

iwmf torch

SPRING 2006

INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

TIME IS RUNNING OUT FOR THE 2006 ED FORUM!

by Don Lindemann

Only a short time is left until the start of the 2006 Educational Forum, planned for May 5-7 in Seattle. This is the premier event of the year for IWmf members, a golden opportunity to hear the latest about current and potential treatments from top clinicians and researchers in the field.

This year we are planning an especially informative program with more speakers than ever before, coupled with the chance to get your questions answered at the Sunday morning "Ask the Doctor" session.

Confirmed speakers include Dr. Steven Treon and several colleagues from the Dana Farber Cancer Institute at Harvard University. Dr. Treon and his team will provide an update on efforts to understand the genetic predisposition to WM as well as an update of the results of ongoing clinical trials with rituximab, bortezomib, sildenafil (Viagra), alemtuzumab, and other biologically based drugs. Many other experts will also be on hand to speak including:

- Dr. Rafat Abonour, Indiana University Bone Marrow and Stem Cell Transplantation Program
- Patty Delaney, Cancer Liaison Program, FDA
- Dr. Morie Gertz, Mayo Clinic
- Dr. Robert Kyle, Mayo Clinic
- Dr. Todd Levine, University of Arizona
- Dr. Amy (Ying Li) Matecki, Alta Bates Cancer Center (Berkeley, CA)
- Dr. Gwen Nichols, Columbia University
- Dr. Linda Pilarski, Cross Cancer Institute, University of Alberta, Canada
- Dr. Donna Weber, MD Anderson Cancer Center, University of Texas
- Dr. Douglas Williams, ZymoGenetics (Seattle)

On-site registration begins at 12 noon on Friday, May 5th. Once again we offer two parallel tracks starting at 1:30 pm on Friday afternoon and wrapping up with a "President's Reception" at 6 pm. On Saturday we will have a full day of presentations and breakout sessions for patients as well as caregivers, followed by the Forum Dinner at 6:30 pm (with

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AN OVERVIEW OF CLINICAL TRIALS

By Guy Sherwood, M.D.

When you or a loved one are diagnosed with the rare cancer known as Waldenstrom's macroglobulinemia, several questions may come to mind: How do we treat this disease? Is there a cure? How do we find a cure?

Exciting discoveries in cancer cell biology are being made at a rapid pace. Basic research, supported in part by the IWmf, is yielding important clues about the nature of cancer, and these clues are directing further research into new and promising treatments. The most promising ones are initially tested in the laboratory, first *in vitro* (test tubes) and then *in vivo* (on animal models of cancer). Finally, treatments that appear to be reasonably safe and beneficial are tried on human beings—in clinical trials.

There is a very small population of WM patients to draw upon for clinical trials. Statistics show that our disease accounts for only 0.1% of all cancers diagnosed in the United States, and the prevalence of WM is estimated at only 5-6 cases per million people. To make matters worse, the sad reality is that only 3-5% of cancer patients choose to enroll in clinical trials. This limits scientific progress towards better treatments and a cure.

This article will elucidate the concept of clinical trials and explore the reasons why some people do or do not participate. Hopefully this will assist you in discussing clinical trials with your oncologist.

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PRESIDENT'S CORNER

by Judith May

With the annual Educational Forum just around the corner, there has been a flurry of activity as we begin the countdown to May 5th in Seattle. Speakers are confirmed, breakout sessions are being firmed up and menus are being planned. I encourage you to come to Seattle to hear the latest updates on research and meet and mingle with other WM patients. In past years we have sold out before the start date, so if you do plan to attend, please register as soon as possible by going to our website [www.iwmf.com]



I have very important and disappointing news regarding the WM Research Consortium proposal. As you know, the Board of Trustees is devoted to making sure that our research dollars are used in the most effective way possible. We spend a lot of time and energy making sure that research proposals are thoroughly and fairly reviewed by our Scientific Advisory Committee (SAC) and the Board of Trustees; we examine them closely in the context of other ongoing WM research, and we make sure that the approved studies are in line with our research goals of developing better treatment therapies and advancing towards a cure for WM.

The WM Consortium proposal, a five-year, five-institute collaboration that attracted a potential \$1 million matching donation, was the centerpiece of our 2005 IWMF fundraising campaign. However, during the review period, our experts on the SAC and the Board of Trustees raised many questions and concerns. Responses to those questions and concerns did not clarify the issues or satisfy the SAC reviewers that this would be the most effective use of our research dollars. After much deliberation, the Board of Trustees decided not to approve the project for funding. As a result, the million dollar match was withdrawn. Our decision was not arrived at quickly, and in fact comes after nearly a year of communications with the consortium proposal authors. Our disappointment is tempered by our determination to make sure our research funds are spent effectively.

The IWMF Board of Trustees continues to encourage the development of new proposals on WM to advance progress towards finding a cure. We are currently reviewing two proposals: a multi-year study of WM cell surface proteins, and a study of chromosome mutations in WM patients. Another proposal is expected in early April, and there are other short-term proposals on the horizon. We are also working towards more collaboration of WM researchers.

