

CONCEPTS AND FUTURE APPLICATIONS OF TARGETED CANCER THERAPY IN WALDENSTROM'S MACROGLOBULINEMIA

by Guy Sherwood, M.D.

What Does the Future Hold?

The past decade has seen marked advances in the treatment of Waldenstrom's macroglobulinemia using immunotherapy. If the past is any indication of what lies ahead, we can expect ever increasing options in the management of WM.

It is reasonable to anticipate that future monoclonal antibodies (mABs) like Rituximab and Campath will be developed and used extensively. Increasing familiarity with the "naked" mABs such as Rituximab has led to further clinical research with newer types of biological therapies called immunoconjugates. These are antibodies that can function as "carriers" for radioisotopes like iodine -131 (Bexxar), and even toxins like Ricin. We are in fact now seeing wider clinical use of the radiolabeled antibodies Bexxar and Zevalin.

Vaccine research continues to progress remarkably rapidly and some vaccine-based treatments are now entering Phase II and III clinical trials for many non-Hodgkins lymphoma patients. Definitively safer treatments are increasingly needed since the use of conventional biological and non-biological treatments has led to increasing survival for many WM patients—and the possibility for transformation into a more aggressive lymphoma.

The Role of the Immune System Revisited

In the previous *Torch* article, "Monoclonal Antibody Therapy for Waldenstrom's Macroglobulinemia," we explored the mechanisms whereby Rituximab targeted the WM cells by tumor cell identification using the immune system and/or harnessing the body's own immune system to destroy or suppress tumor cells. A review of these host immune effector mechanisms is warranted at this time. These mechanisms include (1) antibody-dependent cell

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UPDATE ON THE IWMF SUPPORT GROUP NETWORK

by Karen Pindzola
Support Groups Coordinator

IWMF now has a Support Groups Team, which is comprised of Michelle Blazek, Arlene Hinchcliff, Sara McKinnie, Roy Parker, Karen Pindzola, Laurie Rude, and Penni Wisner. This group has been quite busy during the past year with the process of getting new support groups started and setting up supports for the support group leaders!

One of the first things we did was gather data and suggestions from experienced group leaders and put it all together in a guide for new and old leaders alike.

We've also tried to organize more communication among the support group leaders. Two to four times a year all of the leaders receive a phone call from one of the team members to make sure they're all right and see if there is anything that they need help with. It usually just becomes a friendly chat, but once in a while a leader does have some need. We also send out a *Quarterly Bulletin* to the leaders with current news, helpful hints, and messages from the Board. And the latest mode of communication that we're working on is a Talk List just for the support group leaders, so that they can discuss problems or ideas among themselves.

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PRESIDENT'S CORNER

by Judith May

The IWMF continues to develop relationships with other organizations and is raising awareness of our disease. In June, Tom Myers (VP for Research) and I attended a conference sponsored by the National Cancer Institute (NCI) for officers of national nonprofit cancer organizations.

The two-day conference, hosted by the NCI Director's Consumer Liaison Group, provided ample opportunity to ask questions of the consumer advisers to the NCI and meet with a number of officers of the 61 organizations attending. Like many of the groups, we provided posters describing our purpose and goals.

The conference enabled us to make ourselves better known in the cancer arena. There were several other heads of organizations in the rare disease category, and we spoke about what we might work on together. One of the conclusions is that we should be in Washington, lobbying for more funding for rare diseases. The IWMF has not had a lobbying arm, and as you may or may not know, lobbying activities by nonprofits are limited by the IRS. However, we may want to add our voice on a limited basis to some of these activities in Washington in the future. If there are members in the Washington, D.C. area interested in such activities, please write me directly at judithamay@comcast.net.

* * *

I think it's about time to give a big thank you to our support group leaders. I am seeing more and more networking, and great improvements in the format of meetings, with more effort made to bring medical and other interesting speakers to meetings.

As many of you know, Dr. Steve Treon of the Dana-Farber Cancer Institute has been a frequent speaker at many of the support group meetings around the country. As the *Torch* goes to press, Dr. Treon was scheduled to speak on September 30th in Illinois, and the Illinois group has networked with other state groups to broaden the audience (including by means of teleconferencing). This kind of networking is a distinctive feature of the IWMF community and is one of the reasons we are known among many doctors, NCI staff and other organizations as a very effective and tight-knit group. I applaud all the support group leaders who are making great efforts to develop interesting meeting agendas with a high level of participation. These leaders continue the tradition of calling new members in their areas to invite them to join their groups. This kind of activity started early in the the history of the IWMF, and our previous presidents would be very happy to see how we've grown.

* * *

I am happy to announce that we have added two new trustees to help share the growing workload. Roy Parker, support group co-leader for Colorado and Wyoming, is now a new trustee, and he will continue working on the Fundraising Committee (which he joined over a year ago). Roy will also help with our Awareness Program, an outreach initiative to find new WM patients who haven't found us yet. The second new member of the board is John Austin, support group leader in South Carolina. John will be on the Support Group Team and will be co-chair of the 2007 Ed Forum in Atlanta. We are delighted to have Roy and John on the board.

I hope to see some of you in Los Angeles October 28 at the WM meeting that has been organized as a special session of the Lymphoma Research Foundation's annual Educational Forum. Dr. Treon will be among the speakers. Please visit www.iwmf.com or call 941-927-4963 for more information.

Stay Well,

Judith



WM PATIENTS RAISE FUNDS FOR RESEARCH

by Don Lindemann

As announced recently in a special bulletin mailed to all members, the IWWMF Board of Trustees has approved two grants that will give a major boost to multi-year research projects at the Dana-Farber Cancer Institute (DFCI) in Boston and the Mayo Clinic in Rochester, Minnesota.

The grants, totaling more than \$1.5 million, will more than double the funding that the IWWMF has committed to research in its history. The projects are now off to a good start, but *donations are still needed to fund future years of the projects:*

- A 4-year grant of \$1,038,000 has been awarded to the Bing Center for Waldenstrom's Research at DFCI, which has become one of the world's leading centers for WM research. Three projects will examine genetic abnormalities and molecular "messenger proteins" that affect the growth and survival of WM cells in the bone marrow.
- A 3-year grant of \$515,670 has been awarded to the renowned Mayo Clinic for continued investigation of BLYS (B-Lymphocyte Stimulator), a molecule that plays a role in the proliferation and survival of malignant cells.

What can you do? Maybe you can take some inspiration from some other WM'ers who have risen to the occasion.

