

BASIC RESEARCH AND CLINICAL TRIALS AT THE DANA-FARBER CANCER INSTITUTE

By Guy Sherwood, M.D.

Researchers are making rapid strides at the Dana-Farber Cancer Institute in Boston, as IWMF trustees learned during an afternoon of fascinating presentations before the November board meeting in Boston.

Dr. Steven Treon, Director of the Bing Center for Waldenstrom's Macroglobulinemia, started the session by introducing his ever expanding team of talented young researchers. Over the past year, Dr. Treon has traveled extensively throughout the U.S. to present highlights of the group's research to numerous WM support groups. (The IWMF board approved a large grant to the Bing Center last summer for Dr. Treon's research project, Comprehensive Studies into the Genetic Basis and Pathogenesis of Waldenstrom's Macroglobulinemia.)

A word of warning: the complex issues described here can be overwhelming. Nonetheless, you should feel encouraged and empowered by the exponential increase of knowledge arising from IWMF-sponsored research into the basic science of WM.

Prevalence of WM

There appear to be approximately anywhere from 6,000 to 10,000 cases of WM in the U.S., representing 1% of total hematological malignancies. In contrast, multiple myeloma (MM), also considered a rare disease, accounts for 6% of all U.S. hematological malignancies. There are estimated to be 1000-1200 new cases of WM per year in the U.S. with a distribution of two men for every woman. Consequently, in the U.S., the prevalence of this disease is approximately 3.4 cases per million men, and 1.7 cases per million women.

Research suggests that there may be some familial clustering of WM. In a study published last year by Dr. Treon and others, it was reported that almost one-fifth of WM patients had at least one first-degree relative with either WM or another B-cell disorder. Patients with a familial history of

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ED FORUM COMING UP SOON!

by Don Lindemann

The 12th annual Educational Forum, set for April 27-29 in Atlanta, will once again bring together hundreds of patients and caregivers to hear from top clinicians and researchers about treatments for WM and recent scientific advances in the understanding of our disease.

As the *Torch* goes to press, IWMF volunteers are busy with final arrangements for what promises to be an informative and inspiring event. This year we have chosen the theme "Thriving with WM" to highlight hopeful stories about new discoveries and therapies as well as the ways in which patients are living life to the fullest while waiting for a cure!

If you have not yet registered for the Forum, there may still be time if you act now. Visit the IWMF website (www.iwmf.com) and click on the "Education Forum" box at the top of the page.

Pre-Forum Workshop for Support Group Leaders

IWMF Support Group leaders will have a one-day workshop again this year, to be held Thursday before the Ed Forum.

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PRESIDENT'S CORNER

by Judith May

NCI Names Doctor for Oversight of Waldenstrom's Macroglobulinemia

Dr. Richard Little has joined NCI's Cancer Therapy and Evaluation Program, Clinical Investigations Branch, and will be responsible for oversight of WM in regard to clinical trials and therapy evaluation, in addition to other rare cancers in his portfolio. I will be meeting with Dr. Little in May to explain the purpose and activities of the IWMF and to explore how we might work together. This is significant progress in NCI's recognition of, and involvement with, WM.



NCI Redesigns Clinical Trials Search Website

It is now easier to find clinical trial results by cancer type on NCI's clinical trials online portal. Based on feedback from users, many parts of the site have been simplified and the search feature is now easier to use. To see the new search features and other educational materials for patients, family members, and researchers, go to www.cancer.gov/clinicaltrials.

Mayo Clinic Newsletter Features IWMF Trustees

Congratulations to IWMF trustees Dave Lively and Dick Weiland, who were the focus of an article, *Waldenstrom's Macroglobulinemia—“Small Disease” with Big Consequences*, which appeared in the Spring 2007 issue of **Mayo Magazine**. This is a great article that will develop awareness of our disease among the readers of a magazine with a very large international distribution list. The story came about when Dick Weiland noticed, in a past edition of Mayo Magazine, that the Associate Editor was a former colleague. Dick contacted her and explained his current health situation, his association with the IWMF and IWMF ties to Mayo to see if there was interest in an

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International Waldenstrom's Macroglobulinemia Foundation
3932D Swift Road • Sarasota, FL 34231-6541

Telephone 941-927-4963 • Fax 941-927-4467

E-mail: info@iwmf.com • Website: www.iwmf.com

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Judith May

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GUEST EDITOR (SPRING'07)

Charles Schafer

MEDICAL NEWS EDITOR

Sue Herms

SENIOR WRITERS

Jim Berg

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SUPPORT GROUP NEWS

Penni Wisner

TALKLIST CORRESPONDENT

Mitch Orfuss

LAYOUT

Sara McKinnie

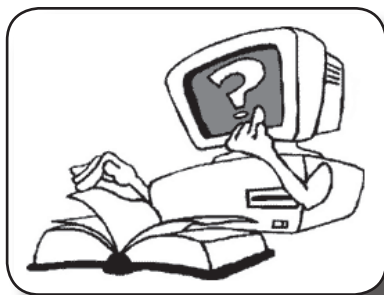
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IWMF PATIENT DATABASE PROJECT PROGRESS REPORT

by Peter DeNardis

Over the past several months, significant progress has been made on the IWMF Patient Database Project (PDBP). Thanks to the exhaustive efforts of several volunteers, your PDBP team is well on its way to making the database available to the IWMF community. In a sense, one can view it as an extension of the TalkList, whereby one can seek out and obtain both detailed and summary information about how other WM patients are dealing with the disease.

Although still in the development stages of the project, the PDBP team is at a point where we will be able to demonstrate some of the key features and functionality of the tool during a breakout session at the Ed Forum in Atlanta. Please, feel free to stop by!



Most people (including database project volunteers) may have first impressions that such an undertaking would simply require developing a series of multiple choice questions, and then placing them in a format that is both viewable and usable via the internet. However, over the past several months, the true complex nature of the project has revealed itself and it has proven to be an exciting challenge to all those involved. Some of the issues that the project volunteers have been grappling with include what questions to ask, how to ask the questions so that they are unambiguous, and what types of responses to make available in order to give respondents the most comprehensive framework in which to explain their condition while also allowing for summary profile building and analysis possibilities.

The Patient Database consists of several modules, each of which contains questions on a different aspect of the patient's experience with WM i.e., *Patient History*, *Symptoms & Syndromes*, *Test Results*, and *Treatments & Drugs*. Information of general benefit to patients and caregivers, along with results of the surveys will be provided through two additional modules: *Glossary*, and *Queries & Reports*. The *Queries & Reports* module will feature graphs and charts of personalized information for individual users of the database, along with summary information based

on all persons who have entered data in the database. At this point, the *Patient History* module and the *Test Results* module (CBC tests only) are projected to be completed and ready for data entry in time for the forthcoming Ed Forum. Ongoing activities are focused on the development of the *Symptoms & Syndromes* module, other elements of the *Test Results* module, and portions of the *Glossary* module.

PDBP Team Coordinators—Ron Draftz, Tom Hoffman, Joe Burke, and Pete DeNardis—wish to acknowledge and offer appreciation for the great efforts being expended by all of the PDBP volunteers. Their efforts will be critical in realizing the completion of a valuable and utilitarian tool to help us better understand our condition and how to manage it. To our knowledge, no other organization provides such a database for patients.

Progress to date is due to the diligence and hard work of many talented individuals. Special recognition is given to the Information Sciences and Technology students at Penn State University's Beaver Campus, and especially to Anthony Ricciardi (an intern whose position was funded by the IWMF). All of the PSUBC students played critical roles in the development of the infrastructure behind the survey questions. Yet, while the design and development of the infrastructure (hardware, software, database tables, online data entry screens) is certainly of key importance to the success of the project, the more challenging and critical aspect of this initiative has been the creation of the survey questions themselves. Volunteers have worked doggedly at creating, reviewing, and revising the question and answers sets and are deserving of our enthusiastic commendation for a job well done.

After the Ed Forum, PDBP work will continue on further development of the modules, development of training aids for users, creation of paper-based versions of the online database for those without computers, promotion of the PDBP to cancer-awareness and medical organizations, statistical analysis of collected data, and ongoing maintenance, enhancements and refinements of the database. If you are not currently working as part of one of the PDBP teams, and if you have interest and expertise in any aspect of the project, we'd like to hear from you. Please contact either Ron Draftz (rondraftz@wowway.com; 847-577-2053) or Pete DeNardis (pdenardis@comcast.net; 724-378-9260) – or come see us at the Ed Forum during the break out session.

WAYS OF GIVING

by Dave Lively and Dick Weiland

There are different ways to experience “the joy of giving.” In the last edition of the *Torch*, we wrote about the new IRA rules and bequests. This time around we are pleased to have an opportunity to outline a wide range of strategies to make a philanthropic investment in the \$5 million Research Fund program currently underway at IWMF. In general, and aside from bequests, “ways of giving” fall under three general categories: outright gifts, life income gifts, and the always omnipresent category of “Other.”

Outright Gifts and Pledges—A “Lively” Way to Give

Cash and Pledges—We love this way of sharing

The convenience of a cash gift makes it the most popular way for people to support IWMF. Gifts of cash may be deducted up to 50 % of your adjusted gross income. Gifts in excess of 50% may be carried over for up to five years as deductions. In other words, a donor may have six years to use the charitable deduction.

Securities—A great way to save on taxes?

The use of stocks, bonds and other appreciated assets to make your donation may reduce the net cost of your gift through tax savings. Donors receive a tax deduction for the fair market value of their securities, with no capital gains tax on the appreciation. The charitable tax deduction is limited to 30% of the donor’s adjusted gross income for the year, but any excess over the 30% limitation can be carried over for up to five additional years.

Life Income Vehicles—Gifts That Give Back

Life income vehicles offer the donor income for life, or for a specified term of years, for making an irrevocable gift to IWMF.

Example A: A Charitable Remainder Trust provides income to the donor’s beneficiaries and allocates the remainder to IWMF. Payments are determined annually and depend on the value of the trust’s assets as recalculated yearly.

Example B: A Gift Annuity provides the donor with a contractual promise of fixed annual income. The payout rate depends upon the age of each beneficiary at the time the gift is made and when the payments are scheduled to begin. Payments can be deferred for several years.

Other Planned Gifts

Below are three examples of other deferred gifts that could be made to IWMF:

Example C: A Life Estate provides IWMF with a gift of a residence or farm while allowing the donor the right to continue to live there for the remainder of his or her life.

Example D: A Charitable Lead Trust provides IWMF with income for a term of years and leaves the remainder to the heirs of the benefactor.

Example E: Life Insurance designations allow a charity to receive benefits upon the death of the insured and can offer a number of tax savings advantages.

Be sure to consult your attorney or tax adviser as an integral part of developing your donation plan. For special advice, feel free to write or call Dave Lively at 1-608-783-4552 or livelyfish@aol.com. Also, plan to stop by to visit us in Atlanta at the Estate Planning Workshop or “What To Do With Grandpa’s Old Buick.”