We realize that many of you may have pledged or contributed more than you otherwise might have, expecting the money to be used for the WM Consortium project. We hope that you are satisfied that the SAC and Board have exercised due diligence in coming to the conclusion not to invest IWMF funds in this project. We will continue to look for proper uses for our research dollars. However, should you want to withdraw your pledge or contribution, we will, of course, return your funds.

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First Person: Participating in a Phase II Clinical Trial

by Jeff Atlin

In the late summer of 2002, after over four years of “Watch and Wait,” my oncologist and I decided that it was time to consider treatment. We spent our monthly appointment considering the available conventional options. The option that I was most interested in—Rituxan—was not available to me since it was not yet (at that time) approved as a first line treatment. I was not anxious to try anything that would damage the bone marrow. My oncologist said he would review the options again and get back to me.

In our next meeting, my doctor told me that a new drug was being tested for multiple myeloma, and that our local cancer hospital was going to open a Phase II Clinical Trial for WM. He gave me a referral to the doctor who was going to run the trial, and in October I met with her. The drug was called PS-341 (bortezomib), now named Velcade.

The decision to opt for the unknown trial drug versus the old standbys was really not all that complicated. My symptoms were fatigue caused by low Hgb (hemoglobin) and the beginnings of peripheral neuropathy (PN) along with night sweats and slightly rising viscosity. I reasoned that if I were to wait another 3-6 months to begin one of the standard treatments, it likely wouldn't cause a problem except for the possibility of a lower hemoglobin level (which could be treated with Procrit or a transfusion). Therefore, if I tried this new drug and it didn't help, I could always stop after a couple of months and switch to one of the known treatments. In addition, there was always the possibility that the new drug would be such an improvement over the existing drugs that I would not need retreatment for a long time. Lastly, it was an opportunity to take part in trying to find a cure for our malady.

The stated objectives of the trial were as follows:

- determine the efficacy of bortezomib in terms of response rate for patients with previously untreated or relapsed Waldenstrom's macroglobulinemia.
- continue to study the toxicity of the drug
- determine the time to progression, stable disease duration, and response duration

Criteria for Joining a Trial

Entry into a clinical trial is not automatic; one has to meet certain criteria. I will outline many of the criteria for the Velcade trial below to give you some idea of the selection process.

The first requirements were easy for me to meet. I was at least 18 and had a life expectancy of at least 12 weeks! If previously untreated, your IgM had to be at least 2000 and Hgb 11 or less; my IgM was in the 5000's and Hgb in the 8's. Participants also had to meet one or more of the following conditions:

- Symptomatic lymphadenopathy (enlargement of lymph nodes)
- Hepatomegaly (enlargement of the liver) and/or splenomegaly (enlargement of the spleen)
- Hyperviscosity syndrome
- No other lymphoproliferative disease including transformed aggressive lymphoma
- Platelet count $\geq 50,000/\text{mm}^3$
- Creatinine ≤ 1.5 times ULN
- Absolute granulocyte count $\geq 1,000/\text{mm}^3$

There were other conditions that also had to be met, but the aforementioned were the main ones. I met ALL of the above conditions, so I passed to the initial interview stage. The trial was explained to me, including the potential complications. I think that they may actually make some of these up just to keep the faint of heart away!

There were also criteria for previously treated patients including the following:

- At least four weeks since prior chemotherapy
- No more than two prior chemotherapy regimens (aside from single-agent rituximab)
- No concurrent cytotoxic chemotherapy
- At least 12 weeks since prior rituximab (for patients who have progressed)
- At least 24 weeks since prior rituximab (for patients who have not progressed)
- No prior high-dose chemotherapy and stem cell transplantation
- No prior radioactive monoclonal antibodies
- No concurrent corticosteroids
- At least 4 weeks since prior radiotherapy (except for low-dose, non-myelosuppressive radiotherapy)
- No prior radiotherapy to more than 25% of bone marrow

The next step was to confirm the staging of my disease. I first had a physical exam by the doctor, who paid particular attention to my budding PN as the trial did not allow for participants with higher than a grade 2 neuropathy. Next

ROW BOB ROW!!!

by our intrepid Florida reporter

My gosh, is he still alive and rowing? YES, he is! Bob Lynch was diagnosed with WM in June of 95. He was 47 years old at the time and working for the Florida Department of Labor. As he had no symptoms, the diagnosis of cancer and a prognosis of “3 to 7 years” were simply unacceptable.

Bob and his wife Sue decided that in the past many “great things” turned out to be less than great, while many “disastrous things” turned out not nearly as bad as first thought. Rather than prejudge this new event, they chose to be observers of life and see what God had in store. Bob’s first reaction to the diagnosis was “I just can’t wait to see the good that’s going to come out of this.”

Bob experienced 18 months of chemo including Fludarabine and Alceran. His IgM counts finally dropped from 5980 to a low of 1200. Bob decided that he needed a rest from all this medical attention and went AWOL from treatment in December of ‘96.

He decided to try some alternative methods of healing including meditation, diet changes, reduced stress and rowing. Yup, rowing! Bob loves the water, and he found the exercise of sliding seat rowing to be very relaxing as well as a great exercise to rebuild the body and lungs after chemo.