As reported in a previous issue of the *Torch*, **Bob Lynch** (WM patient in Florida) has been energetically raising money for the IWWMF. It has required *lots* of energy in his case because he has been doing long rowing trips on the coast of Florida to draw attention to WM and the need for research. The resulting publicity has resulted in many donations, large and small.

This year Bob's weeklong 167-mile row started on June 5th in Melbourne, and his daily diary is full of interesting observations about shark sightings, high winds, and brusque encounters with manatees. His adventures elicited articles in several Florida newspapers and magazines, as well as more than \$12,500 in donations to the IWWMF. A videographer friend is working on a documentary about Bob.

Another story comes to us from Wisconsin, where **Karen and Ted Templeton** of Oconomowoc made a presentation to a local religious hospital foundation about the IWWMF. As a result, they were able to secure a \$25,000 grant for our IWWMF Research Fund for the second year in a row!

Meanwhile, in New Jersey, **Carole Cohen** came up with the idea to design, print and sell "Waliday" greeting cards as a fundraising activity for the IWWMF. In June she sent an email to the IWWMF-Talk about the idea, saying the cards "will be great gifts for your mailperson, cleaning person, lawn person, teachers, grandkids' teachers, and especially for our physicians." Many offers of help came forth from people with special skills (in design, photography, etc.) and a number of support group leaders also pledged assistance.

At the end of September Carole forwarded this note to the *Torch*:

"As I write this, the Waliday Greeting cards, all 5000 of them, have just arrived in my house. So I have started to stuff mailers and will try to get the orders out as soon as possible. We have four different prints (or images). A lovely scene with bridge taken from a photo by our graphic artist Cynthia, a gathering of sheep which came from an oil painting by our professional artist, Judy, a pink orchid raised and photographed by one of our caregivers, as well as a dogwood blossom by David who enjoys photographing flowers. I think you'll like the cards a lot. They are wonderful to use for greeting cards, note paper, to fill a Christmas stocking, gifts for your DOCTORS, friends and relatives and if you feel really ambitious, perhaps to sell at your local events. I don't think I can take the responsibility to personally sell 5000 greeting cards. I see this as a group effort.

"Of course I'd like more orders. We've had orders for about 140 packs of cards out of 625 packs ordered. Please add that we'll be happy to fill orders for holiday packs (bridge, and sheep cards), 4 of each print. Then we have our all occasion packs which include 4 each of orchids and 4 each of dogwood blossoms. If people prefer, we can send sample packs which would be 2 each of each print. All packs of 8 cards are \$15.00 each which includes S&H."

Checks should be made out to IWWMF-Cards and mailed to:
Carole Cohen
9 Morningside Drive
Toms River, NJ 08755
732-349-7581 phone

Obviously, we have a powerful story to tell in our struggle to fight this orphan disease, and it's sure to receive a positive response from many altruistic organizations and individuals. Keep those good ideas coming!

You can of course send contributions directly to the IWWMF Research Fund. Mail your check to the IWWMF office, 3932D Swift Rd., Sarasota, FL 34231. Or visit the IWWMF website www.iwwmf.com and click the "Donate Now" button on the right side of the screen.

MEDICAL RESEARCH NEWS

by Sue Herms

Ice Chips for Melphalan-Associated Mouth Sores – Researchers from the Fred Hutchinson Cancer Research Center have concluded that sucking on ice chips may help to prevent mouth sores associated with high-dose melphalan. Patients received ice chips 30 minutes prior to chemo and continued to use the ice chips for six hours. Severe mouth sores occurred in 14% of patients given ice chips, compared with 74% of patients treated with standard saline therapy.

Management of Nausea and Vomiting for Chemo/Radiation Patients – The American Society of Clinical Oncology has issued new guidelines for prevention of nausea and vomiting during chemo and radiation. Patients receiving an anthracycline and cyclophosphamide chemo regimen should receive three drugs: a 5-HT₃ serotonin receptor antagonist (Anzemet, Kytril, Zofran, Navoban), dexamethasone, and aprepitant (Emend). For chemo agents that have a lower risk of nausea and vomiting, two drugs, a 5-HT₃ serotonin receptor antagonist and dexamethasone, are recommended. In either case, the anti-nausea drugs should be given for at least 2-3 days after chemo is completed. Patients receiving total body irradiation should be given a 5-HT₃ serotonin receptor antagonist before each radiation fraction given and for at least 24 hours afterward.

New Dosage of PROCRIT Recommended Once Every Two Weeks for Chemo-Related Anemia – A new study demonstrates that using 80,000 units of PROCRIT once every two weeks is comparable in effect to the current recommended dosage of 40,000 units once weekly for chemo-related anemia.

Defect in Gene TCL1 Can Cause Several Types of Non-Hodgkin's Lymphoma – A team of researchers at the University of California Los Angeles and collaborators at Harvard Medical School, The Rockefeller University and the National Institutes of Health have discovered that abnormal TCL1 gene expression is frequently detected in B cell non-Hodgkin's lymphomas. The researchers engineered mice to express the TCL1 gene, and those mice developed B cell lymphomas at a very high rate within the germinal centers of lymphoid tissues, such as lymph nodes and the spleen, where B cells normally develop. Further, the researchers determined that these lymphomas only arise when the TCL1 abnormalities are accompanied by companion genetic defects. The researchers identified several of these, including the Myc oncogene, already known to play a role in causing lymphoma. The researchers will next determine the particular molecular defect(s) on the TCL1 gene and hope to use these molecules as targets for new therapies.

Novel Peptide Molecule Targets Leukemia and Lymphoma Cells – The UC Davis Cancer Center has developed a novel peptide (amino acid) molecule called LLP2A that binds more strongly to surface receptors of leukemia and lymphoma cells than to normal B or T cells. LLP2A works like a monoclonal antibody but is smaller and can penetrate the malignant cell more successfully. It is intended to be used as a vehicle to deliver radiation, toxic agents, and nanoparticles to lymphoid cancers. The UC Davis researchers are currently testing this peptide on dog and mouse models.

New Commercial Cord Blood Stem-Cell Product to Be Available in 2009 for Allogeneic Stem Cell Transplantation – A company in Israel called Gamida Cell has developed a product from cord blood stem cells that can successfully engraft in large children and adults who cannot locate matched donors for allogeneic transplantation. Gamida Cell's technology expands the limited population of cord blood stem cells into a product named StemEx®. It has been tested in a Phase I/II clinical trial and has been granted a special orphan drug designation by the FDA. Gamida Cell hopes to produce StemEx® commercially in 2009.