Tribute and Memorial Giving Cards Now Available

IWMF has designed two new personalized giving cards. These cards were created for your convenience and are available at no cost to you. A sample of both cards is enclosed with this issue.

The **In Tribute** card is for those who wish to send a gift to IWMF to acknowledge a friend, family member, colleague or a special person associated with an upcoming special occasion such as a wedding, birthday, anniversary, holiday, etc.

The **In Memory** card is to serve you and your loved ones during difficult times to accompany a personalized condolence or “in memoriam” gift.

These cards may also be appropriate if you are participating in or coordinating an event to raise funds for IWMF. Please advise the IWMF Business Office if you would like a supply of either or both cards. All honorarium and memoriam donations are published in our newsletter. The names of the person(s) you honor or commemorate are always recognized in the *Torch*.

Note to Canadian Members: Cards similar to these for use in Canada can be obtained from Arlene Hinchcliffe at WMF Canada 905-337-2455 or wmfc@noco.ca

NEW DEVELOPMENTS IN GENETIC RESEARCH SPONSORED BY IWWMF

by Guy Sherwood, M.D.

Dr. Linda Pilarski is a world recognized expert studying the genetic characteristics of Waldenstrom's macroglobulinemia (WM). Her laboratory at the Cross Cancer Institute of the University of Alberta in Edmonton, Canada houses her team of talented researchers. The Pilarski team is elucidating the multiple genetic events that lead to the eventual formation of the malignant WM B-cell.

In her most recent research report to the IWWMF Research Committee, Dr. Pilarski described the existence of bclonal WM cells in a relatively high percentage of WM patients. This research will soon appear in *Clinical Cancer Research*, a highly respected and peer-reviewed journal. Four of the 20 WM patients studied exhibited two B-cell clones or *partner clones* and one patient demonstrated IgM / IgA bclonality. In IgM/IgA bclonality, the IgM clone occurs in the bone marrow while the IgA clone is present in the circulation. It appears, therefore, that sometimes two partner WM cell clones can co-exist, one in the marrow and one in the blood. The three other patients exhibiting bclonality were categorized as IgM / IgM clones.

Dr. Pilarski's research suggests that WM is manifested by multiple transformation events occurring in multiple independent B cell clones. These clones sometimes predominate at different tissue sites. Based on her results to date, she speculates that multiple and unrelated malignant clones may arise during pre-clinical stages of WM. She notes that for most patients, only one of the two possible clones becomes dominant but for others the two clones can apparently coexist. The detection of multiple clones was done using molecular markers, making it difficult at this point to determine the relative contributions of each clone to disease symptoms or clinical outcomes.

Dr. Pilarski was awarded a three year research grant from the IWWMF in May 2005 for her research proposal Genetic Characteristics of Waldenstrom's Macroglobulinemia. She communicates and collaborates frequently with Dr. Steven Treon, who was the recipient of a large IWWMF research grant in 2006. His research is focused, in part, on the genetic characteristics of WM (see related article).

In 2006, Dr. Sherwood was appointed Project Liaison Officer for Dr. Pilarski's IWWMF-sponsored research project.

New Booklet MANAGING CHEMOTHERAPY SIDE EFFECTS

Reviewed by Charles Schafer

You've probably seen examples of popular books in the "for Dummies" series, all of which try to explain intimidating subjects in friendly, jargon-free language. Now, believe it or not, there is a booklet called *Managing Chemotherapy Side Effects for Dummies*.

By the time you read your way to the last page of this 23-page pamphlet, you will realize that it has a two-fold mission. The first is to provide an abbreviated and easy-reading summary of common sense hints for dealing with chemo side effects, particularly nausea. The topics covered range from combating nausea to *Battling Intestinal Disarray* (need I say more). The second part of the pamphlet's mission appears to be to advertise the presumably more voluminous and comprehensive *Chemotherapy & Radiation for Dummies* publication, which features the same suite of authors as the pamphlet.

One neat inclusion found on the last two pages of the pamphlet is a list of questions that you may wish to ask your oncologist or chemotherapy nurse. Another useful section comprises a list of cancer resource organizations along with their respective web page addresses and 1-800 phone numbers. I suspect that this publication might lead some of us to the larger publication although all of the basics needed to launch an initial attack on chemo nausea seem to be covered in the pamphlet. To order your free copy, set your web browser to www.chemofordummies.com.

To broaden the scope of information that IWWMF members receive, and to encourage contributions from some of the keen readers among us, we plan to print short book reviews in future issues of the Torch. The next issue will list the titles of books available for review. Members will be able to request a complimentary copy of a book that is of special interest to them in return for preparing a short article with their impressions of the work.

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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 Don Lindemann at 510-848-4069 or torcheditor@gmail.com

CANCERCARE OFFERS WORKSHOPS

Chemotherapy-related Anemia

CancerCare, a national nonprofit organization that provides free, professional support services to anyone affected by cancer, is offering a free telephone Education Workshop Series for people living with cancer. The series will consist of two one-hour teleconferences under the title of *Chemotherapy Related Anemia: Taking a Step Forward*.

Part I : To be held on Wednesday, May 23, 2007 at 1:30-2:30 p.m. EST. The topic to be covered is: *Understanding your CBC and Anemia: How Your Blood Count Affects How You Feel*. The presenters will be: David H. Garfield, M.D., Associate Clinical Professor of Medicine, University of Colorado Health Sciences Center; Ann Fish-Stegall, RN, BXN, OCN, Clinical Nurse Coordinator, University of North Carolina-Chapel Hill, Division of Hematology/Oncology; and Floyd Allen, MSW, Senior Clinical Supervisor at CancerCare.

Part II: To be held Wednesday, June 20, 2007 at 1:30-2:30 p.m. EST. The topic to be covered is: *Creating A Plan to Continue Working When You Have Anemia*. The presenters will be: Susan Scelzo Slavin, Esq., Slavin Law Firm; Christine A. Fossaceca, Vice President, Global Work-Life Solutions Manager, JP Morgan Chase; and Patricia Spicer, MSW, Breast Cancer Program Coordinator, CancerCare.

You must register in advance in order to participate. You can register by mailing your name, address and the phone number where you can be reached on the day of the workshop to CancerCare. Please write the name of the workshop, whether you will attend just one or both workshops, and whether or not you are a healthcare professional. Please send this information to: Carolyn Messner, DSW, MSW, Director of Education and Training, CancerCare, 275 Seventh Avenue, New York, NY 10001. Alternatively, you may also register on-line by going to www.cancercare.org

Living With, Through and Beyond Cancer

CancerCare is offering another workshop on the topic *Living With, Through and Beyond Cancer*. This event will be a three-part series of one-hour teleconferences.

Part I: To be held Tuesday, April 17, 2007, 1:30-2:30 p.m. EST. The topic to be covered is: *Neuropathy and Joint Aches: New Post-Treatment Challenges*. The presenters will be: Julie Silver, MD, Cancer Survivor, Assistant Professor, Department of Physical Medicine and Rehabilitation, Harvard Medical School; and Nessa Coyle, NP, PhD, FAAN,

Pain and Palliative Care Service, Department of Neurology, Memorial Sloan-Kettering Cancer Center.

Part II: To be held Tuesday, May 15, 2007, 1:30 – 2:30 p.m. EST. The topic will be *My Treatment is Over: Why Do I Feel So Alone and Sad?* The presenters are: Elizabeth McKinley, MD, MPH, Cancer Survivor and Assistant Professor of Medicine, Case School of Medicine, Case Western Reserve University; Stewart B. Fleishman, MD, Director Cancer Supportive Services, Beth Israel Cancer Center & Continuum Partners; and Guadalupe R. Palos, RN, LMSW, PHD, Clinical Research Faculty, Division of Internal Medicine, University of Texas MD Anderson Cancer Center.

Part III: To be held Tuesday, June 19, 2007, 1:30 – 2:30 p.m. EST. The topic will be *Finding Hope and Meaning After Treatment*. The presenters are: Susan Leigh, BSN, RN, Cancer Survivor, Cancer Survivorship Consultant; Keith Bellizzi, PhD, MPH, Program Director, Office of Cancer Survivorship, NCI; and Suzanne Lechner, PhD, Director of Psychosocial Support and Research, Assistant Professor of Psychiatry, Miller School of Medicine, University of Miami.

You must register in advance in order to participate. You can register by mailing your name, address, phone number [daytime], to CancerCare. Please write the name of the workshop, and whether or not you will attend one, two, or all of the workshops, and indicate whether or not you are a healthcare professional. Please send your request to: Carolyn Messner, DSW, MSW, Director of Education and Training, CancerCare, 275 Seventh Avenue, New York, NY 10001. Alternatively, you may also register on-line by going to www.cancercare.org

HOW TO JOIN THE IWMF-TALK

Here are three ways to join:

1. Send a blank e-mail to: iwmf-talk-subscribe-request@home.ease.Lsoft.com

Do not sign or put anything in the subject or message area. Do not put a "period" after "com" or it will reject. Once approved you can post by sending e-mail to iwmf-talk@home.ease.Lsoft.com

2. Contact Peter DeNardis at pdenardis@comcast.net and provide your full name
3. Go to the following web link: home.ease.Lsoft.com/archives/iwmf-talk.html

THE SURVIVORSHIP MOVEMENT

by Guy Sherwood, M.D.

With the rise in the number of cancer survivors and caregivers (increasingly defined as “cancer survivors” themselves), there is an increasing focus on life after cancer, during cancer, or quite simply after one receives the dreaded cancer diagnosis.

Like many *Torch* readers, I was diagnosed with Waldenstrom’s macroglobulinemia by pure happenstance in March of 2001. After five years of on-again off-again treatment that culminated in an autologous peripheral stem cell transplant in February 2006, I have become increasingly interested in developing improved coping strategies to deal with what I now realize is likely to be a lifelong disease. I am convinced that how I live my life in between treatments is just as important as those precautionary steps I take during active treatment. For that reason, and also as a result of my professional interest in the popularity and patient-driven demand for complementary cancer survivorship clinics (now found at many major cancer centers in the U.S.), I decided last year to attend a few conferences that focused on the concept of cancer survivorship.

The first conference I attended was the Patient & Survivor Forum, sponsored by CURE magazine last September in Washington. Approximately 200 attendees from all walks of the cancer patient spectrum attended this two-day survivorship meeting, which offered lectures by experts in various cancers. Clinical trials were promoted as an absolutely essential strategy for making progress in cancer research.

Dr. Lawrence Einhorn discussed the latest news from the American Society for Clinical Oncology (ASCO) and also gave the keynote address, “Cancer Then and Now.” Medical breakout sessions were held in the afternoon for patients with specific types of cancer(s); the hematological cancer session was moderated by an oncologist who focused primarily on emerging biological targeted therapies. Other breakout sessions explored topics such as spiritual fitness, exercise and recovery, fear of recurrence, sexuality and intimacy, music therapy, food and nutrition, making medical decisions, cognitive behavioral therapy for coping with cancer, and cancer advocacy.