This love of rowing led Bob and Sue to the first “Either Oar, Cancer Survivor Row” in 1998, when he rowed his little 15’ boat named “Prosperity” from Key West to Miami, a trip of 150 miles. Through donations (mostly by the mile) they raised about \$30,000 for WM research.

As Bob finished this journey, one of the first people he saw at the finish line was IWFM founder Arnie Smokler waving a banner and chanting, “Row Bob Row!” One of the first questions Arnie asked was, “So what’s next?” Bob later said he really had no idea how to answer that question, since he figured “the row” was going to kill him—but there was a “next.”

In the year 2000 Bob and Sue celebrated continued good health with Either Oar II: 200 miles for Y2K. Bob put his new 15’ boat named “Attitude” in the water in Melbourne, Florida. The reason for this location was to allow Bob’s mom the thrill of pushing the boat away from the dock at the age of 93. Bob rowed for nine days, arriving in Miami to the cheers of hundreds of well-wishers and believers that anything is possible. There was much champagne and fireworks through the evening, celebrating life and raising approximately \$30,000 for WM research.

Row Bob Row, cont on page 5

MEMBERS FIND WAYS TO FUND A CURE FOR WM

by David Lively

It is a wonderful thing to see good people unite in a worthy cause. The IWFM Research Fund efforts have included some notable tactics recently. Many of our members have successfully written letters to their friends that have been chronicled in the *Torch*, but we are also fortunate to have some of our members go the “extra mile.”

Some of you may have heard of Lisa Lawton in Methuen, Massachusetts who, with her family, has raised thousands annually by holding a benefit in the local tavern with raffle tickets and a band! Lisa has fun while raising funds!

Another of our regular fundraisers for WM is Lynn Mara, who with her husband Jim, put on a very successful and well attended annual golf outing to raise money for WM research. The outing is held in August each year and benefits familial WM research.

Bob Lynch is one of our earliest supporters from the days of Arnie Smokler. For the last several years Bob has rowed his little craft down the panhandle of Florida with pledges for miles rowed but, as many of us have heard, the weather conditions in Florida have included some nasty hurricanes. Bob will be taking to the waters off the Florida coast again this year on a rowing excursion from Jacksonville to Melbourne! We are hopeful that Bob will not tempt any more hurricanes and that his trip will be safe above all else. For details, or to pledge to his wonderful personal effort to find a cure for WM, contact him at ROWBOBROW@yahoo.com. Also, see the article at left.

You too can make a difference for the benefit of present and future WM’ers in your own unique ways. Write a letter, start a golf tournament, row a boat, hold a raffle, or maybe hold a fishing contest! More of us are here today because someone, somewhere, made a difference in finding better treatments. Each one of us can make our world a better place by helping fund and find a cure for WM.

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

This time it was a question from the media... "What's next?"

Two years of preparation and continued good health brought about Either Oar III. This found Bob and nine other crazy people rowing across the state of Florida. Starting in Stuart, the trip covered the St. Lucie Canal, five locks, Lake Okeechobee, the Caloosahatchee River and 185 miles before arriving in Ft. Myers. The incredible amount of work Sue did in the pre-row provided a celebration with hundreds of well wishers on both land and water. WM research was the recipient of approximately \$35,000. Sponsors, including a very large Budweiser truck, provided a party that was not to be soon forgotten.

He made it almost through the whole party before "it" happened. A TV interviewer asked the question, "What's next?" By now he was prepared, and told him the next area to row will be the Gulf Coast of Florida. Well, anyone who knows what hurricanes have done to the Gulf Coast over the past two years will understand why he was finally given in and changed the next row to a different area. Finally, a NEW PLAN. The beginning of June will find Bob putting his new 15' boat, "Inner Voice," into the water in Jacksonville and rowing south to Melbourne, a trip of approximately 200 miles.

The universe works in wonderful ways. Bob's Igm counts have continued to rise and are currently around 7000. Bob was thinking of taking a little down time to just work on his golf game, but he heard a song by a group called Devotion. The words are as follows: "Do all you can with what you have, in the time you have, in the place you are, do all you can." With those words bouncing around in his head, Either Oar IV has been born.

Over the years, the folks of IWWMF have been huge supporters and we want to thank everyone in advance, for their support again. Bob will be the first to tell you that he doesn't do these rows alone. When his hands are blistered and bleeding and his back and butt just plain hurt, he thinks of the people who, like himself, believe that what we do now will someday help those behind us. Heck, we're getting close enough now that maybe we can get it cured before Bob has to row the whole country.

You can be a part of this adventure by donating by the mile, i.e. 50¢ per mile = \$100.00, \$1.00 per mile = \$200.00 etc. Maybe just making a flat donation of whatever your heart dictates. Checks can be made out to IWWMF, or donations can be made on the IWWMF website by clicking on the "contribute" box. To make a pledge by the mile, contact Dave Lively at livelyfish@aol.com.

Bob and Sue are also creating a drawing where the proceeds will be split between the winning number and IWWMF. There will be no more than 100 tickets at a donation of \$100.00 each. This will generate \$10,000. and a chance at winning \$5,000. If you would like to acquire some of these chances and/or are willing to help get these tickets into the right hands, please contact Bob & Sue at rowbobrow@yahoo.com, or call them at 772-388-6417 or 305-978-5937. Their current address is 9632 Riverside Dr. #1, Sebastian FL 32958.