Leumeta™ Plasma-Based Assays May Provide an Alternative to Bone Marrow Biopsies for Diagnosis and Monitoring of Leukemia and Lymphoma – Quest Diagnostics is developing plasma-based cancer testing for leukemia and lymphoma that may in the future reduce or eliminate the need for bone marrow biopsies. The Leumeta™ assays, developed from research at M.D. Anderson Cancer Center, look for tumor proteins found circulating in the peripheral blood.

Experimental Antibody to IL-6 in Phase I Clinical Trial – IL-6 is a chemical produced by immune system cells that helps B cells survive and grow. It is thought that IL-6 production is increased in chronic lymphocytic leukemia and B cell lymphomas and that targeting this chemical will induce B cell death. A human/mouse antibody manufactured by Centocor and called CNTO-328 acts against IL-6 and is currently in a Phase I clinical trial at Cornell and other institutions. One of our fellow WM'ers, Robin Benjamin, is currently participating in this trial and has seen very good results. Anyone interested in speaking with Robin can reach her at Robinbenjamin@aol.com. At this time, CNTO-328 has shown no toxicity at fairly high dosing.

Gleevec Can Be Toxic to the Heart in a Percentage of Cancer Patients – Researchers at the Center for Translational Medicine at Jefferson Medical College in Philadelphia have indicated that the anti-cancer drug Gleevec is implicated in the development of congestive heart failure in leukemia patients. Studies in both mice and in heart cells in culture

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by James Bunton

indicate that Gleevec targets tyrosine kinase protein, which serves a maintenance function in cardiac muscle cells and is necessary for their health. The researchers also stated that Gleevec “is a wonderful drug and patients...need to be on it” but that some percentage of patients may have problems, and clinicians should be aware of this.

Retrospective Review of Autologous or Allogeneic Stem Cell Transplantation in WM – A retrospective study of 36 WM patients who received autologous or allogeneic stem cell transplants between 1986 and 2002 reached several conclusions. After a median follow-up of 65 months, 42% of the patients are still alive. Primary disease accounted for 29% of deaths in the allogeneic group and 25% of deaths in the autologous group. The relapse rate at 3 years was 29% in the allogeneic group and 24% in the autologous group. Overall survival was 46% in the allogeneic group and 70% in the autologous group, with the allogeneic group having a higher incidence of non-relapse mortality. Autologous transplant is a safe and feasible treatment option for patients with WM, especially for those with adverse prognostic factors; however allogeneic transplant carries a much higher risk of transplant-associated mortality and should not be considered except in the context of a clinical trial.

BiovaxID Vaccine in Phase 3 Trials for Follicular Lymphoma – Biovest International has developed a technology for a follicular lymphoma (non-Hodgkin’s B cell cancer) vaccine based on hallmark surface antigens found on each patient’s cancer cells. The vaccine induces an immune response against the cancerous cells and is a targeted, customized therapy with almost no side effects. As a result of promising Phase 2 clinical study results, with 95% of treated patients surviving more than nine years, the FDA has approved a Phase 3 study involving 375 patients in 20 major U.S. medical centers. While the study only involves follicular lymphoma at this point, it is hoped that the technology will be applicable to other B cell lymphomas.

Sue Herms is a medical technologist specializing in microbiology in Charleston, S.C.

Our organization was officially incorporated as the IWFM in 1998 in Florida. Since then it has changed significantly: the membership has grown to 2,500 (of which 450 are outside the US), member services programs have been expanded, we have committed over \$2.4 million for research, and we have become recognized in the medical community as the principal voice of WM patient advocacy. In other words, the last eight years have brought growth, change and maturity to the organization.

These changes raise the question as to whether or not the governance system adopted in 1998 is appropriate today and, most importantly, for the future. One of the difficulties in our present system is finding new trustees who are well qualified and prepared to spend a substantial amount of time to serve. The current process is cumbersome and costly as it involves a request for candidates from the membership, a nominating committee, approval by the board, submission to the membership for a vote by mail, scrutineers, and approval at the annual meeting for all members in the spring. This process has not worked well, and additions to the board have often been made by board appointment.

Accordingly, the Board proposes to change the present method whereby members elect the trustees to one where the nominating committee will recommend candidates to the Board, which will then elect new trustees. As a matter of practice, this is the method that has been applied in the past few years. It is also the method commonly used by organizations of our sort, such as the Lymphoma Research Foundation, the Leukemia and Lymphoma Society and the Multiple Myeloma Research Foundation.

To effect this change will require us to amend the articles of incorporation and the bylaws and requires the approval of the members. The amendments will be presented at the annual meeting to be held April 29, 2007 following the annual Educational Forum in Atlanta. In the meantime, if you would like to discuss the matter, please do not hesitate to contact me directly at 416-621-7864.

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

UPDATE ON WM FAMILY STUDY

by Don Lindemann

The Maryland support group was recently provided with an update on an ongoing study of families in which more than one member has been diagnosed with Waldenström's macroglobulinemia. Dr. Mary McMaster, of the Genetic Epidemiology Branch of the National Cancer Institute (NCI), National Institutes of Health, presented a summary of her work.

Although rare, WM can occur in more than one member of a family. Before 2000, when Dr. McMaster began her study, only 12 such families had been reported in the world medical literature. Since the NCI WM family study began, nearly 45 families have participated in the U.S. alone.

The main goal of the WM family study is to identify a gene or genes that may cause an individual to be susceptible to WM. Family studies are a good way to look for such genes, because the genes may be passed down from one generation to the next. At the support group meeting, Dr. McMaster described three approaches that she has used to search for susceptibility genes.

The first approach takes advantage of the fact that most blood and lymph node cancers have changes in their chromosomes that can be seen using a microscope. The science of studying chromosomes is called "cytogenetics". Inherited cytogenetic changes would be expected to be seen in the WM cells and the normal white blood cells from all members of a family who have WM.

Dr. McMaster studied the chromosomes of WM cells from the first 25 patients who participated in the family study. Although several cytogenetic changes were seen, none of them were present in more than one member of a family who had WM. Therefore, Dr. McMaster decided to try different approaches.

A second approach goes beyond the microscopic level of cytogenetics to the sub-microscopic level of individual genes. In the "candidate gene" approach, scientists consider everything that they know about a disease, the normal cells that give rise to the disease, and other information about how cells grow and multiply. A list of genes that are known to be involved in the development of WM or related diseases, or that control the growth and division of B-cells (the normal cell that gives rise to the WM cell), is compiled. This is the list of candidate genes. Each gene must then be studied individually to see whether it has been changed in WM patients. This is a logical approach. However, it represents the scientist's "best guess" at a particular point in time, and is very time-consuming, labor-intensive and expensive, even

when the scientist has a reason to suspect some gene(s) more than others.