The stated goal of the conference was to make the journey with cancer easier from both the medical and emotional sides. In 2007, three similar conferences will be held in the U.S. (For details, see www.curetoday.com/forums.)

The second conference I attended, presented by The Center for Mind-Body Medicine last fall in Chicago, was the *CancerGuides Professional Training Program*. This highly interactive conference and training program in *integrative oncology* was attended by over 150 individuals: oncologists,

family physicians, nurses, social workers, other health care professionals, and patients. The participants spent a week together in an intense environment of learning about comprehensive cancer care and survivorship skills. Lectures were presented on various topics such as the biological aspects of cancer, the promise and limitations of conventional cancer treatment, nutrition and supplements, exercise, clinical trials, and evaluating the medical literature.

A significant part of the conference was devoted to an examination of the new model of integrative oncology care and research, and to the steps necessary for creating a comprehensive and integrative cancer care program in one’s community or organization. Models of existing practices were presented in a panel format. The participants in the conference were also placed in small breakout groups where mind-body treatments or therapies were described, discussed and practiced.

This conference was notable for the quality of its speakers, the evidence-based scientific approach to the evaluation of “complementary” therapies, and the high level of recognition of the often-forgotten topic of post-treatment survivorship issues. It was also a formal training course for CancerGuides: individuals who will act as advocates for the bewildered newly-diagnosed cancer patient and who have been trained in techniques aimed at assisting the patient on their journey through cancer, be it making proper treatment choices and/or dealing with post-treatment issues. Training in specific aspects of Complementary Cancer Care is available through the Center for Mind-Body Medicine.

The third conference I attended was the Lance Armstrong Foundation *Livestrong Summit* held during October in Austin, Texas. Over 700 invited delegates participated in this lively and spirited advocacy conference, which was distinguished by the number of young attendees, the quality of the speakers and the focus on national and local cancer advocacy and volunteerism.

Well-organized roundtable discussions, orchestrated by small groups of experts charged with specific session themes, were held over the weekend. The first two discussion sessions were used to identify unrealized needs and for brainstorming possible solutions. The final session deliberated on the development of a personal action plan aimed at providing volunteer services and cancer advocacy, be it on the local or national level.

The Lance Armstrong Foundation inspires and empowers people afflicted by cancer. Its obvious popularity is driven by the charismatic Lance Armstrong. Foundation ties to incredibly influential (and wealthy) individuals, its well oiled and professional management team, and the exuberance of the cancer patients and delegates that I witnessed at this

Survivorship Movement, cont on page 8

CRYOGLOBULINEMIA

by Sue Herms

Cryoglobulinemia (“cryo”) literally means “cold antibody in the blood” and refers to the fact that those antibodies involved precipitate at a temperature below 37°C (body temperature) and then re-dissolve upon warming. Cryo may develop due to unknown causes or may be associated with an underlying disease such as Waldenstrom’s. There are three types of cryo, based on the type of antibody present.

Type I cryo (simple cryo) is usually a single monoclonal IgM, less frequently a monoclonal IgG or IgA. This type may be related to the presence of a lymphoid cancer such as Waldenstrom’s, multiple myeloma, or chronic lymphocytic leukemia. Frequently, Type I does not cause symptoms until the concentration of monoclonal antibody reaches high levels. At that point it can produce a variety of symptoms because the precipitated antibody physically obstructs smaller blood vessels. If present, symptoms can include blueness of hands and feet from the cold, Raynaud’s phenomenon (whiteness and numbness of the fingers and toes from the cold), purpura (purple skin marks), bleeding conditions, and ulcers and gangrene of the fingers and toes.

PAGE 8 Type II cryo is also called mixed cryo because, unlike Type I, it is a combination of two antibody types – monoclonal rheumatoid factor (an antibody that can attach to other antibodies and cause inflammation) and polyclonal IgG. These two antibodies form immune complexes and activate an immune system protein called complement that causes injury, primarily to the blood vessels. Type II cryo has been closely associated with the presence of chronic hepatitis C infection, although it can have other causes. Patients with Type II may develop a B-cell cancer such as Waldenstrom’s several years after the cryo diagnosis. It has been suggested that a single clone of IgM-secreting cells develops as a result of chronic stimulation of the immune system by a disease such as hepatitis C and that the clonal cells become malignant over time. Type II cryo can manifest many of the same symptoms as Type I, but the inflammation from deposition of the immune complexes in Type II can also cause more severe problems such as kidney disease, peripheral neuropathy, fatigue, joint and muscle pain, abdominal pain, and liver and lung involvement.

Type III cryo is also characterized as mixed cryo. It is a combination of polyclonal rheumatoid factor and polyclonal IgG – there is no monoclonal antibody present with this type. A large number of infectious diseases and autoimmune diseases, such as lupus, exhibit Type III cryo; however, lymphoid cancers are not typically associated with this type. The symptoms associated with Type III are similar to those observed in Type II.

Waldenstrom’s patients should be tested for cryoglobulinemia at diagnosis, since it can not only complicate treatment, but can also affect the results of other lab testing used in the management of WM. It has been estimated from some studies that up to 20% of Waldenstrom’s patients have some degree of cryo. For the cryo test, a blood specimen is collected in warm (37°C) vials and kept warm while the serum is removed by centrifugation. The serum sample is then incubated at 4°C and observed for the development of a precipitate. Type I tends to produce a precipitate within 24 hours, while Type III can take up to 7 days. Other tests can help to characterize the type and severity of cryoglobulinemia. These include rheumatoid factor and other auto-antibodies, serum filters for viral and other infections, urinalysis, complement evaluation, serum protein electrophoresis, serum viscosity, liver function studies, and tissue biopsy.

Fay Langer, a WM patient who has Type I cryo, suggests that serum viscosity testing requires special handling of the blood specimen if the patient also has cryo, especially if the specimen has to be sent to an off-site reference lab. If the blood is not collected, transported, and processed at a warm temperature, the precipitation of the cryo can cause an inaccurate result.

Treatment for cryoglobulinemia can depend upon whether an associated disease is present. Asymptomatic cryo does not usually require treatment. Patients with mild symptoms are treated with low-dose steroids and NSAIDs (non-steroidal anti-inflammatory drugs). Those with severe problems may receive high-dose steroids with or without cyclophosphamide. If it is determined that chronic hepatitis C is present, the main aim of therapy is the attempted eradication of the virus with interferon and/or ribavirin. Plasmapheresis (plasma exchange) may be helpful when serum cryo levels are very high, but special handling is needed since the blood circulating during this process must be kept warm. Rituximab therapy has also alleviated symptoms in many cases because of its action against CD20+ lymphocytes that are known to manufacture antibodies.

Survivorship Movement, cont from page 7

meeting bodes well for the future of cancer research, and the eventual elimination of this dreadful disease.

Yes, the war on cancer seems to have new legs. Advocacy movements are growing rapidly and show definite signs of perseverance, resolve and tenacity. There is a pronounced need and desire from cancer patients for more emphasis on cancer survivorship issues. The ranks of cancer survivors are growing every year. They are no longer willing to hide in the back rooms, and they are insisting that their voices be heard loud and clear – or they will quite simply raise the volume and advocate—as Lance Armstrong is fond of saying—*relentlessly and ruthlessly.*

WM or a related disorder were diagnosed at a younger age and with greater bone marrow involvement.

Genetic Basis of WM

Dr. Treon's 2006 research award from the IWMMF will seek, in part, to conduct further study of the chromosome deletion/abnormality at the genetic region 6q21-22. Some of the genes found in this "region" include TACI, XBP1, HAS1, BLIMP-1, PAX-5, and IRE1. It is becoming increasingly evident that WM may be a genetically heterogeneous disease.

The APRIL→TACI→TRAF Pathway

This is a very complex molecular biological pathway involving multiple receptors (BAFFR, BCMA, and TACI), and the ligands B-LYS (B LYmphocyte Stimulator) and APRIL (A Proliferating Inducing Ligand). For the purposes of this article, we may permit ourselves the following oversimplification: ligands are molecules that attach to receptors and thereby trigger complex cellular biochemical reactions. The TACI receptor, for example, may be responsible in part for class switching i.e., the ability of a developing and maturing B-cell to "switch" from the initial ubiquitous production of IgM to the more "advanced" production of IgG, IgA, or IgE (vital elements of the immune system). This loss of "class switch" function (IgM IgG, IgA, or IgE) is a fundamental genetic flaw of WM cells. They have indeed been referred to as "pre-switch" cells for that reason.

The TRAF-2 gene (located downstream from TACI) suppresses proliferation of WM cells. It is missing in 10-20% of WM patients. A decrease in TRAF-2 expression might therefore encourage proliferation of WM cells.

The Role of HAS in WM

HAS (Hyaluronan Synthase) is a biochemical molecule that forms a matrix surrounding the cell; the gene for HAS-1 is on chromosome 19. HAS is associated with cell movement and likely plays a key role in the spread of malignant WM cells throughout the body. There are novel and abnormal gene variants of HAS in WM (as well as multiple myeloma). These variants are of inherited hematopoietic stem cell origin. Healthy donor B cells do not have these variants. (Dr. Linda Pilarski from the Cross Cancer Institute at the University of Alberta in Canada is also actively involved in this research (see related article in this issue).

The BLIMP-XBP-1 Pathway

This pathway is one of the last pathways involved in the final differentiation of B-cells (B-cell→Lymphoplasmacytic

cell→Plasma cell). The malignant transformation in WM involves the BLIMP-1, PAX-5, IRE1 and XBP1 genes. Of interest is the observation that an increase in XBP1 (X Box Binding protein) corresponds to an elevated IgM and β -2 microglobulin level, as well as increased bone marrow involvement. A simple and singular genetic mutation, also known as single nucleotide polymorphism, in the 4XBP1 gene has been noted in some WM patients.

The Bone Marrow Microenvironment in WM

Role of Mast Cells

Among WM patients, mast cells are about 3.5 times more common in the bone marrow, where they support the growth and survival of WM cells. The CD40 Ligand (CD40L) from mast cells is a potent stimulator of both normal as well as malignant B-cell proliferation through the CD40 receptor pathway. Gleevec, the "miracle drug" used in treating CML, inhibits signaling through the Stem Cell Factor (SCF) and Platelet Derived Growth Factor (PDGF) receptors present on WM cells and associated mast cells. Additionally, the monoclonal antibody Campath acts on the CD52 receptor found on WM and mast cells.