Sue was in a car accident December 26th and is still doing therapy for a broken knee cap. Bob will be doing his training in this area (Sebastian) while Sue is recovering. Any of you who know Bob and Sue know that nothing would make them happier than a personal hello from you and an update on how your own challenges are coming along.

Remember, this could be the year when we find that cure. So keep those special words bouncing around in your head:

DO ALL YOU CAN WITH WHAT YOU HAVE,
IN THE TIME YOU HAVE,
IN THE PLACE YOU ARE,
DO ALL YOU CAN.

I promise that I will do all I can and hope you will help me in this effort. — Bob

ADMINISTRATIVE MATTERS

By James Bunton

Membership for 2006. We have had a wonderful response from members to our campaign to renew 2006 memberships. It has put us in the position where we clearly have adequate funding to carry out, and expand, our member services programs for this year.

However, there are still a few members we have not heard from. If you are one of them, please complete the enclosed contribution envelope and return it to the business office. If it is more convenient you may contribute electronically through our secure payment site at www.iwmmf.com by clicking on the membership button on the home page. Even if you are not able to make a donation we would like to hear from you so we can be sure we have your correct address and other information.

Your e-mail address. We would like to be able to expand our e-mail communication with members. However, about one half of our members have not supplied us with an e-mail address so we have no way of communicating electronically with them. If you have recently acquired an e-mail address or if you think we may not have your current address, please send an e-mail to the office at info@iwmmf.com including your name and we will be sure to enter your correct e-mail address in our member database.

TREASURER'S REPORT FOR THE YEAR 2005

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 the accounting records. The detailed financial statements are on the web site. For the sake of simplicity they are summarized as follows, with amounts rounded to the nearest thousand.

Research Fund

Contributions received during 2005	\$ 682,000
Interest earned	<u>18,000</u>
	700,000
Research grants awarded	<u>321,000</u>
Increase in the fund during 2005	<u>\$ 379,000</u>

Contributions received during 2005 of \$682,000 compares with \$188,000 in the year 2004. The significant increase in contributions is a result of our 2005 fundraising campaign. Research grants awarded in 2005 of \$321,000 were higher than in 2004 when \$222,000 was awarded. No operating expenses are charged to the Research Fund.

The Research Fund now has \$766,000 of assets at year end available for future research grants. The Trustees are currently considering several large research projects which we hope to fund in 2006.

Member Services Fund

Contributions received during 2005	\$ 333,000
Member services and operating expenses	<u>306,000</u>
Increase in the fund during 2005	<u>\$ 27,000</u>

Contributions received during 2005 of \$333,000 compares with \$367,000 in 2004. The decrease is due to the reduction in corporate contributions. Expenses in total were up over last year largely due to an increase in support for WM conferences. Operating expenses in 2005 were only 9.5% of our total income which means that over 90% of all contributions went to help those with WM through member services or research towards ultimately finding a cure. This percentage compares favorably with other organizations similar to IWMF.

The fund balance at the end of 2005 is \$337,000 which should allow us to improve a number of our existing member services programs.

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

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keynote speaker Dr. Morie Gertz). The Ed Forum wraps up on Sunday with the ever-popular "Ask the Doctor" session.

Cost of the Ed Forum (not including hotel room) is \$150 (\$175 after April 15th). You can register via our website (www.iwmf.com), which provides visitor information about Seattle as well as the Ed Forum. Alternatively, you can send your name/address/phone/email address to the IWMF office accompanied by a personal check or credit card information (type of card/ number/ expiration date). Mailing address is 3932 D Swift Rd., Sarasota FL 34231. Reservations by fax—with credit card info—may be sent to 941-927-4467.

To make hotel reservations contact the Marriott Sea-Tac Airport Hotel (201-241-2000) and mention IWMF (group code IWMIWMA). The special IWMF room rate is \$94.00 per night plus tax. Please reserve by April 22, the cut-off date for the special room rate. The special rate is also effective two days before and two days after the event.

Clinical trials are experiments carried out on human beings to answer a specific therapeutic question. Essentially, investigators want to obtain answers to three types of questions in a series of these experiments:

- Phase I: Is the new treatment safe?
- Phase II: Is the new treatment effective?
- Phase III: Is the new treatment better than other treatments?

New treatments, or new combinations of existing treatments, can reach the general public only if all three of these questions have been answered to the FDA's satisfaction.

Phase I Trials

Phase I clinical trials are not intended to demonstrate whether a treatment works; they are designed to evaluate the toxicity of a treatment, determine the maximum tolerated dose (MTD), identify major side effects and compare various means of administering the treatment (intravenously, orally, etc.). Some Phase I trial participants will go into remission, to everyone's delight, but that is not the main focus of the study.

Phase I trials in WM are relatively rare, as the treatments in question have usually been evaluated in trials for multiple myeloma (MM) or chronic lymphocytic leukemia (CLL), blood cancers that are similar to but much more common than WM.