A third approach analyzes information from DNA using statistics. "Linkage analysis" takes advantage of the fact that DNA is passed from generation to generation in segments. Each of these segments of DNA contains more than one gene. The genes that are contained within a single segment of DNA are said to be "linked". If a scientist knows the identity of one gene on a given segment of DNA, then (s)he can trace how all the linked genes are passing through a particular family.

Linkage analysis is done by collecting DNA from all members of many families, whether or not they have WM. By tracing the known genes, scientists can use statistics to see whether one or more specific segments of DNA are present more often in the family members who have WM, as opposed to the family members who do not have WM. Once a suspicious segment of DNA is identified, it can then be targeted for further study to try to determine which of its genes is associated with WM.

Dr. McMaster has recently completed a linkage analysis using a subset of the WM families. The results are to be published this fall in the *American Journal of Human Genetics*. Dr. McMaster will use those results to plan the next stage of her detective work to understand why WM can run in families. Once a gene or genes are discovered, it will be possible to then look to see whether these same genes are important in non-familial WM (the kind most patients have).

Dr. McMaster expressed her gratitude to the families participating in this research project. Without their generous cooperation and participation, this research would not be possible.

For more information about the study, contact the NCI Division of Cancer Epidemiology and Genetics, Genetic Epidemiology Branch referral nurse at 1-800-518-8474, or call the NCI Clinical Studies Support Center (CSSC) at 1-888-NCI-1937.

HOLD THAT DATE!

We hope you will join us at our 2007 Educational Forum, which will be held April 27-29 in Atlanta, Ga. Further details and registration information will be provided in the next issue of the *Torch* and on our website, www.iwmf.com

VACCINATIONS FOR THE CANCER PATIENT

by Sue Herms

In general, cancer patients who are receiving chemotherapy, radiation, or transplantation, or who have hematologic cancer such as leukemia and lymphoma, are immunocompromised. For this reason, vaccines that are composed of live, attenuated bacteria or viruses are not recommended for these patients, as they can potentially cause serious problems.

Vaccines manufactured from killed bacteria or viruses, toxoids, or partial bacterial or viral components are usually safe for people with immune system deficiencies, with the *caveat* that a certain proportion of the population may have allergic reactions to substances in the vaccines. Also, it is frequently suggested that pregnant women should not be given certain vaccines.

The Centers for Disease Control and Prevention (CDC) in Atlanta states that the following vaccines are safe for most adult immunocompromised patients: anthrax, *Haemophilus influenzae* type b, hepatitis A, hepatitis B, influenza shot, Japanese encephalitis, meningococcal polysaccharide and meningococcal conjugate, pneumococcal polysaccharide, polio shot, tetanus/diphtheria booster, typhoid shot, and rabies.

It should be noted that not all of these vaccines are given on a routine basis. Some are only administered to health-care workers, after a specific exposure, or for those traveling to areas of endemic disease. For vaccines that are routinely given, the CDC recommends that immunocompromised people receive flu shots yearly and pneumococcal polysaccharide shots at diagnosis and once every five years thereafter to help prevent these particular diseases, or at least reduce their severity.

Although there is a question with immunocompromised patients as to how well their systems can mount a response to vaccination, it is still considered good practice to immunize with safe vaccines, on the principle that some benefit may be derived.

Vaccines that generally should **not** be administered to such patients include the following: chicken pox, measles/mumps/rubella, nasal flu, oral polio, smallpox, the new shingles vaccine, oral typhoid, and yellow fever. Patients who have immune system deficiencies should also avoid close contact with others who have recently received vaccines on the prohibited list.

Always consult with your physician if you have any questions about vaccination.

Sue Herms is a medical technologist specializing in microbiology in Charleston, S.C.

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mediated cytotoxicity (ADCC), where the mAB attaches itself to the target receptors on tumor cells and “recruits” the body’s own immune killer cells to destroy the WM cells; (2) complement-dependent cytotoxicity (CDC), where the mAB activates specific “complement” proteins in the circulation that in turn destroy the WM cells; (3) direct biologic effects on the tumor cells by binding to the target receptor; (4) producing secondary immune reactions; and (5) synergistic effects when combined with chemotherapy.

A Strategy for a Complex Problem

Tumor cells have many alternative and redundant signaling pathways that render targeting of one singular pathway, for cell death for example, insufficient to cause cell death. It is for this reason that mABs are often best used in combination with chemotherapy and/or radiation therapy. Immunoconjugates can not only use the mAB’s inherent properties, but can deliver to the WM cell either a dose of radiation, a chemotherapeutic drug and possibly a toxin.

Monoclonal Antibody Therapy and Radioisotopes

Radioimmunotherapy with anti-CD20 radioconjugates (Bexxar and Zevalin) has been shown to have superior antitumor activity than Rituximab alone. Also, compared to standard chemotherapy, complete responses are more durable, side-effects can be managed appropriately, and the therapy itself is better tolerated. The treatments are less toxic, and the duration of treatment is usually shorter than that of chemotherapy and radiation therapy. As radiation oncologists gain increasing experience with these treatments, more and more patients who may not have been eligible for therapy because of tumor burden or other factors are now being treated with increasing success. It is important to note that in general, NHL remains to this day exquisitely sensitive to radiation therapy.

Monoclonal Antibody Therapy, Drugs and Toxins

The addition, or “conjugation,” of a molecule to an antibody can alter the compound’s pharmacodynamics to the point where certain drugs or toxins that would have been far too toxic or dangerous for use in humans can now be tested as antibody-drug immunoconjugates. The current research and clinical trials in this specialized field almost always use drugs that are far more powerful than most chemotherapeutic agents. Toxic agents like Ricin are under investigation as well. Leukemias and certain types of lymphomas are particularly attractive to this kind of therapy since the individual tumor cells are easily accessible in the bloodstream and in the bone marrow. The receptor CD74, found on B-cells and monocytes, is an attractive target since the CD74-mAB complex is readily absorbed into the target cells, permitting the drug or toxin to

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be “liberated” from the mAB, thus becoming very active. Once again, continued research and clinical experience will lead to proper use of these therapies to maximum benefit with minimal toxicities.

Vaccine Therapy

Tumor vaccines use “active” immunotherapy: the stimulation of the host immune response to deliver a direct attack to the tumor cells (in contrast to “passive” immunotherapy employed by the mAB Rituximab—identification of the tumor cells to the immune system). Active immunotherapy by vaccination can use both antibodies and immune cells to destroy the tumor cells. Not only can vaccination result in the formation of lifetime immune memory, but the immune response can also be directed at multiple targets, thus recruiting and using multiple specialized memory cells that target different antigens on the tumor cell.

