwmf.com.
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