Phase I trials have the following advantages: 1) you have the opportunity to receive a treatment that might be better and less toxic than anything else available for years to come, 2) eligibility requirements are usually not as stringent as in other trials, 3) all patients receive the new treatment, 4) you can usually continue receiving the treatment post-trial if it seems to be working in your case, and 5) you contribute to the advancement of science and help your fellow cancer patients down the road.

Phase I trials have the following disadvantages: 1) the study design is meant to test a treatment's toxicity, not its efficacy, 2) you may be the first human to receive this treatment, which may lead to unknown and possibly severe side effects, and 3) the treatment may be ineffective, or the dose may be too low for your cancer.

Phase I trials are usually shorter than other trials and conducted at large institutions that may be far from your home.

Phase II Trials

Phase II clinical trials are primarily designed to determine whether a treatment is effective. They are not intended to determine whether the new treatment is better than other existing treatments. There are no guarantees that a treatment evaluated in a Phase II trial will work at all; fewer than half the treatments in these trials go on to Phase III. However, most treatments evaluated in Phase II trials for WM have seen Phase III trials in other more common cancers such as in MM and/or CLL. This will likely change in the future as more targeted therapies are developed specifically for WM (e.g. vaccines).

Phase II trials have the following advantages: 1) you receive a treatment that is years away from mainstream availability, 2) toxicity levels have largely been established by Phase I trials, 3) you will receive the highest dose that has acceptable side effects. In addition, as with Phase I trials, your participation benefits others with WM.

Phase II trials have the following disadvantages: 1) the treatment may be ineffective, 2) serious side effects are still possible, 3) eligibility requirements are quite strict, and 4) trials are usually of a longer duration, meaning that a greater time commitment is required. In addition, you may still need to travel a fair distance to participate.

Phase III Trials

Phase III trials are designed to make direct clinical comparisons between a proposed treatment or combination of treatments and an existing standard treatment. These trials can also compare two standard treatments to decide which is better based on number of remissions, side effects, etc.

Randomization of patients enrolled in Phase III trials is an important concept to understand, as it distinguishes this type of trial from the other two previous ones. Simply put, in a Phase III trial you will be randomly assigned to receive either the new experimental treatment or the best existing standard treatment. Phase III trials can also have two or more versions of the experimental treatment for comparison to two or more versions of existing treatments. Patients considering a Phase III trial therefore need to be well informed as to the design of the trial itself and the potential to be randomly assigned to one of several different treatments, be they experimental or standard.

The very nature of an illness such as cancer makes "blind" and "double-blind" Phase III trials quite difficult, and as a result these types of Phase III trials are relatively rare, although they do exist whenever it is feasible to do so. (In a blind study, the participant does not know what treatment he or she is receiving; in a double-blind study, both the investigator and the participant are unaware of the nature of the treatment.)

Phase III trials have the following advantages: 1) you have the chance to receive a new treatment that might be better than any existing treatment, 2) the treatment in question has already passed the Phase I trial's toxicity evaluation and the Phase II trial's effectiveness testing, 3) eligibility criteria are usually less stringent than the other types of trials and 4) Phase III trials are usually large multi-center trials, so travel time may be less of a problem. Even though you may be randomly assigned to receive a certain treatment, the Data Safety and Monitoring Board will switch you to the most effective treatment if it is significantly more beneficial. You will contribute to medical science and will provide valuable information that will help future cancer patients.

Phase III trials have the following disadvantages: 1) certain individuals may object to be randomly assigned to the standard treatment arm, and in "blinded" trials many people do not like not knowing what they are receiving and 2) the experimental treatment may be less effective than the standard one. In addition, side effects that may not have been seen in the smaller Phase I and II trials may become more apparent in the larger Phase III trials. Finally, Phase III trials are often reserved for newly diagnosed patients who have not received any previous treatment (treatment naive patients).

Why Does It Take So Long?

Clinical trials may take years to complete. This may be due in part to the FDA's stringent guidelines—pharmaceutical companies formerly had to demonstrate that a proposed new treatment actually increased average survival times in order for it to be considered effective. New FDA rules in 1996 relaxed the requirements somewhat—researchers can now use "surrogate markers," such as tumor shrinkage, as an indirect indication of effectiveness. This seems to have accelerated the drug approval process significantly.

However, the necessary and protective FDA rules are not the only reason that novel cancer treatments take so long to be evaluated. As noted above, the National Cancer Institute (NCI) has stated that fewer than 5% of cancer patients ever participate in clinical trials. It has been suggested by many researchers that if twice the number of cancer patients could be persuaded to participate, new and potentially curative treatments could be evaluated in half the time it takes now! This is a crucial point, particularly for an orphan disease like WM.

Why do so few people participate in clinical trials? There seem to be a number of reasons including a lack of awareness, a reluctance to second-guess the treating oncologist, an unreceptive oncologist, the reluctance of some oncologists to refer their patients to clinical trials, overly strict eligibility requirements, difficulty finding clinical trials in the patient's

geographic area, difficulty with insurance coverage (almost exclusively in the U.S.), financial burdens, fear of side effects, a good prognosis, and the desire to let someone else take the perceived risk of entering a clinical trial.