As can be expected, there have been some difficulties in producing a custom vaccine for each patient’s individual tumor. The capacity of the tumor cells to modify the target receptor for the vaccine suggests that multiple target vaccines (polyclonal immune response to multiple epitopes) is preferable to single target vaccines (clonal response to a singular antigen/epitope). Vaccine-based research is incredibly complex, yet incredibly fascinating. Textbooks need to be rewritten every few years to keep up with this explosion in “nano-biology.” The speed at which new insights, new research techniques, and new discoveries are being made in this field of immunology is awe-inspiring to say the least!

Immune-boosting Therapies

Whether one is being treated with “naked” mABs, immunoconjugates (using radionucleotides, drugs or toxins), or vaccine-based therapy, a healthy host immune system remains key. Unfortunately, this is not always possible in individuals heavily pre-treated with chemotherapy or in individuals with a cancer that weakens the immune system like WM.

The enhancement of the mechanisms whereby the immune system kills tumor cells using cytokines (molecular signals, or messengers used by immune cells) can help overcome a weakened immune response. The use of Neupogen (granulocyte-colony stimulating factor: G-CSF) to effectively “turbocharge” natural killer cells of the immune system is already being used in combination with Rituximab. Conversely, blocking certain cytokines (IL-2) can lead to better overall tumor cell destruction. One should not exclude as well the “CAM-like” therapeutics such as proper nutrition, exercise, and other modalities to improve or at least preserve immune system function.

Transformation of WM

Transformation from an indolent form of NHL such as WM to a more aggressive lymphoma such as diffuse large B-cell lymphoma (DLBCL) is, unfortunately, a relatively common event. The risk of developing a more aggressive tumor has been estimated at 3% per year. A recent study in British Columbia reported a 10% occurrence of transformation from the indolent lymphoplasmacytic lymphoma over a follow-up period of 84 months. The development of additional genetic abnormalities is thought to be responsible for the majority of cases of transformation. Whereas we are quick to point out the use of toxic chemotherapeutic regimens as the major underlying reason for transformation, we need to be ever cautious and vigilant that biological therapies, which in many cases directly exert their effects on the cellular genetic machinery, do not increase the risk of transformation by mechanisms not yet elucidated.

What about costs?

It is becoming increasingly evident that most of the existing and newer biological agents are more effective when used in combination with other biologicals and/or conventional chemotherapeutic agents. It is sadly evident as well to many of us that not everybody is a “responder” to Rituximab. Monoclonal antibodies and other biologicals may need to be slightly modified to provide better response rates in different individuals (monoclonal antibody engineering). Molecular and genetic testing on an individual basis will become part of standard clinical evaluation to choose drugs that hold the greatest promise for the individual patient. The costs involved in additional sophisticated patient testing and the subsequent use of several expensive biological therapies, over months possibly, will certainly cause quite a challenge for the healthcare system and third-party payers, irrespective of the system in use.

The Value of Research and Clinical Trials

We certainly live in interesting times. As the body of knowledge in basic and clinical immunology continues to grow, and as we learn more and more about the WM cancer cells, novel biological therapeutics using monoclonal antibodies, immunoconjugates, vaccines and other drugs will be used in ever-increasing frequency, to the benefit of WM patients and their loved ones. However, as Dr. David Maloney from the Fred Hutchinson Cancer Research Institute is quick to point out, “Treatment of patients on clinical trials is essential to continue the current pace of progress.”

All references for data in the above article(s) are available by contacting the author by email, guysherwood@comcast.net.

By: Jim Bunton

Of course, the “hit” of the year was our Support Group Leader Retreat, which was held on the day before the Ed Forum in Seattle. There were speakers and a lot of discussion, both formally and informally throughout the retreat. We plan to do it again in conjunction with next year’s Ed Forum in Atlanta.

Currently there are fifty support groups in the U.S., Canada and the United Kingdom. In addition, we now have three telephone contact people for areas that are too sparsely populated for a support group—one for North Central U.S., one for South Central U.S. and one for Eastern Tennessee. The idea is that these people will be available for phone contact and support in lieu of a support group in these areas.

We are always looking for people who might be interested in starting a new group in some area that does not have one. If you think you might be interested and would just like a little more information about it before you decide, you can call or email me at 717-845-5937 or kpindzola@yahoo.com.

Hearing impaired members One of our members, Betty McFee, has a TTY machine and the ability to use it. She will be glad to assist hearing impaired members who feel more comfortable using this method of communication to ask questions or just talk with another person who has WM. Betty’s phone number is listed in the Lifeline section. We hope this new service will be of help to our hearing impaired members.

Educational forum DVD’s If by chance the DVD’s you received have a technical problem of skipping or stopping please send them back to the manufacturer for free replacement. That address is Rocket Digital, 4909 Thomas Lane, Sarasota, Florida, 34238.

To those who did not order these DVD’s earlier you will be pleased to know we still have a few copies available. You can order a set of them for \$35 by contacting the office.

Privacy Our policy is that we do not exchange or sell our mailing lists of member names to any other organization. However, we do give those members who sign up for the telephone/email network the numbers of individual members in their area. Also, most support groups share the names and addresses of members in the group. While we have not yet had any problems in this regard we want to remind everyone of our policy. Most members want to maintain their privacy and we should respect that.

Electronic Communication. We currently use posted mail to send out the quarterly *Torch* and special Bulletins. The cost of postage, especially to overseas members, is very high and the delivery time can be very slow. You may not be aware of it but, the *Torch* is posted on our web site at the same time as we send it out by posted mail. Accordingly, using the web site you can read the *Torch* the same day it is mailed out.

If you would feel comfortable receiving the *Torch* electronically by printing it off your computer you would save IWMF the printing and postage costs which average close to two dollars per individual copy. Please send us an email if you would like to help out in this way.

PARTICIPATING IN THE CAREGIVER TALK LIST

This site provides a place for caregivers to share concerns and opinions and provide a way for raising questions such as how to handle specific situations. Please note that this site is not intended to discuss medical issues related to WM as those should be addressed on the regular talklist.

Please respect the privacy of members and use the new talklist only if you are a caregiver.

To participate, send an email to Charlie Koch (bonnie143@bellsouth.net) including your full name.

HOW TO SIGN UP FOR THE CAMLIST

(an internet talklist for complementary and alternative medicine and treatments)

If you would like to participate, please send an email to: jerry.berman@sympatico.ca

FROM IWMF-TALK

by Jeanne Pond

IWMF-Talk contributors often marvel at the amount they learn about our disease from the IWMF-Talk. We go from abysmal, fearful ignorance when we are first diagnosed to becoming sophisticated cognoscente.