The Role of BLYS-APRIL in WM

The APRIL ligand), which protects WM cells from apoptosis (cell death), and BLYS (B LYmphocyte stimulator) genes are over-expressed in B-cell malignancies. Blocking the production of both these ligands results in a decrease in WM cells. The discoveries of these important interactions between WM cells and their "co-conspirator" mast cells has led to the investigation of the relationship between WM cells and other "duped" cells in the bone marrow *microenvironment* (e.g., fibroblasts and osteoclasts) that also can potentially manufacture APRIL & BLYS. As a result of this fascinating research, new therapies such as BLYS monoclonal antibodies (mAb), radiolabeled BLYS mAb, BAFFR mAb, and TACI-Ig (also an mAb) are emerging.

Targeting WM-Mast Cell Interactions in WM

Soluble CD27 (sCD27) in WM

The molecule sCD27 is a fragment of CD27, a transmembrane protein, found in the circulation. It is produced by B and T cells after antigenic stimulation. It has been noted that sCD27 reflects IgM levels and that sCD27 induces the expression of APRIL and CD40L on WM-associated mast cells.

CD27 and CD70 Expression in WM

Interactions between the CD27 and CD70 bio-molecules play a critical role in B-cell activation and survival. CD27

is the receptor for CD70, and is found on 42% of WM cells. CD70, the ligand for CD27, is found in 77% of WM cells (and at a rate 2.6 times higher on tumor cells).

Targeting CD27 and CD70 in WM

The development of a mAb to CD70 (SGN-70: Seattle Genomics) inhibits the upregulation of APRIL and CD40L. Finally, it is interesting to note that the biological molecules CD40L, BLYS, APRIL, CD70, and CD30 Ligand are members of the Tumor Necrosis Family (TNF) of cytokines (cytokines being molecules released by certain immune cells that act as intracellular mediators). TNF members play a role in the growth and survival of B-cells and in IgM production. They are also involved in symptoms of auto-immune diseases including neuropathies, rheumatoid arthritis, cold agglutininemia, and cryoglobulinemia which are seen in over half of all WM patients.

Current Clinical Trials for WM (as of November 2006)

Dana Farber Clinical Trials

- ❑ Phase II – Gleevec in Relapsed or Refractory WM (The “miracle” drug for CML shows promise in WM, targeting mast cell and WM cell interaction.)
- ❑ Phase II – Revlimid + Rituxan in WM (Thalidomide has been noted to help overcome polymorphism resistance against Rituxan – leading to an increased median time to progression. Neuropathy and anemia are side-effects.)
- ❑ Phase II – Velcade, Dexamethasone, Rituxan in WM (Four cycles followed by 3 month rest – 15 months total – minimizes neuropathy caused by Velcade.)
- ❑ Phase II – Velcade + Rituxan in relapsed/refractory WM (6 cycles of Velcade followed by 3 month rest – then every 3 months for total of 2 years)
- ❑ Phase II – RAD001 (Everolimus) in relapsed/refractory lymphoma (oral therapy – 4 weeks x 12 cycles – reassessed after 3rd cycle) This targets P13K/Akt pathway – Dr. Ghobrial’s research interest.
- ❑ Phase II – Perifosine in relapsed/refractory WM (Dr. Ghobrial’s research proposal accepted by WM Board – very good in vitro results; an oral-based therapy).

Sildenafil, aka Viagra, seems to be effective for a short period of time, then resistance seems to develop. Do we need a higher dose e.g., more than 100 mg/day (!) or more potent compounds?

Cholesterol Metabolism

The class of anti-cholesterol drugs called statins, and specifically the non-synthetic simvastatin (Zocor), inhibit certain lipids that are constituents of the cell membrane. Their action leads to decreased signaling of certain noxious biochemical pathways in WM. This research, and a probable upcoming clinical trial, results in part from WM patients making observations that their cholesterol levels were low when their disease was active. and that cholesterol levels would rebound (increase) in patients experiencing WM remissions – a vindication for the ever-popular IWMF TalkList and the contributions from its subscribers!

*P13K / AKT pathway research
(and clinical trial with Perifosine)*

This research project was recently approved for funding by the IWMF Board of Trustees. It was conceptualized by Dr. Irene Ghobrial of the Dana-Farber Cancer Center (Harvard University in Boston) and formerly of the Mayo Clinic in Rochester, Minn. (home of Drs. Kyle, Gertz and Ansell of WM fame). WM cells are mobile in both the bone marrow and circulatory system. The bone marrow environment “protects” WM cells so that killing them is more effectively accomplished in the blood. Therefore, the prevention of migration of WM cells to the bone marrow, or conversely, the promotion of the movement of WM cells from the bone marrow into the circulation is a desirable process.

AKT is a survival protein targeted by the drug Perifosine. Preliminary research indicates that Perifosine selectively kills bad cells, and doesn’t seem to harm good cells or stem cells. Perifosine also prevents migration of WM cells to the bone marrow and adhesion of WM cells in the bone marrow. As previously stated, the WM cells are easier to kill when they are in the circulatory system. Other research shows that there appears to be synergy (additive benefit) when Perifosine is used with Rituxan and/or Velcade.

In this article, I have tried to describe some of the "edge of the envelope" research and clinical trials that are presently underway at the research laboratories of Drs. Treon and Ghobrial. There are many other talented individuals who participate in this research and I have had the good fortune of meeting many of them over the past few years. To Zachary, Christopher, Xavier, Kelly, Sophia, Lian, Daniel, Aldo, Bryan, Yang, Evdoxia, Jacob, Marybeth, Renee, Anne-Marie, Robert, Gerald, those I have forgotten, and of course Irene and Steve, thank you for all that you do for us.

Donate and participate!

President's Corner, cont from page 2

article. She indicated that it would be a very interesting article for their readership and asked both Dave and Dick to come for an interview. The rest is history. Thanks to you both for so ably representing the foundation and all of its WM patients. You can read the article online at this link: www.mayoclinic.org/mayo-magazine/2007-spr-wm.html

ASH Conference and SAC Annual Meeting

The 2006 American Society of Hematology's annual conference was held in Orlando, Florida in December. IWWMF regularly attends this conference and staffs an information booth along with many pharmaceutical companies and other patient advocacy organizations that come to share information. Every ASH conference has hundreds to thousands of medical papers and posters presented that treat recent findings. Each year witnesses a growing number of papers and posters dealing with Waldenstrom's macroglobulinemia. If you are a IWWMF-Talk member, then you benefited from the wonderful coverage of ASH 2006 presentations by Bert Visheau, who searched out those papers pertinent to our disease and published summaries of them on the IWWMF-Talk. While many of the results reported are still preliminary, their publication gives us more research to watch and track in the future.

Our Scientific Advisory Committee meeting is held each year as an annual luncheon at the ASH conference due to the availability of most of our SAC members who attend this conference. We thank trustee and SAC Director Dr. Robert Kyle of the Mayo Clinic for once again organizing and leading the IWWMF's annual SAC meeting. Discussions covered issues such as: (1) the direction of WM research; (2) the lack of funding from NCI for rare diseases; and (3) the difficulty in getting patients to participate in clinical trials. This led to the suggestion that the IWWMF take the lead in banding together the organizations representing orphan diseases to push for progress in all the above areas. The Board will be discussing ways to do this in the near future.

IWWMF Awareness Project

The IWWMF has a lot to offer newly diagnosed patients, and makes it a priority to send a package of pertinent literature, at no expense, to any WM patient in the U.S. or abroad who contacts us. According to medical statisticians, there are approximately 1,500 newly diagnosed WM patients each year in the U.S. alone; however, only 10% ever find their way to the IWWMF. For this reason, we have launched a volunteer effort to find more of these patients by contacting local medical facilities to locate the office and individual responsible for organizing cancer support groups.

It is our belief that many WM patients who do not live within range of a WM support group are guided to join a generic cancer group, if at all. By making contact with the medical facility coordinators for support groups, we believe we can develop an avenue for our literature to be given to many more newly diagnosed WM patients each year. To make it easier for volunteers, and for the Awareness Project coordinator (trustee Elinor Howenstine), the IWWMF has purchased a recently published compilation of all the hospitals in the U.S. with offices listed. The missing ingredient is YOU. This would be a mammoth undertaking for Elinor alone, or even for a committee. It can only be successful if we have volunteers from all over the country who are willing to spend one day to make a visit to one hospital and make contact with the one person who could give our literature to WM patients in their groups. And, if you happen to have TWO days to do this, that would double the potential for reaching the newly diagnosed.

This kind of volunteer activity is an essential part of what we do as a member-driven organization. I hope more of you will want to participate. To discuss the particulars in greater detail, please contact Elinor Howenstine at 415-927-1536, or email her at Laraellie@aol.com. Thank you for thinking about this initiative and please consider helping us.

Stay well.

Judith

SEARCHING FOR RESEARCH

by Dave Lively

A new search engine called *GoodSearch* donates 50% of its revenue to charities designated by its users. While this may only amount to a penny per search, it can add up fast if a significant number of people use the service even a few times a day!

GoodSearch uses the Yahoo search engine, so you will get the same results that you would from searching on Yahoo. The service does not cost the user any money; advertisers pay the freight.

To use the service for the first time, go to GoodSearch.com, enter "Waldenstrom's" in the "Who do you GoodSearch for?" box, and then click to confirm your choice: "International Waldenstrom's Macroglobulinemia Foundation". Now you can go ahead and search as you usually do! (The *GoodSearch* program only requires the user to enter Waldenstrom's one time; this is retained for future searches.) We will keep you informed as to how quickly the pennies add up into dollars, and how those dollars are being turned into hope by researchers that are successful recipients of IWWMF research grants.

TREASURER'S REPORT FOR 2006

by James Bunton, Treasurer

The finances of IWMF are operated through two separate funds: the Research Fund and the Member Services Fund. The assets for these funds are kept separately as are their accounting records. Detailed financial statements for both funds can be found on the IWMF web site. For the sake of simplicity, the two funds are summarized as follows, with amounts rounded to the nearest thousand.

Research Fund

Contributions received during 2006	\$582,000
Interest earned	<u>42,000</u>
	626,000
Research grants awarded	<u>1,797,000</u>
Decrease during 2006	<u>\$(1,171,000)</u>

Contributions received during 2006 of \$582,000 compares with \$682,000 for 2005. Last year's contributions were particularly high as a result of the 2005 fundraising campaign. The total of all 2006 grants is by far the largest amount ever awarded by the IWMF in one year. The details of these research projects were reported to members during the year. Grants in 2006 bring the total awarded by IWMF to fund WM research to over \$3 million.

As a result of the large grants awarded in 2006, the amount payable on all outstanding awards is \$405,000 greater than the assets in the fund. This could be considered a matter of concern except for two factors. First, the amounts payable are spread out over four years. Second, a number of members have pledged, either orally or in writing, to make contributions over the next three years which will be more than sufficient to offset the current deficit.

These are exciting times in WM research, and it can be anticipated that there will be additional important projects presented to us for funding in 2007. If you have not already done so, please consider making a five year pledge for research funding. Remember that no operating costs are charged to the Research Fund, so every dollar pledged to research goes to research.