Why Consider a Clinical Trial?

To summarize, participants in clinical trials have the opportunity to receive a new treatment years before it is available to other cancer patients. Experimental treatments may not have a proven benefit, but they were proposed by knowledgeable physicians and researchers because they appeared promising. The level of medical care you will receive in a clinical trial will be highly individualized and you will therefore benefit from a notably higher level of medical care.

In addition, even though the treatment received may not provide the desired results, many participants derive personal satisfaction and comfort from the knowledge that they have increased scientific knowledge and helped future cancer patients. The altruism of some participants makes it more likely that a cure will be found for WM and many other cancers.

Obviously some people decide not to participate in clinical trials for valid reasons. In the end, the decision to participate in a clinical trial is a truly personal one that you must make after careful consultation with friends, relatives, physicians, and spiritual advisors.

Many medical professionals who are deeply involved in the search for a cure, and who devote themselves to the alleviation of human suffering, believe that a cancer patient should at the very least consider a clinical trial along with standard treatment options. If you are not even considering clinical trials, you are overlooking options that may obtain the best possible results from your future treatments.

"I think that all patients with cancer should be in a clinical trial," said a well respected cancer surgeon at the University of California. "If they're not in a clinical trial, it implies that we know how to treat the disease, which for all but a few cases, we don't."

The IWCF Board of Trustees and Scientific Advisory Committee hope that WM patients will participate in clinical trials in greater numbers, leading to advances that will result in a greater quality of life for WM patients and their supportive, loving families. Most importantly, we will find the cure!

came a bone marrow biopsy to see the degree of involvement. My bone marrow was “fully impacted” to the extent that in two attempts she could not aspirate any liquid and settled for two marrow samples instead.

Tests and More Tests

Next were scheduled a CT scan with contrast and a heart test called a MUGA. For those of you who have not had the pleasure of a MUGA, it is riding a bike while on your back with a CT scanner an inch from your chest. Every three minutes they raised the tension on the bike until I could not continue. I told the doctors that if this had been invented in the 1600’s, the rest of the torture equipment in the Spanish Inquisition would have been unnecessary! I ended up having one of these tests (and a CT scan) about every six weeks throughout the treatment period.

Once I completed and passed the physical tests and reviewed all of the potential dangers of the trial (once again) with the doctor, I was ready for the paperwork. What good bureaucracy exists without a ream of paperwork! Consent forms for participating in the trial, for releasing your results to the drug company, sharing unidentifiable data and who knows what else.

Once I was approved, I found out that the trial had not yet received all of the regulatory and hospital approvals necessary to get going. I waited from October to the end of January 2003 to get started.

One of the nice things about most clinical trials of this type is that all of your main medication, medical care and clinical testing are fully covered by the drug company, the trial sponsor or the hospital. Other than time (a fair bit of that), the only cost that I incurred was for parking my car (usually \$10 a day) and a couple of prescriptions.

The schedule for taking Velcade entails an infusion on days 1, 4, 8 and 11 followed by 10 days off. This represented one cycle. That meant going to the hospital twice a week, two weeks out of three. The minimum number of cycles was six (except for those with an adverse reaction that required discontinuing the drug). This meant a minimum commitment of 18 weeks.

Velcade is injected by needle into the IV line — it takes only five or ten seconds. But my time commitment easily approached a half day after factoring in travel to and from the hospital, blood draws, waiting for the results, waiting for a nurse to insert the IV and receiving fluid for about one-half hour after the infusion.

In addition, I had to see the doctor once per cycle (usually at the beginning), have CT scans and the dreaded MUGA’s every six weeks or so. On the other hand, I received top-notch care for practically free and contributed to the knowledge about our disease.

Results

Because Velcade kept working for me, I ended up taking it for 18 cycles over a total of 53 weeks. This is no longer the record; a friend of mine who entered the same trial a while after I did has just completed her 36th cycle and is still going strong!

After a while you get used to the schedule and it becomes part of your routine. You learn the little scheduling tricks at your particular institution to get you through an hour earlier, and you become friends with the staff (and in some cases with other patients). It is almost a second family, and I know I went through some psychological withdrawal upon completing the program. I made good friendships with several other trial participants, and I am still in contact with them.

I had great results for 18 months from Velcade. I did suffer a couple of side effects; in any trial you have to keep an eye on these and keep the medical staff current on your symptoms. I suffered some fatigue from the drug, and my PN worsened for a time. Then, amazingly, it almost disappeared. There are those who developed severe PN from Velcade and had to stop using it — and there are those like my friend who have sailed through 36 cycles with no side effects whatsoever!

Clinical trials like mine are designed to determine what percentage of participants benefit and to what extent, and how many have or don’t have certain symptoms at various levels. Without patient participation these questions would never get answered. I can only tell you that my experience was a very positive one overall, and I would recommend that you consider participating in a clinical trial if the opportunity is available to you.

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

Word of new treatment possibilities for Waldenström's macroglobulinemia and updates from members on their experiences with standard treatments continue to highlight our IWMF-Talk.

Bert Visheau sent in a press release from Accentia Biopharmaceuticals about results of its phase II clinical trial of Biovax ID, a personalized vaccine for follicular lymphoma, a non-Hodgkins lymphoma.