Of course our own doctors have given us facts, but it is interchange of experiences from the members which really educates us. As **Dr. Guy Sherwood** says, “I have a sense of wonderment at the great strides that the IWMF-Talk has made insofar as educating the membership and how those non-physician members in turn have become very knowledgeable and helpful in answering many of the IWMF-Talk queries.”

Dave Lively adds, “As is often said, all of us have to be very careful when making broad statements about WM, as we all seem to have a different disease with a common name! We can give our opinions and we can learn as much as possible about our disease to understand when we should be listening to our bodies when they are calling for help. We should also know enough about our disease to recognize when there is a debatable course of action that should be examined by a WM expert. By the time the owner’s manual for WM is finalized, I expect I will have already been recalled by my Manufacturer.”

Extending our long dialogue on the value of Rituxan as maintenance therapy for already treated patients was an announcement forwarded by **Bert Visheau** that Health Canada has approved the process, a step that is similar to FDA approval in the U.S. The major study that led to the decision enrolled 465 patients throughout the world, and results were presented in December of last year. (The Canadian and other patients in the studies had follicular non-Hodgkins lymphoma but therapy for it and WM has been nearly identical.) The study showed Rituxan was found to increase the length of time from initial treatment from 15 to 52 months, more than tripling progression-free survival time compared to standard management or “watch and wait.”

Meanwhile, current thinking on maintenance Rituxan is very aptly summarized by **Ron Draftz** in answer to a question by **John Muratore**: “Shouldn’t the IgM levels following the initial infusions of Rituxan be a factor when considering maintenance?” Ron says, “The feelings of most is that IgM levels should not dictate treatment unless one is suffering from hyperviscosity symptoms and at risk for eye vessel ruptures, a stroke, or heart attack. The function of maintenance Rituxan as stated by Dr Steve Treon is a prolonged duration of remission and repression of symptoms. That approach is not shared by other doctors who believe that data is still needed to show the benefits of maintenance

Rituxan in WM. Dr. Gwen Nichols cautions that the same duration might be reached with as-needed treatments and Dr. Morie Gertz agrees. Both Nichols and Gertz worry about resistance or refraction from repeated Rituxan treatments. Treon states that the use of combinations can overcome resistance and to date no resistance to maintenance Rituxan has been reported.”

Gareth Evans notes that we will know more about the current opinions of all these doctors after a conference in New York in October at which the subject is bound to be discussed at length. Dr. Nichols will address the WM session on “What should be considered standard initial therapy for WM?” Dr. Treon’s topic is titled “New approaches for the treatment of WM”, Dr. David Maloney will address the question “Should every patient with indolent lymphoma receive maintenance anti-CD20 therapy?” and Drs. Robert Kyle and Gertz will also participate in the conference.

In the last issue of the *Torch* we commented on tests of the drug Perifosine on multiple myeloma patients. Now we hear from Gareth Evans that it is being tested with WM cell lines and that it has “significant anti-tumor activity” in WM in vitro. In vivo studies are ongoing and these results provide the framework to test Perifosine in patients with WM.

These tests are being conducted at Dana-Farber Cancer Institute and are reported by doctors there. Perifosine works by inhibiting Akt, a protein essential to tumor cell growth. Akt stimulates cell proliferation and inhibits apoptosis. (That means it furthers IgM growth and stops cell death.)

Two more experimental drugs that show promise in inhibiting proteins in cancer cells that protect them from apoptosis are YM155 and Apo2L. It is hoped that one day both compounds can be incorporated into conventional cancer treatments to finish off malignant cells that refuse to die. YM155 showed effects in patients with non-Hodgkins lymphoma and prostate cancer and Apo2L in patients with sarcoma.

Other studies at Dana-Farber of mast cells (very large cells found in WM patients’ bone marrow) have led researchers to believe there is a very direct relationship of these cells to WM. They have found that mast cells may support tumor cell expansion in WM, and the CD52 protein expressed on them provide a rationale for use of alemtuzumab (Campath) which targets CD52 the way Rituxan targets CD20 on WM cells. Dr. Guy Sherwood hails this discovery as being fortuitous. “Five years ago nobody even thought about mast cells in WM really, but thanks to dedicated young scientists and their mentors, and thanks to medical research funding of which the IWMF is playing an ever increasing role, this discovery is being made. Continue to support IWMF research by sending in your contributions and ask your oncologist or search the web www.cancer.gov for the nearest appropriate clinical trial in your neck of the woods.”

From IWMF Talk, cont on page 11

We are all aware of the ban on federal financing of embryonic stem cell research. But research on stem cells from babies' umbilical cord blood has continued. A major hurdle exists in the use of these cells in bone marrow transplants—there are seldom enough stem cells from one cord to treat a large child or an adult. As we have said in another part of this issue, Gamida Cell of Israel has announced that it has a product named StemEx which “expands” the number of stem cells to create a population large enough to treat larger children and adults. And a unique property of cord stem cells is, of course, that they have a lower histocompatibility (matching) requirement, thus reducing the risk of graft vs. host disease. So the 50% of those seeking bone marrow transplants who can't find matched donors will now have a chance at a match. Gamida Cell says it is poised to produce its first commercial stem-cell product in 2009.

Eileen Kent asked if “one's ESR (erythrocyte sedimentation rate) is above average (0-20) is that related to WM?” This may be a question many of us are wondering, having heard of the test but not having had one ourselves. **Jerry Fleming** wrote saying he'd been given one long before his WM diagnosis by a neurologist because he was having weakness and peripheral neuropathy. The doctor diagnosed him with polymyalgia rheumatica because of his extremely high ESR (100+). Of course later it was discovered he had WM, not myalgia. A high ESR shows inflammation somewhere in the body. And Sue Herms says that in a WM patient an ESR test may show a false elevation, but it is not a test routinely given to WM patients.

“**BJ,**” who likes to be known as BJ Da Boss, sent in a list of suggestions to reduce our exposure to infectious diseases on air flights. These tips could extend to most any public situation with the thought that we WMers are unusually susceptible to opportunistic infection.

1. Wash hands well and often. Avoid touching your eyes and nose, the main entry point for disease-causing microorganisms.
2. Carry disinfectant wipes to wipe down anything you will be touching that others have touched.
3. On short flights avoid using the bathroom. If you must go, take those wipes with you.
4. If your seat mate appears ill, try to get another seat.
5. Bring your own reading material.
6. Stay hydrated. When your mucous membranes dry out you are more susceptible to respiratory infections. (It's good to know a good, solid reason to drink a lot of water. We are more likely to drink our eight glasses a day.)