Member Services Fund

Contributions received during 2006	\$368,000
Member services and operating expenses	<u>342,000</u>
Increase during 2006	<u>\$ 26,000</u>

Income in 2006 of \$368,000 compares with \$333,000 in 2005 for an increase of \$35,000. The IWMF membership

responded generously to our 2006 membership campaign. Member services and operating expenses were up over 2005 by a similar amount resulting in a surplus of \$26,000 which is virtually the same as last year. Operating and fundraising expenses in 2006 amounted to only 13% of our total income. This means that 87% of all contributions went to help those with WM through member services or for research aimed at ultimately finding a cure. These percentages compare favorably with those of other similar organizations.

Assets in the fund at the end of 2006 totalled \$363,000, which should allow the Foundation to improve several of its member services programs.

If you have any questions about IWMF financial matters please do not hesitate to contact me directly at 416-621-7864 or by e-mail at jbunton@sympatico.ca.

CAM PRODUCTS TO BE REGULATED BY FDA

The Food and Drug Administration (FDA) recently announced a new draft guidance for "Complementary and Alternative Medicine Products and their Regulation by the Food and Drug Administration."

The move toward regulation is to clear up confusion as to whether a product used in a CAM therapy or practice may be subject to regulation as a biological product, cosmetic, drug, device, or food, including additives and dietary supplements, and come under either the Public Health Service Act or the Federal Food, Drug and Cosmetic Act.

The document may be read in PDF format at:
<http://www.fda.gov/OHRMS/DOCKETS/98fr/06d-0480-gld0001.pdf>

Or, in a text version at: <http://www.fda.gov/cber/gdlns/altmed.htm>

Those who wish to comment to the FDA on their draft guidance may do so by submitting written comments to: Food and Drug Administration, Center for Biologics Evaluation and Research, 1401 Rockville Pike, Suite 200N, Rockville, MD 20852-1448. Comments must be received by April 30, 2007. Written comments may also be submitted electronically to: <http://www.fda.gov/dockets/ecomments>

FROM IWFM-TALK

by Jim Berg

The TalkList continues to be active. Some of its content is predictable. Among the topics, there has been the usual discussion of the pros and cons of maintenance rituximab, on which even the medical experts disagree. **Raphael Altman** warned that weeks or even months after treatment there can be a decline in white cell counts.

Late February brought a brief flurry of the praises of plasmapheresis by **Caral Bennett** and others, not as a substitute for other treatment (though some have used no other for years on end), but as a great way to clear the mind and invigorate the body if you're being dragged down by high IgM levels. On the down side, the procedure does involve hours tied to a machine while your blood is being partially exchanged.

Matt's query about the effectiveness of interferon in combating WM brought both positive and negative responses. **Michael Turner** said it was working for him, while **Karen Pindzola's** reply was that, though it did the job, its side effects were so negative that she gave up on it long before her doctor wanted her to.

IgG infusion discussions centered on this treatment as a means of staving off infections. It is effective, but since it is another immunoglobulin like IgM, **Ron Draftz** warned that it can provoke reactions such as a temporarily elevated serum viscosity. In addition, as a foreign substance, it may produce allergic reactions that are usually controllable with Benadryl, etc. Given the nature of WM, **Dr. Jacob Weintraub** reminded TalkList readers that natural IgG levels usually cannot be permanently raised but that most of us get along reasonably well in spite of that constraint. However, if you tend to contract pneumonia, ask your doctor about trying the IgG treatment.

Testing came up a few times. Serum viscosity (SV) is a possible problem if it exceeds 3.0, but, as Dr. Weintraub again reminded us, an IgM of less than 3000 almost never produces that high of an SV value. If your SV rises above 3.0, be sure to ask your ophthalmologist to check your retinal capillaries. The subject of bone marrow biopsies was also raised. **Dr. Tom Hoffmann** reminded us that, except for the initial diagnosis of WM, repeat biopsies are seldom necessary unless something strange happens, or unless a patient enters a clinical trial.

The issue of testing often led to questions of prognosis, particularly from newly diagnosed patients, and the usual comment that the old 5-7 year median survival estimate is no longer current. Testing also brought up a long thread on

beta-2 microglobulin as an indicator, and why some doctors only look at it at the time of diagnosis and never again. Partly because B2M is so non-specific, it simply indicates that all is not well somewhere in your system and is not necessarily WM-related. A study by Dr. Dimopoulos even showed a slightly lower median survival for those with B2M under 2.5 compared to patients having a B2M of between 2.5 and 5.0.

One of the TalkList's most ardent followers of developments in the medical research world was, as usual, **Bert Visheau**. Over the past several months, he had many interesting topics to offer. One of them concerns the use of gene expression patterns to identify a patient as definitely having WM, as opposed to CLL, to which our disease is apparently more closely related than to multiple myeloma. Several TalkList members wrote to say that they had initially been misdiagnosed as having CLL or MM. IWFM President **Judith May** reminded us of a study that Bert had posted last year which reached some of the same conclusions. Both studies seem to indicate that one of the genes that should be given further attention is IL6.

So you think you need chemotherapy or radiation to kill cancer cells? Bert's research has discovered a few new approaches that are currently under development. Prof. Michael King of the University of Rochester has come up with a device to capture cancer cells from the blood or, alternatively, he can capture stem cells. Normal cells are not affected. Researchers at the University of Kentucky have discovered a substance that provokes stem cells to reproduce. Other recent discoveries are suggesting that some stem cells are important in the origin and persistence of cancer.

TalkList contributions were received indicating that more and more antibodies are being developed against, for example, CD23. There has even been a campaign to get us to lobby for inclusion of WM patients in ongoing CLL trials of the Humax-CD20 antibody, which we all hope will someday allow patients to avoid the allergic reaction to rituximab.

Two more things remain to be said in this TalkList report. The first is to call attention to the fact that WM and the IWFM have just been featured in an article in Mayo Magazine. The article tells the stories of **Dave Lively** and **Dick Weiland**, and includes a description of the IWFM's role in funding research by Mayo's Dr. Stephen Ansell. If you have internet access, go to www.mayoclinic.org/mayo-magazine/2007-spr-wm.html for more information.

Finally, we all owe a great debt of gratitude to **Cathy Gadbois** and her husband **Blain** for their willingness to openly share their ongoing experience in dealing with Blain's allogeneic transplant and its subsequent complications. We can only hope that the many replying messages of support from TalkList members have helped to strengthen both of them.

MEDICAL NEWS ROUNDUP

by Sue Herms

Gastrointestinal Graft vs. Host Disease in Allo Transplants

– Gastrointestinal graft vs. host disease in allogeneic stem cell transplants is a common and potentially serious side effect. A study from the Fred Hutchinson Cancer Research Center used a widely available topical corticosteroid called beclomethasone dipropionate (BDP) and reformulated it into pill form, thereby allowing the drug to be delivered through the stomach and small intestine. During the one-year Phase III clinical trial, the disease was held in remission and deaths were reduced by 46%. The Food and Drug Administration is expected to decide whether to approve the oral formulation by July.

Enzastaurin Tested against WM Cell Lines – The Dana-Farber Cancer Institute has studied protein kinase Cbeta (PKCbeta) in tissue culture and in mouse models and demonstrated its regulation of cell survival and growth in many B-cell malignancies. An inhibitor of this protein, called enzastaurin, was introduced into WM cell lines and caused a significant decrease in proliferation of the tumor cells alone as well as in combination with bortezomib and fludarabine.

Certain Genes Appear to Distinguish Normal B-Cells from WM and Other B-Cell Diseases

– The University of Salamanca in Spain has identified several genes whose expression distinguishes normal B-cells from the clonal cells of WM and chronic lymphocytic leukemia. The genes are designated LEF1, MARCKS, ATXN1, and FMOD. Other genes, such as PAX5, IRF4, and BLIMP1 are expressed differently in WM than they are in multiple myeloma. These particular genes could have implications for the development of targeted therapies in the treatment of these diseases.

Deletion of Chromosome 6q in WM and MGUS – Several studies have shown that approximately 55% of WM patients have a deletion of the long arm of chromosome 6 (6q). In comparison, no 6q deletions were found in patients with monoclonal gammopathy of undetermined significance (MGUS). This result may be useful in separating WM patients from those with MGUS and in predicting which MGUS patients may eventually develop WM.

PCR Testing for Lymphomas – A European Union-supported research team has developed PCR (polymerase chain reaction) testing to detect the clones of certain lymphomas and to help distinguish them from polyclonal reactive processes. The PCR process is useful because of its fast performance and limited need for high-quality DNA. PCR assays developed by the EU team detected 99% of B-cell malignancies and 94% of T-cell malignancies, as well as 90% of polyclonal reactive lesions.

Inex Product Enhances Rituxan® Activity – Inex Pharmaceuticals Corporation has presented pre-clinical data from a primate study indicating that its product, INX-0167, improves the immune response and enhances the anti-tumor activity of both Rituxan® and Herceptin®.

Atacicept Study on WM and Multiple Myeloma

– ZymoGenetics Inc. presented results from Phase I&II studies of atacicept for the treatment of refractory or relapsed multiple myeloma and active previously treated WM. Atacicept (formerly known as TACI-Ig) is a protein that binds to APRIL and BlyS. APRIL and BlyS are overly expressed in B-cell malignancies and autoimmune diseases and prevent normal cell death. Disease stabilization was seen in several patients. Treatment was well-tolerated during the studies with no dose limiting toxicity.

Gemin X Product Suppresses Bcl-2 Protein

– Gemin X Biotechnologies Inc. announced its results of several pre-clinical studies of GX 15-070, a small molecule specifically designed to suppress the Bcl-2 protein. Bcl-2 protein inhibits normal cell death and has been observed in a wide range of cancers. GX 15-070 restores normal cell death in tumor cells and was tested as a single agent and in combination with other cancer drugs such as rituximab. The drug is currently in Phase II trials.

New Monoclonal Antibody Targets CD70

– Seattle Genetics presented pre-clinical data on SGN-70, a humanized monoclonal antibody that targets CD70 antigen. The CD70 antigen is expressed in many types of lymphoma, including WM. The treatment was shown to block tumor growth in a model of WM.

BDR Therapy Effective against WM

– Therapy incorporating bortezomib, dexamethasone, and rituximab (BDR) appeared to be highly active in primary treatment of WM. Interim results showed that all patients achieved a response with median serum IgM levels declining from 5,095 mg/dL to 2,850 mg/dL.

Serum Free Light Chain Test to Monitor WM

– The serum IgM level is an important marker of diagnosis and response in WM. However, because of its long half-life in the body, it is not an especially sensitive test for response or a good prognostic indicator. Thus there is a need for more sensitive serum markers that predict tumor burden accurately. A presentation at the recent American Society of Hematology Conference indicated that measurement of serum free light chains (whether kappa or gamma) by nephelometry more accurately predicted the severity of disease and correlated with other prognostic markers. In addition, serum free light chain readings were significantly higher in WM compared to MGUS.