Patients in first clinical remission six months after chemotherapy were treated with a series of vaccinations of Biovax ID. With a median followup of 9.2 years, 45% of the patients remained in remission and the overall survival rate was 95%. These results compare favorably with chemo alone and with CHOP-R, where median disease-free survival is 2.2 years and 6.9 years respectively. [*CHOP-R is a chemotherapy regimen consisting of the drugs cyclophosphamide, doxorubicin, vincristine and prednisone (CHOP) plus Rituxan - Ed.*]

Biovax is designed to prime each patient's immune system to recognize and eliminate cancerous cells while sparing normal B cells. It uses "complete high fidelity" copies of each patient's unique tumor antigen, according to the press release. Other vaccines currently being tested are made by molecular cloning and splicing and use only a portion of the patient's tumor antigen.

Next question: when is this vaccine going to be tested on a WM patient?

Merck Pharmaceuticals is testing a shingles vaccine, Zostavax, in people over 60. It is planning to start a trial for younger people with severely compromised immune systems and is due to report results to the FDA soon.

A study from the University of Amsterdam was designed to test the effectiveness of rituximab for patients with indolent non-Hodgkins lymphoma. In the trial, 465 patients with relapsed and refractory (unresponsive to treatment) indolent NHL were randomized to receive either CHOP therapy or rituximab plus CHOP. Responding patients were then again randomized to either rituximab maintenance or observation. Rituxan maintenance therapy consisted of a single infusion every three months over a period of two years.

Results of the first part of the trial showed that patients who received R-CHOP had a significantly higher rate of complete remission than patients who received CHOP alone (29% vs. 16%). Most strikingly, results of the maintenance

study showed that two years of rituximab can extend progression free survival by 2.5 years and reduce disease-related mortality by 50%. The lead investigator, Professor Anton Hagenbeek, said, "Our trial confirms that rituximab maintenance therapy is highly beneficial for all patients including those who have already received rituximab as part of their initial therapy. We have not seen such an impressive improvement in progression free and overall survival for indolent NHL in the last 30 years. This may well become the new standard of care for these patients."

This report brought on another lively debate. Among others joining in were **Ron Draftz**, who expressed a concern that "those on Rituxan may reach a point where they become refractory to Rituxan." He also pointed out that the study does not seem to establish that Rituxan maintenance therapy results in improved survival compared to a strategy of using Rituxan on as-needed basis (e.g. when IgM exceeds a certain level). Meanwhile, **Dave Lively** offered the opinion that not enough research has been done yet to assume that all WMers would become refractory.

Tony Peterson recently finished a trial involving Velcade plus Rituxan with excellent results. He replied to an e-mail asking whether he experienced peripheral neuropathy after the trial began (many patients have had that problem). He said no, he hasn't had any PN; he believes that might be because he was administered only 60% of the standard dose of Velcade. Part of the purpose of the trial was to determine what effect giving a smaller dose would have.

Use of fludarabine was brought up by **Eileen Sullivan**. She says her white blood count has never recovered from her sessions with it, and she warned about using it. Immediately, patients who have had good results with Fludara [a brand name of fludarabine] posted their stories. **Bill Gee** says that three of the presenting doctors at our Ed Forum in Tampa spoke of using it successfully, and his doctors says he will recommend it again for Bill if he relapses because it was so successful the first time.

Fiona Eden-Bushell chimed in from England, saying her treatment with Fludara has been a success.

Wan Len asked, "Does Fludara or 2Cd prime the WM cells and make them more susceptible to Rituxan years later?" **Liane Cochran-Stafira** answered, "From what I was told by my hem/onc, the use of Fludara or 2Cd helps reduce tumor load and thus gives you more 'bang for your buck' when you use Rituxan. Each WM cell has multiple CD20 surface antigens, and if there are fewer cells to start with, there is an increased chance for each Rituxan infusion to bind with as many CD20 antigens per cell as possible. Nucleoside analogs help reduce competition for Rituxan binding sites,

which is important considering the limited number of Rituxan molecules per dose.”

....

People having severe PN are writing in to let us know what is helping them most in dealing with the pain. **Jerry Fleming** has tried a new treatment called Neurovas. Electrodes are applied to the affected area and electric current administered until it becomes painful. Then it is reduced a little. The pulses go on for three seconds repeatedly for 45 minutes and the idea is that blood flow is stimulated to heal the damaged nerves. Jerry is not sure it is helping him. He's had seven treatments with 12 to go. He is the only WM patient being treated at this site; several diabetic patients think it is helping them. **Lou Birenbaum** is “guinea pigging for us” with another new treatment called anodyne therapy. It consists of infrared light focused on the feet and lower legs. His feet felt better after one treatment, but after 10 more 40-minute exposures followed by 10 minutes of deep massage, he says his tingling is gone, the numbness has decreased, improving his balance, but the pain has not been affected. He will continue for another few weeks and then report how things are going.