In our column in the last issue we told you about **Sybil Whitman's** autologous stem cell transplant in April. She writes to say that it was successful in that it has reduced the amount of her WM disease and has very much reduced the pain she had from bone lesions. Before the transplant she was taking morphine and dilaudid. The doctors suspect she may have multiple myeloma or some other disorder because she has these lesions. She is headed for a mini-allogeneic transplant in October to try to clear that up. Meanwhile she's having a breather, enjoying the summer and getting fatter up for the mini-allo. We offer this brave lady all our good wishes for a successful result.

Ron Payne also had an unusual symptom, treatment of which has been highly successful to date. He was diagnosed with WM in 2000, first treated with chlorambucil, and then Rituxan. But in the spring of 2002 he developed severe leg pain and had an MRI that showed a pre-sacral tumor on the spinal column. Because the location of the tumor made treatment with radiation difficult, he began receiving fludarabine and by late fall that year the tumor had disappeared. For about 18 months he was on a maintenance Rituxan regimen and in his latest bone marrow biopsy only “isolated lymphocytic cells” could be found. As Ron points out, fludarabine turned out to be a blessing with a soft tissue tumor, but warns that WM seems to be a disease that expresses itself uniquely with each individual and it is not always appropriate to generalize from one case to another. We seem to hear that warning frequently!

Andrew Merchant has also had what looks like successful treatment. He was diagnosed in 2002 at age 53 when a routine blood test showed him to be anemic and to have an IgM of 1150. He also exhibited an enlarged spleen and had severe fatigue. After being treated with chlorambucil for six months with no results but with increasing spleen size, he was given six treatments, three to four weekly, of R-CVP (Rituxan plus cyclophosphamide, vincristine, and prednisone). He continued to work except for a few days off after each treatment. His last bone marrow biopsy showed no evidence of disease and his HgB is 17, the IgM, 100. His wife Anne reports that they had “a lovely holiday in Canada with their daughter this summer, something we could not have imagined possible a year ago” The Merchants live in Brentwood, Essex, which is about 20 miles from London. Anne thanks people on the List for their information and encouragement.

TREASURER'S REPORT

James Bunton, Treasurer

Following is a summary of the financial results for the first six months of 2006.

Revenues	
Contributions - Research fund	\$ 63,000
Contributions - Member services fund	116,000
Interest	<u>25,000</u>
Total	<u>204,000</u>
Expenses	
Research grants awarded	-
Member services and general	<u>137,000</u>
Total	<u>137,000</u>
Excess of revenues over expenses	<u>\$67,000</u>

Contributions to the Research Fund were weak for the first six months of this year. If you made a pledge last year and have not yet made a 2006 payment, please consider doing so as soon as possible. During the first six months of 2006 we did not incur any expenses for research grants. However, subsequent to June 30, the Board approved two grants totalling \$1,550,000. These were to Dr. Ansell at Mayo and Dr. Treon at Dana-Farber and were the subject of a special letter sent to all members in August. For accounting purposes this amount will be fully charged to our accounts when set up in August 2006 and will give rise to a significant accounting loss in 2006. Fortunately, the amounts involved in these grants will be paid over the next three to four years. In that period the challenge will be to raise enough money in the Research Fund to meet these obligations.

Contributions to the Members Services Fund of \$116,000 were not quite enough to cover the expenses in that fund of \$137,000. However, we will soon be asking you to renew your membership for next year. Hopefully, those contributions will be generous and we will end the year in a positive position.

WHAT YOU CAN DO TO LIVE BETTER WITH WM

The following tips were offered to WM patients by Sue Sumpter RN at a recent meeting of the Oregon Support Group.

1. Make sure you hydrate adequately; water is the beverage of choice.
2. Exercise – those who exercise have fewer relapses, and exercise increases circulation.
Exercise also raises serotonin levels to make you feel better.
3. Smile – fake the smile if you have to!
4. Eat a balanced, nutritious diet.

Regarding multiple vitamins and supplements, be careful about taking substances that boost the immune system when receiving chemotherapy that targets B-lymphocytes. Multivitamins and antioxidants may protect the cells the chemotherapy is trying to destroy.

A little known side effect of chemotherapy experienced by a small number of patients is called “chemo-brain” or “chemo-fog”. Some of the activities affected are concentration, memory, comprehension and reasoning. For more information check out the American Cancer Society website (www.cancer.org) and search for “chemo-brain.”

SUPPORT GROUP NEWS

CALIFORNIA

Sacramento and Bay Area

Members in Northern California recently heard from Carol Schlesinger, LCSW, Bereavement Coordinator for Hospice by the Bay, who is a cancer patient herself and spoke about the emotional aspects of coping with cancer. According to support group co-leader **Penni Wisner**, Carol described dealing with cancer as a very personal process which we each will engage in according to our character. "She said that learning to live with a cancer diagnosis is a grieving process and that we need to think about and acknowledge what we have lost." The presentation was followed by a personal report from each of the 30 attendees. The next meeting is planned for November.

COLORADO & WYOMING

Roy Parker says that the Rocky Mountain Support Group recently enjoyed a presentation on CAM (complementary and alternative medicine) by Dr. Lisa Ware Corbin, Medical Director at the Center for Integrative Medicine at the University of Colorado Hospital. She talked about specific benefits and risks of common CAM approaches such as acupuncture, herbs/supplements, dietary regimens, mind/body therapies and massage therapy. A lively question and answer period followed. The next meeting is set for January 20th, when Roy hopes to have a guest speaker about caregiving.

Incidentally, Roy mentions that **Cindy Furst** has pioneered an outreach program to contact IWMF members who live far away from Denver. She contacted many of these members and is facilitating establishing "mini" support groups in smaller cities. Also, the Rocky Mountain Support Group is looking at the feasibility of using teleconferencing to allow distant members to participate in the guest speaker portion of regular meetings in Denver.

FLORIDA

Southwest Florida

The Southwest Florida Support Group, which meets in Sarasota, will have Dr. Steven Treon as guest speaker again this year in January. Contact **Herb Kallman** for details.

MINNESOTA & WESTERN WISCONSIN

About 20 members met in September and heard from IWMF Trustees **Dave Lively** and **Dick Weiland**, who provided updates on IWMF fundraising activities and the recently approved research grants. "We shared the 'Waliday' greeting cards, which generated a good deal of excitement," reports group leader **Michelle Blazek**. "We also shared the fact that the 2006 Lymphoma & Myeloma Conference in New York includes an entire section on WM that will be presented by a number of our good friends (Dr. Kyle, Dr. Treon, Dr. Nichols, and Dr. Gertz on other topics.) Then, we spent the rest of the afternoon going around the room to get individual updates. This always results in a rich discussion and encouragement." In addition to regular meetings in 2007, Michelle says there may be a picnic next summer. Stay tuned.