Medical News, cont on page 15

Low Cholesterol and WM – Low cholesterol has often been observed in WM patients, although its incidence and significance have not been previously investigated. Cholesterol levels in 110 WM patients were evaluated. Decreased total cholesterol (<160 mg/dL) was observed in 37.3% of patients; decreased LDL (<100 mg/dL) occurred in 61.8% of patients; and decreased VLDL (<40 mg/dL) was observed in 81.8% of patients. In patients with low cholesterol levels, higher IgM levels were seen. Moreover, significantly lower IgM levels were seen in those patients taking lipid-lowering agents (statins). Given these results, there may be a possible disease dependency on cholesterol metabolism. Studies exploring the impact of statins on clonal WM cells have indicated that they inhibit proliferation and cause the death of the tumor cells. Statin agents may represent clinically useful agents for the treatment of WM.

New Proteasome Inhibitor Used Against WM – Nereus Pharmaceuticals has developed a new proteasome inhibitor called NPI-0052 that was tested alone and in combination with bortezomib on CD19+ malignant cells from WM patients. Used alone, the new agent induced 50% tumor cell death at 48 hours in all cell lines tested. In combination with bortezomib, an even more significant response was obtained.

Perifosine Used Alone and in Combination Therapy against WM – An oral agent called perifosine, produced by Keryx Biopharmaceuticals, has been tested on CD19+ WM cell lines. Perifosine inhibits the AKt pathway, which is a critical regulator of cell survival, and induced the death of the WM cells without toxicity to normal cells. Perifosine was also investigated in combination with chlorambucil, dexamethasone, doxorubicin, fludarabine, rituximab, bortezomib, and melphalan and showed synergistic anti-tumor activity with these agents.

Possible Mechanism for Rituximab Resistance – Resistance to the anti-CD20 antibody rituximab is an important issue that needs to be clarified because of the increased use of this drug. A total of 50 non-Hodgkin's lymphoma patients were analyzed after their lymphomas appeared to be refractory or resistant to rituximab activity. Four types of mutations of the CD20 surface marker were found in 11 (22%) of these patients. One mutation, called C-terminal deletion, occurred in 8% of patients and caused significantly lower CD20 expression and a shorter time to disease progression (7 months) vs. patients without this particular mutation (18 months).

Testing for Humanized Anti-CD20 Antibody – Roche is testing its second generation humanized anti-CD20 monoclonal antibody called ocrelizumab in Phase I and

Phase II trials on patients with follicular NHL. Genmab is recruiting follicular lymphoma patients for its Phase III testing of HuMax-CD20, a fully human monoclonal anti-CD20 antibody.

Safety Issues with Aranesp and Procrit – Several studies are raising safety questions about the use of Aranesp, Procrit, and other similar drugs used to treat anemia. All the drugs are versions of erythropoietin, or Epo, a substance made by the human kidney that increases levels of hemoglobin, the oxygen-carrying component of red blood cells. These drugs were approved to treat anemia due to chemotherapy, but many physicians have been using them “off-label” to treat anemia which may be due to the cancer itself. The studies have linked a greater risk of death to the use of Epo-type drugs. It is known that raising hemoglobin levels too high with such drugs increases the risk of blood clots; however some experts say Epo drugs may actually spur tumor growth in certain cancers. The Food and Drug Administration is planning to convene an advisory committee to review the products.

The author gratefully acknowledges the efforts of Howard Prestwich, Bert Visheau and Mike Dewhirst in disseminating news of interest to the WM community.

Ed Forum, cont from page 1

The purpose of this gathering is to bring together all Support Group leaders for discussions on how they have structured their meetings, how they try to maintain membership interest, to share ideas for speakers and agendas, and to provide facilitator training and updates from the Board of Trustees.

The lead presenter will be Mary Lieder Cebuhar, who has had many years of professional experience in group training and staff development, and who was herself an IWMF Support Group Leader in Minnesota/Wisconsin. In addition, there will be a session lead by Terry Cherry, Ottawa Support Group Leader, devoted to questions about the practical aspects of facilitating a group, as well as lots of time for interaction among the support group leaders for sharing experiences in leading their groups.

If you live in an area that is not served by an IWMF Support Group, and would like to start one in your area, this workshop would be very helpful to you in getting your group going. If you are interested, please contact Karen Pindzola, Support Groups Coordinator, at 717-845-5937 (email kpindzola@yahoo.com) or Sara McKinnie at the IWMF office, 941-927-4963 (email info@iwmf.com).

NOTICE TO FORUM ATTENDEES: If you have signed up for the IWMF Educational Forum and have not received a registration acknowledgement letter with program information, please contact the IWMF Business Office to be sure your registration was received.

SUPPORT GROUP NEWS

edited by Penni Wisner

CALIFORNIA

Sacramento and Bay Area

Members heard Dr. Steven Treon's presentation on February 3. The Leukemia & Lymphoma Society (LLS) provided the meeting room and another room for sample collection for Dr. Treon's genetic study. At the meeting, the group collected \$644 to further Dr. Treon's activities at the Bing Center for Waldenstrom's. **Penni Wisner** added, "When I emailed our group to announce the dollar tally, another member who had not attended joined the effort. We sent \$1,144!" Penni also reported that long-time group member, Frances McInerney, died on December 7. She was 91 and continued to travel and fully enjoy her life until very close to the end. She would attend meetings with her son and daughter-in-law, Norm and Colleen Marks. The next meeting will be in May or June.

Southern California

The group held its inaugural meeting in October at **Emil Parente's** home in Laguna Niguel. Attendance totaled 19, including ten WMers. The second meeting was on March 24, when Dr. Louis Vandermolen from the Orange Coast Oncology Hematology group addressed the group.

COLORADO & WYOMING

The Rocky Mountain Support Group met on January 20 in Denver. Group member and WM patient, Dr. Don Hood gave a presentation on WM and the eyes. He explained how WM may affect the vision of WM patients and the importance of early detection of eye problems. The next meeting will be in May.

FLORIDA

Southwest Florida

Charles Schaffer provided the following report on a recent meeting organized by Support Group Leader **Herb Kallman**:

Three cheers to Herb, his wife and to an obviously very enthusiastic team of SWFSG volunteers for organizing another *winner*. This is the second year that I have been invited to *crash* the SWFSG meeting (thanks again Herb) and I was not disappointed one bit by its menu of offerings. The hospitality was without bounds and the chocolate chip cookies were, as usual, gourmet caliber.

Highlights of the event centered on presentations by Jim Bunton (IWMF Board Member) and Dr. Steve Treon (Bing Center for Waldenstrom's Research). Jim started the show by reviewing the details of recent IWMF grant awards and gave his patient's perspective on their potential significance in the battle to achieve a cure for WM. Dr. Treon's talk was *all over the map* and I savored every minute of it. He started on an upbeat note by reminding the attendees that

[WM] cells are not smarter than us and then moved on to explain the most recent medical definition of WM i.e., high monoclonal protein irrespective of IgM level. Over the next hour, he covered aspects of neuropathy, drugs that may provoke the start of WM (e.g., some malaria drugs), why IgG's and IgA's sometimes don't recover after chemotherapy, and a host of new research news (e.g., TACI & APRIL, mast cell relationships and new, but still experimental, drugs such as SGN-70).

The follow-up question period was lively and lengthy. I am certain that it would have continued into the early evening except for Herb's *soft policing*.

For further details about the work of Dr. Treon and his zealous team of researchers, check out the Bing Center's web site (<http://www.wmprogram.com>). For that exceptionally dedicated SWFSG volunteer team, I just want to say thank you and BRAVO! BRAVO! BRAVO!

EASTERN IDAHO

Group members celebrated the 30th anniversary of two members in late February. **Barbara Britschgi** notes that since they are a small group (four members and three caregivers) it is easy to communicate by telephone. The group will also hold a memorial meeting to honor a former member who died in 2006 of MDS. Meetings are open to residents of the neighboring states of western Wyoming, northern Utah and southern Montana.

GEORGIA

Members of the group have volunteered to help register attendees during April's IWMF educational Forum in Atlanta. **Mal Roseman** writes, "Atlanta is a very exciting city and we look forward to demonstrating our southern hospitality."

ILLINOIS

As the *Torch* was going to press on March 18, we received the following sad news relayed to us by **Ron Draftz**: "I just received word from one of **John Hynes'** daughters that he died this evening around 6 PM. He was the first and only support group leader of the Chicagoland area group. He was friend and counsel to many in the group which led to its growth to over 100 members. We will miss his warm smile and the encouragement and knowledge he gave to all who knew him."

SUPPORT GROUP LEADERS TALK LIST

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 email Support Group Coordinator, Karen Pidnzola at kpindzola@yahoo.com if you would like to participate.

MICHIGAN

On March 17th, the Michigan support group met in Saginaw. **Heather Grzemkowski** says, "Our group continues to be a strong one with about 30 people attending each meeting."

W. OHIO, E. INDIANA, N. KENTUCKY

Moving its meeting location to accommodate a broader participation, the W.O.E.I.N.KY Support Group met in Cincinnati at the southern Ohio chapter office of the LLS. Meeting sites will alternate between Cincinnati and Troy, Ohio. The April session, in Troy, will celebrate the group's sixth anniversary. **Ron Payne** reported, "There is strong interest in spinning off a northern Kentucky group. Effective leadership has emerged to help bring this new group into being."

E. OHIO, W. PA & W. VIRGINIA

The group met Sept. 30, 2006 in Youngstown, Ohio. **Shariann Hall** said, "We tried something new and listened to Dr. Steve Treon speaking live at the Chicago regional support group via a telephone link set up with the assistance of Ron Draftz and Don Brown. **Bob Shaffrey** and Shariann, co-leaders, are tentatively planning the next meeting for May 19 in the Pennsylvania area.

MINNESOTA & WESTERN WISCONSIN

A total of 29 people, including 16 patients, six of whom were first-timers, attended the group's January 13th meeting. A date was chosen for a summer picnic (Saturday, July 14). The remaining meeting dates for 2007 are Saturday, May 19th and Saturday, September 8th.

NEW YORK

Rochester, Western and Central NY

Gail Burgie wrote, "It is with heavy hearts we report the death on January 31, 2007 of **Trudy Cayo**, one of our most engaging and active support group members. Despite numerous hospitalizations and continued WM treatment over the past 17 years, Trudy displayed incredible courage, strength of spirit, and an infectious sense of humor. We extend our deepest sympathy to her loving and devoted family and to her legions of caring and admiring friends."

Eastern NY/Western New England

A large number of members met on January 20 at the Albany area Gilda's Club for a special program: "Informed Consent: Understanding the Line Between Treatment and Research" led by group member, attorney **Leslie Neustadt**. She was joined by her physician husband Gary. The program was taped and is available to other support groups. The LLS provided lunch for this special meeting. The group will meet on May 12 for a discussion of the Atlanta Forum and July 14 for the annual picnic.

OREGON

Dr. William "Bud" Pierce gave an overview of Waldenstrom's at the January meeting of the Oregon/SW Washington Support Group, writes **Joan Berglund**. Of the 14 patients attending, most had received their diagnoses of WM since 2000. Others were eight, nine, 12, and 17 years since diagnosis.

The Caregivers and friends in attendance shared how the patient's diagnosis had affected their lives. Responses ranged from no change to becoming educated about WM, becoming a patient advocate, taking over home and garden chores previously done by the patient, changing retirement dates and plans and learning extra jokes to keep laughter in the home.

The next meeting is April 14 in Lake Oswego. The tentative schedule for future meetings is July 28 and October 27, 2007.

PENNSYLVANIA

Central PA and Northern MD

At our February meeting, a full room of attendees welcomed Dr. James Ballard, a Professor and an MD in the Oncology and Hematology Department at Hershey Medical. **Nancy Lambert** reported, "Because Dr. Ballard spoke with such clarity and depth of knowledge, we came away with a much greater understanding of WM." The group hopes to have a speaker on neuropathy for the May meeting.

Philadelphia

The group of twenty-plus people met in February with group member, **John White**, leading the session. The next meeting will be the Sunday after Easter. They hope to have a nutritionist speak.

SOUTH CAROLINA

The group plans to hold its next meeting in mid-May in the Charleston area.

TENNESSEE

Bill Paul has started two new groups in this area. Congratulations, Bill!

W. Tennessee, E. Arkansas, N. Mississippi

The Greater Memphis Area Support Group met on February 11, 2007 to view the Dr. Morie Gertz "Introduction to WM" video, better known as the "Weeds in the Garden" presentation. Bill reported, "Our group has not been meeting for long. While we are well represented by Tennessee and Mississippi, we have yet to hear from our neighbors in Eastern Arkansas. We know you're out there, please join us!" The next meeting will be in May. Bill wishes to thank the Memphis Center for Women and Families for providing a meeting place.

Central Tennessee

The initial meeting of the Central Tennessee Support Group will be held on Saturday, April 21, at the Nashville Airport Marriott Hotel. The Marriott is graciously providing a suite for us at no cost to attendees. This will be a get-acquainted meeting. The date is just a week before the Educational Forum in Atlanta, just in time to compile questions for the "Ask the Doctor" session. Bill added, "I would like to thank **Michela Marneli** for her assistance in setting up this Nashville area group.

TEXAS

Dallas & Northern Texas

The North Texas Support Group will be hosting a presentation by Dr. Steve Treon on May 19. He will be speaking on "Advances in the Biology and Therapy of Waldenstrom's Macroglobulinemia". His associates will be taking samples from volunteers with WM and their family members for research purposes.

Houston

The Houston group will host Dr. Treon on Sunday, May 20th, at 21 Briar Hollow Lane, Houston, from 2 PM to 6 PM. Dinner will be included. Dr. Treon and his team will be taking samples after the program for those who would like to participate in his research studies.

NORTHERN GREAT PLAINS

How does the IWMF provide support for WM patients in a part of the country where the population is low and widely dispersed? We asked **Cindy Furst** of Loveland, Colorado for a brief update about the assistance she provides for members in several nearby states. "What I've done is to collect contact information for all WMers (about 18 so far) from Montana, Wyoming, North Dakota and South Dakota, and added them to an email list. Four are without internet access, so I send them snail mail. I've now added one WMer from Western Minnesota near Fargo, and one in Omaha. I send out some kind of communication regularly and respond with advice, encouragement, and resources when people contact me. About 14 people have contacted me since I started, some a few times. I feel rewarded by the wonderful connection I've made with so many of these folks."

CANADA

Ottawa

The Ottawa Support Group (OWMSG) covers the Ottawa valley from Pembroke to Hawkesbury and the eastern St. Lawrence region from Cornwall to Kingston. Meetings are held six times per year from September to June. The annual Christmas social was December 19 and all but four of the members were able to attend. **Terry Cherry** reported, "It was wonderful to be able to share the good times as well as the not-so-good times with each other in an informal setting. Terrific food and lots of good wine certainly added to the occasion." The group was saddened by the death of a founding

member, **Frances Mulligan**, at the end of October. Fran's WM transformed to Large Diffuse B-Cell Lymphoma which quickly spread to her brain. The group has lost six members since its inception four years ago, all from transformations of their WM into LDBCL or CLL. We currently have just over 20 members (including significant others); all but two are currently in remission. The next meeting will be April 12.

Nova Scotia

The Halifax, Nova Scotia Support Group has grown from four members in 2004 to its current 11 WM patients, who also bring family and/or friends to meetings. They began meeting in a coffee shop, but the next meeting, on Tuesday, April 24, 2007 from 10:30 am-12:30 pm, will be held at a regional hospital. Dr Darrell White, hematologist, will address the topic, "Current Treatment Modalities for Waldenstrom's Patients Offered at the Dixon Centre." Light refreshments will be provided.

UNITED KINGDOM

In the United Kingdom, **Cheryl Luckie** and **Nigel Pardoe** have created a series of regional meetings in different areas of the UK. They wrote: "The main purpose of our regional meetings is to give everyone an opportunity to meet fellow WM patients and their families well as to have a chance to talk face to face with our doctors. This arrangement will also benefit those who are unable to travel to London for our annual meetings." Each region will have a local group coordinator.

The next meeting will be April 14 in Leeds. This is a change from our original date, April 7. Future regional meeting dates and locations are: Essex, August 11; London, June 9; Ayrshire, Scotland, July 7.

Birmingham and the West Midlands

The first UK regional meeting was held in November, attended by 14 members. Dr. Roger Owen, of Leeds Hospital, gave an overview of current clinical trials and treatment options available to WM patients. He is involved with the Bing Center for Waldenstrom's Macroglobulinemia at Dana-Farber Cancer Center in Boston and in other research projects in Europe and US. **Geoff Willsher** volunteered to be the regional coordinator for Birmingham and other parts of the West Midlands.

Brighton and East and West Sussex

The second UK regional meeting was held in Brighton on February 17. Dr. John Duncan from Royal Sussex County Hospital fielded the question and answer session. Eight members attended, with just one from the West Sussex area and the rest arriving from Hemel, Hempstead, Hertfordshire, and as far away as Dublin, Ireland. **Mike Dewhirst** volunteered to be the regional co-ordinator for Brighton and other parts of the West and East Sussex.

Raphael Altman volunteered to set up a UK web site/chat room for our members who have access to the Internet.

IWMF SUPPORT GROUP CHAPTER LISTINGS AS OF 03/22/07

ALABAMA

Mal Roseman
770-392-1255
malroseman@comcast.net

Ann Gray
501-915-0825
anngray1@cox.net

ARIZONA

Phoenix
Ed Nadel
480-502-5045
EnadeL63@aol.com

Tucson

Jackie Smith
Winter-520-299-5470
Summer-605-717-2862
(Nov. 1 – Apr. 1)

ARKANSAS

Eastern
Bill Paul
901-767-6630
biLLpauL1@juno.com

Western

(area not currently served by support group)

General Contact:

Ann Gray
501-915-0825
anngray1@cox.net

CALIFORNIA

Los Angeles
Lynn Bickle
805-492-4927
flb134@msn.com

Orange County

Emil Parente
949-388-9666
pnepar@cox.net

Marty Glassman
949-951-6903
mglassman@cox.net

Sacramento

Cynthia Nicholson
916-852-6012
nicholson26@comcast.net

Santa Barbara

Ceci Menchen
805-687-1736
cici.menchen@sbcxmail.com

CALIFORNIA (cont.)

San Francisco
Penni Wisner
415-552-6579
penniw@pacbell.net

COLORADO

Roy Parker
303-470-6699
roypar@comcast.net

Bill Bass
303-753-4006
wmbass@ix.netcom.com

CONNECTICUT

Francoise Lampe
203-431-1455
wmfgL@sbcglobal.net

Bob Hammond
203-426-2772
Rhamm17@aol.com

DELAWARE

Karen Pindzola
717-845-5937
kpindzola@yahoo.com

FLORIDA

Treasure Coast
Gail Murdough
772-564-9910
Golphin@comcast.net

Ft. Lauderdale Area

Charlie Koch
954-476-8726
Bonnie143@bellsouth.net

Tallahassee

Doris Mathis
850-545-5529
dmathis521@aol.com

West Coast

Herb Kallman
239-466-6911
margerina@aol.com

Tampa

Linda Rothenberg
352-688-0316
Alpets@tampabay.rr.com

GEORGIA

Atlanta
Mal & Judy Roseman
770-392-1255
malroseman@comcast.net

HAWAII

(Nov – Apr)
Sandy Skillikorn
808-891-2882
jLsLs@aol.com

IDAHO

Eastern
John Stanger
208-529-4462
johns@dolefresh.com

Barbara Britschgi
208-522-2130
cbrits@cableone.net

Northern

Judy Clark
208-888-0346
jzclark@cableone.net

ILLINOIS

Chicago
Don Brown
630-323-5894
ldonbrown@msn.com

INDIANA

Ron Payne
937-349-4344
revrpayne@earthlink.net

KENTUCKY

Northern KY
Ron Payne
937-349-4344
revrpayne@earthlink.net

LOUISIANA

(area not currently served by support group)

Regional Contact:

Ann Gray
501-915-0825
anngray1@cox.net

MARYLAND

Catherine Naylor
301-229-0319
catherinenaylor@verizon.net

MARYLAND (cont.)