NEW JERSEY

Carole Cohen, founder of the N.J. group, reports that there have been three meetings to date. "My very own oncologist, Dr. Seth Cohen, of Monmouth Hematology, spoke to our group. He was very well received and people flocked around him after his talk." As of press time, Carole was thinking about having the next meeting at her home, which is quite close to the local hospital. "We can watch part of the DVD collection from the last Ed Forum in Seattle. And we can talk a bit about fundraising. Maybe have some goodies to eat and enjoy an afternoon." We tip our hat to Carole for organizing the project to sell "Waliday" greeting cards as a fundraiser for the IWMF. (See article elsewhere in this issue.)

NEW YORK

New York City

As of press time, the New York City support group was planning a meeting on November 12th with Dr. Richard Furman of the WM program at Weill Cornell Medical Center. The topic, according to group leader **Neil Massoth**, was expected to be "Understanding Blood Test Results."

Rochester, Western and Central NY

From this group comes the following note by **Gail Burgie**: "It is with much sadness we report that one of our support group members, Richard Naas, from Hornell, New York, has passed away. Rick had undergone a stem cell transplant for his WM but suffered from other medical conditions, including mesothelioma, which took his life on June 26, 2006. He displayed amazing courage, humor, and strength of spirit that deeply touched us all and he will be greatly missed but remembered always. We extend our sincere sympathy to his loving family and many caring friends."

OREGON/SW WASHINGTON

Joan Berglund reports that 8 WM patients and 7 caregivers attended the first meeting of this group and heard from Sue Sumpter RN, Patient Services Manager of The Leukemia & Lymphoma Society in Portland (LLS). After introductions, Sue offered advice for living better with WM (see box). She also shared copies of a recent LLS newsletter and explained that the LLS provides a wide range of services and resources to patients with WM, including financial aid, free education programs, a toll-free information line (800-955-4572) and a program similar to the IWMF Lifeline that connects patients with other patients who have been trained to answer questions. The next meeting will be Saturday, January 27, at the LLS office in Portland. RSVP to Sue Sumpter 503-245-9866, ext. 214 or sue.sumpter@lls.org .

PENNSYLVANIA

Central PA and N. Maryland

According to **Nancy Lambert**, "Our annual August picnic in the country was highlighted by the presence of IWMF board member Karen Pindzola, who spoke to us about the promising new research being funded by our donations." The next meeting is set for November 12. Maggie Davitt-Harris of Lancaster General Hospital will explain the meaning of blood test results.

Philadelphia

The Philadelphia Area Support Group greeted some new members this summer, one of whom had moved to Philly from his flood-stricken home in New Orleans, reports **Karen Pindzola**. "So in addition to his WM story, we also heard all about his ordeal in escaping Katrina last year. It brought the whole tragedy a lot closer to home for us. In addition, we all enjoyed sharing with each other our own personal WM stories, and getting caught up with some members we had not seen recently."

SOUTH CAROLINA

The South Carolina Support Group had a mix of new patients and regulars at a summer meeting in Aiken. "We shared our experiences over lunch and discussed some of the information presented at the Seattle Educational Forum," report **John and Paula Austin**. During the past few months, John and Paula corresponded by phone and email with a newly diagnosed patient and caregiver in North Carolina. "Since there is not yet a North Carolina support group, North Carolinians are welcome to contact us and attend our meetings." The next meeting will be held in early 2007.

TEXAS

Houston

John and Barbara Manouso report that the next meeting of the Houston support group meeting will be on Saturday, November 11, at 2 PM. (Note the change of day from Sunday to Saturday). The meeting will be at the usual place, 21 Briar Hollow Lane, Houston, inside the 610 West Loop in Uptown

VIRGINIA

The Central Virginia support group met on August 20 in Williamsburg, Virginia. "We were very pleased and honored to have Dr. Steve Treon as our speaker," reports **June Canter**. "Dr. Treon's presentation included the definition of WM, some of the complications, present treatments and research on the horizon." Following the presentation, Dr. Treon answered questions from the audience. "We had 52 people in attendance—some had driven over 200 miles. **Bill Hayes** was kind enough to videotape the presentation." There are plans to to sell the DVD's to anyone interested and donate any profits to IWMF. June adds, "All of us are so grateful to our support group leader, **Bob Zehner**, for arranging this most informative meeting for us."

ENGLAND

Cheryl Luckie reports that the support group in England plans meetings in different locations in the coming months, starting with a meeting November 18th in Birmingham. Future meetings are planned for in various other locations.

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 Eddy Andersen at eddyandersen@earthlink.net and provide your full name
3. Go to the following web link: home.ease.Lsoft.com/archives/iwfmf-talk.html

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THE LIFELINE

If you can't get to a local support meeting, use our IWWM 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 IWWM 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	253-874-8820
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

WATCH AND WAIT

Mel Horowitz	518-449-8817
Renee Paley-Bain	203-744-7851
Polly Oldberg	513-932-7486

YOUNG WM

Nobby Riedy	650-879-9104
Bob Bailey	770-664-8213

HEARING IMPAIRED TTY FACILITY

Betty Mc Phee	905-775-3413
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SPANISH SPEAKER

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VOLUNTEERS STILL NEEDED

As described in a previous issue of the *Torch*, we are trying to reach out to more WM patients by making contacts at hospitals and clinics that offer cancer support groups and/or have literature displays in waiting rooms. Many thanks to those of you who have already contacted a health care institution. We still need more volunteers as there are many areas in the U.S. and Canada where no contacts have been made to date. The basic procedure for volunteers is as follows:

- Contact local hospitals and healthcare institutions to find out if they have a cancer support group.
- If a group exists, ask for the name of the coordinator and try to reach this person by phone. Introduce yourself and find out if there are any WM patients in the group. Mention that you have a type of nonHodgkin's Lymphoma-Waldenstrom's macroglobulinemia-and that you are a member of the IWMF Foundation.
- Make an appointment to meet with the coordinator and also plan to attend a support group meeting. Take copies of all the IWMF publications and information with you (the *Torch*, bulletins, booklets, etc.) and hand these out to the group coordinator and WM patients.
- Send the names and addresses of the coordinators to Sara McKinnie in the IWMF office so that she can add them to our mailing list.

If you can help, please contact Elinor Howenstine at 415-927-1536 or email her at laraellie@aol.com to get more information and details. This is a very worthwhile project for the IWMF. Let's get the word out about our great organization!