Northern
Nancy Lambert
717-432-2121
LLne3@aol.com

MASSACHUSETTS

Boston
Lynne & Joe Mara
781-749-0204
jmara@nordicgroupusa.com

Judy Christensen
781-335-5698

MICHIGAN

Peter & Barbra Boyse
989-415-9936
peterdboyse@earthlink.net
baboyse@earthlink.net

MINNESOTA

Minneapolis/St. Paul
Michelle Blazek
651-730-0061
mandsblazek@aol.com

MISSISSIPPI

Bill Paul
901-767-6630
biLLpauL1@juno.com

Ann Gray
501-915-0825
anngray1@cox.net

MISSOURI

Nancy Gerhardy
417-889-2461
Gerhardy2000@yahoo.com

MONTANA

John Stanger
208-529-4462
johns@dolefresh.com

Northern

Barbara Britschgi
208-522-2130
bbrits2@cableone.net

NEBRASKA

(area not currently served by support group)

Regional Contact:

Cindy Furst 970-667-5343
cindyfurst@msn.com

NEVADA*Eastern*

Gerri McDonald
804-484-0360
gerri-sLc@comcast.net

NEW ENGLAND*Boston*

Lynne & Joe Mara
781-749-0204
jmara@nordicgroupusa.com

Judy Christensen
781-335-5698

Western MA, VT & CT

Mel Horowitz
518-449-8817
wmcure@yahoo.com

NEW MEXICO

Bill Bilbro
505-642-4987
wbilbro@gmail.com

NEW YORK*Albany*

Mel Horowitz
518-449-8817
wmcure@yahoo.com

New York City

Neil Massoth
201-444-6253
nmassoth@aol.com

Rochester, Central & Western

Gail Burgie
585-248-3609
ghburgie@mymailstation.com

NORTH CAROLINA

Bob Zehner
804-796-3571
bobnbetsz@comcast.net

NORTH DAKOTA

(area not currently served by
support group)

Regional Contact:

Cindy Furst
970-667-5343
Cindyfurst@msn.com

WESTERN OH, E. IN

Ron Payne
937-349-4344
revrpayne@earthlink.net

OREGON

Joan Berglund
503-668-5037
rjbergie@verizon.net

PENNSYLVANIA*Philadelphia*

Karen Pindzola
717-845-5937
kpindzola@yahoo.com

Harrisburg Area

Nancy Lambert
717-432-2121
LLne3@aol.com

Terrie Eshleman
717-665-7393
tmeshleman@paonline.com

W. PENN, E. OH, WV

Bob Shaffrey
724-443-2284
LioneL@connecttime.net

Shariann Hall
330-533-4921
shari19@juno.com

SOUTH CAROLINA

John & Paula Austin
803-644-6002
jhaustin@bellsouth.net

SOUTH DAKOTA

(area not currently served by
support group)

Regional Contact

Cindy Furst
970-667-5343 Cindyfurst@
msn.com

TENNESSEE*Central & Western*

Bill Paul
901-767-6630
biLLpauL1@juno.com

(area not currently served by
support group)

Regional Contact:

Myrna Daniel
706-539-2866
mdmermer@yahoo.com

TEXAS*Dallas*

Lawrence Cottle
214-987-3326
superdc@sbcglobal.net

TEXAS (cont.)

Jerry Fleming
972-867-5102
NTWMSG@verizon.net

Houston

Barbara & John Manouso
713-840-0828
wm@manouso.net

Western

Bill Bilbro
505-642-4987
wbilbro@gmail.com

UTAH

Gerri McDonald
801-484-0360
or 801-232-5811
gerri-sLc@comcast.net

VIRGINIA

Bob Zehner
804-796-3571
bobnbetsz@comcast.net

WASHINGTON

Peg Horton
253-874-8820
Peggy.horton@comcast.net

WASHINGTON D.C.,**NORTHERN VA**

Catherine Naylor
301-229-0319
catherinenaylor@verizon.net

WISCONSIN

Dan Lotts
920-295-3018
danlts@aol.com

Fon Du Lac

Cheryl Callahan
920-921-4854
chercal@charter.net

Western WI

Michelle Blazek
651-730-0061
mandsblazek@aol.com

WYOMING

Roy Parker
303-470-6699
roypar@comcast.net

Bill Bass

303-753-4006
wmbass@ix.netcom.com

INTERNATIONAL**AUSTRALIA**

Gareth Evans
WMozzies-owner@
yahogroups.com

CANADA*Alberta*

Cam Fraser
403-281-8278
cmfraser@shaw.ca

Stu Boland
403-281-0271
Stu_boland@hotmail.com

Halifax

Susan Gagnon
902-446-9533
sgagnon@eastlink.ca

Montreal

Sandra Proctor
450-672-4336
sandra.proctor@sympatico.ca

Ottawa

Terry Cherry
613-596-1413
terry@tccherry.com

Toronto

Arlene Hinchcliffe
905-337-2455
wmfc@noco.ca

Vancouver

Charlene Kornaga
604-487-1100
dennischarlene.kornaga@shaw.ca

FINLAND

Veikko Hoikkala
+35 8500 48 4864
veikko.hoikkala@finnforest.com

UNITED KINGDOM

Nigel Pardoe & Cheryl Luckie
+44 020 8579 8120
info@septemberservices.com

Brighton West & East Sussex

Mike Dewhirst
+44 1323 841735
dewhirst_6@hotmail.com

Birmingham & West Midlands

Geoffrey Willsher
+44 0121429 1038
willsher.s@btinternet.com

INDIA

(area not currently served by
support group)

Regional Contact:

Sanjeev Kharwadkar
swkharwadkar@yahoo.co.in

THE LIFELINE

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.

2-CdA	Norm Spector	858-454-6313
2-CdA WITH RITUXAN	Bernard Swichkow	305-665-5303
CAREGIVING	Lynn Bickle Brad Alexander	805-492-4927 972-529-2002
CLINICAL TRIALS	Tom Hoffmann Guy Sherwood	501-868-8305 765-282-4377
CRYOGLOBULINEMIA	Fay Langer	973-464-6696
FLUDARABINE	Peg Horton Dave Lively	253-874-8820 608-783-4552
FLUDARABINE with Rituxan	Marty Kopin Jerry Block	310-390-1546 301-460-9799
LATEST RESEARCH	Bert Visheau	905-528-1789
NEWLY DIAGNOSED	Guy Sherwood Norm Spector Sallie Moore	765-282-4377 858-454-6313 516-795-3746
ORAL CYTOXAN	Lou Birenbaum	314-961-5591
PLASMAPHERESIS	Fred Bickle Arlou Brahm	805-492-4927 203-264-7995
RITUXAN	Charles Vassollo Allen Weinert James Townsend	201-947-6977 603-863-5347 352-376-3664
SOCIAL SECURITY DISABILITY	Howard Prestwich	815-233-0915
SPLENECTOMY	Kathleen Ugenti	631-470-0971
STEM CELL TRANSPLANT	Howard Donley Davell Hays	307-587-3397 530-295-1344
THALIDOMIDE	Mel Horowitz	518-449-8817
VELCADE	Jeff Atlin	905-731-7756

VETERANS	Jerry Fleming	972-867-5102
WATCH AND WAIT	Mel Horowitz Renee Paley-Bain Polly Oldberg	518-449-8817 203-744-7851 513-932-7486
YOUNG WM	Nobby Riedy Bob Bailey	650-879-9104 770-664-8213

HEARING IMPAIRED TTY FACILITY	Betty Mc Phee	905-775-3413
-------------------------------	---------------	--------------

INTERNATIONAL

SWEDEN/NORWAY

Anne Odmark 46 0270-18668
anneodmark@privat.utfors.se

GERMAN SPEAKER

Roy Parker (Colorado, USA)
303-470-6699
Rnvp38@hotmail.com

DUTCH SPEAKER

Lia van Ginneken-Noordman
Ginneken.noordman@wxs.nl

SPANISH SPEAKER

Peter Mitro
440-247-3460
stonehill@earthlink.net

Betsy Beazley
510-527-5827
bestybeazley@gmail.com

UNITED KINGDOM LIFELINE

2Cda
Roger Brown +44 01285 650107
roger@bookworm.uk.com

CHLORAMBUCIL
John Povall +44 1606 833022
jpovall@mmm.com

FLUDARABINE
Ken Rideout +44 1278 782108
ken@4rossetree.fs.co.uk

FLUDARABINE AND CYCLOPHOSPHAMIDE
John Povall +44 1606 833022
jpovall@mmm.com

FLUDARABINE AND RITUXIMAB
Mike Dewhurst +44 1323 841735
dewhurst_6@hotmail.com

OPHTHALMOLOGY
Terry Betts +44 01992 583643
tjb-planning@freeuk.com

PLASMAPHERESIS
Roger Brown +44 1285 650107
roger@bookworm.uk.com

RITUXAN
Nigel Pardoe +44 0208 326 3270
pardoe@aol.com



Since January, 2007 the following contributions to the International Waldenstrom's Macroglobulinemia Foundation were made in memory of:

In memory of Ed Alber:
Pete & Sharon Dagostino
Robert H. Damon
Peter & Elaine Gaenicke
James & Joanne Lockwood
Heidi Lopata & Allen Sherman

In memory of Diane Allen:
Robert J. Allen
Doug & Nita Davis
Vera Foote
Cindy Halstead
Cheryl & Dale Sawyer & Family

In memory of Freddy Bastin:
Nicole Bastin

In memory of Roland Beck:
Dorothy A. Beck

In memory of Elizabeth Blonk:
Rainbow's End Ladies' Golf Assn.

In memory of Donald Burstein:
Dr. & Mrs. A.M. Poisner

In memory of Trudy Cayo:
Nancy Andrews
Bay Trail Sunshine
Robert & Joyce Binggeli
Rita D. Boas
Gail H. Burgie
Carol & Nancy Cayo
William & Inez Cayo
William & Lisa Cayo
Joyce Church
Dean & Joyce Condos
Davie, Kaplan, Chapman & Braverman
Connie Dodsworth
Roger & Janelle Ettema
Paul & Nan Farley
Ginn Fitch
David & Marian Hartney
Lorie, Katie, John & James Hawkins
Wm. & Barbara Hossler
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International Waldenstrom's
Macroglobulinemia Foundation
3932D Swift Road
Sarasota, FL 34231-6541

Telephone 941-927-4963 • Fax 941-927-4467
E-mail: info@iwmf.com. • www.iwmf.com
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REPORT ON DANA-FARBER CHOLESTEROL STUDY

Low cholesterol (hypocholesterolemia) has been an intriguing observation in WM patients. Based on this observation and a 2004 *Torch* article by Dr. C. W. Biedel entitled "The Relationship Between IgM and Cholesterol," the Bing Center for Waldenstrom's Macroglobulinemia at Dana Farber Cancer Institute initiated a study of cholesterol levels among WM patients.

Blood and DNA samples were taken from WM patients and healthy donors at last year's Educational Forum in Seattle and subsequently in some other cities around the country.

Low cholesterol values (less than 160 mg/dL) were seen for 65 of 163 WM patients (almost 40% of the total). While 13 of the 65 patients were on cholesterol-lowering drugs called statins (Lovastatin, Simvastatin, or Pravastatin), the remainder were not. The patients with low cholesterol who were not on statins tended to have higher median serum IgM levels (3510 vs 1502 mg.dL), an indication of greater disease burden. Significantly, the patients on statins had lower median serum IgM levels (1023 vs. 2330 mg/dL).

These results suggested a possible disease dependency on cholesterol metabolism, as well as a possible anti-tumor effect of statin drugs. To test this theory, two statins, Lovastatin and Simvastatin, were added to WM cell culture lines in the laboratory. Both statins induced apoptosis (cell death), with Simvastatin showing a stronger effect.

Based on these preliminary studies, a protocol for treatment of WM patients with Simvastatin and similar drugs is now in the development stage and should be available sometime in late Spring-early Summer of 2007. Further information can be obtained by contacting Christopher_patterson@dfci.harvard.edu.

This article was written by Sue Herms based on information provided by Christopher Patterson, Clinical Research Coordinator at the Bing Center for Waldenstrom's Research.