We reported in the last issue that **Dave Lively** was taking methadone for PN pain. **Michael Cooper**, who has had pain going from his fingers to his shoulder, sometimes feeling like “lightening bolts,” e-mailed Dave and then talked to his doctor. He was put on 2.5 mg twice a day and by two weeks the edge was off the small to medium pains. He felt no side effects—feeling “stupid” at work, for instance—as other pain medicines made him feel. His doctor then suggested adding Lyrica to his daily medication and he hasn't had a “lightening bolt” since.

Guy Sherwood was left with severe PN after his Velcade trial and he, too, has switched from other painkillers to methadone. He warns that it can cause irregular heart rhythm in “certain predisposed individuals” so suggests we insist on at least an EKG before “joining the rest of the ex-junkies on the methadone love boat.” He is taking Lyrica, also, and adds that his neuropathy was slowly resolving anyway, so his experiences may not accurately reflect the chronic pain of IgM neuropathy.

Steve Pine writes that he understands that peripheral nerves include nerves in the face. **Tom Hoffmann** writes back that that is true, but the longer nerves have more surface for the IgM to work on and they—including feet and hands—become symptomatic first. If a shorter nerve has another problem already that has weakened it (herpes, etc.) it may show PN before the feet.

We've known Dr. Steve Treon has been conducting a trial using Campath, a monoclonal antibody that acts like Rituxan. **Mike Pennington** finished his trial late in 2005. He is 33 years old and was diagnosed when he went to his ophthalmologist because of extreme eye discomfort. The doctor found “sausaging” in his retinas and eventually Mike got to an oncologist who diagnosed WM. His IgM was very high, in the 7000-8000 range, and his doctor referred him to Dr. Treon. Treon thought he would be an ideal candidate for the Campath trial because of his age (as this therapy would preserve a future option of having a stem cell transplant).

After three days of “ramp up” doses in Boston, he went home to Cincinnati and his own oncologist oversaw the 12 weeks of three-day-a-week infusions. He works for a food processing firm and they were very liberal in allowing him time off for the lengthy infusions. He tolerated the protocol very well, was able to work, play tennis three days a week, and go hiking, and now is very happy he went with this treatment.

Asked how he feels about having this oldsters' disease at such a young age, Mike said he had always been so healthy that he felt invincible. He was also impatient with himself, with his tennis game, and thought, “Life wasn't fair that I wasn't as good a player as I wanted to be. Well, I've been knocked down a notch. Going through what I have, now I feel lucky to be playing at all. Enjoy it all while I can!”

More research on the so-called cancer stem cells has revealed “an inherent feature of stem and progenitor cells that promote initiation and progression of cancerous tumors” according to a press release sent along by **Bert Visheau**. The research was done at Columbia University Medical Center. Stem cells are susceptible to a specific error during division

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 eddyanders@earthlink.net and provide your full name
3. Go to the following web link: home.ease.Lsoft.com/archives/iwmf-talk.html

INTERNATIONAL CONFERENCE ON MALIGNANT LYMPHOMA

by Tom Myers, Vice President for Research

The 9th International Conference on Malignant Lymphoma, held in Switzerland in June of 2005, had sessions on Waldenstrom's macroglobulinemia. The IWMF was asked to support the conference in order to enable key researchers in the disease to attend.

A highlight of the conference was an evening symposium entitled "Advances in the Biology and Therapy of Waldenstrom's Macroglobulinemia." This symposium was dedicated to the memory of Ben Rude, the former President of the IWMF, and was chaired by Dr. Steven Treon of the Dana Farber Cancer Institute. Leading researchers in WM presented their research, and many doctors learned about the results of the Third International Workshop on Waldenström's Macroglobulinemia (held in Paris in 2004).

Several members of the WM team at Dana Farber made oral presentations of their research work. Of particular interest to IWMF members were the results of the study in which attendees at the Tampa Ed Forum participated. Ninety-seven patients with WM contributed blood and familial information for a study of the incidence of thyroid abnormalities. It was learned that 14% of the patients tested had thyroid antibodies. Further studies are underway to determine the implications of these findings.

Other presentations described genetic studies aimed at predicting the severity of the disease and the response to rituximab. Finally, some of the clinical trial work with bortezomib (Velcade) was described. There was an 85% response rate during these trials and a 53% reduction in bone marrow infiltration.

that can result in severe chromosomal defects. Usually during cell division, cells control quality with a series of checkpoints. One checkpoint confirms that the cell's chromosomes have been disentangled before they are pulled apart in mitosis, but stem cells deficient in this checkpoint will divide without disentangling. Surviving cells end up with too many chromosomes, they may lose chromosomes, or they get rearranged. These types of chromosomal defects are the hallmark of cancer cells. (See the Spring 2005 *Torch*, page 6, for more).

Dave Schlosberg says he has been taking Chlorambucil and going in for weekly blood work. His IgM, IgA, and IgG have been measured along with everything else. Having so many lab results led him to look for patterns, and he has seen a strong correlation (.9 out of 1.0) between IgM movement and IgA. For IgM and IgG it is .664, not highly coordinated. Tom Hoffmann explained that IgA and IgG are breakdown products of IgM. Without IgM there would be no IgA and IgG. Our WM IgM does not break down properly, so our levels of the other two are normally low. All three are products of our B lymphocytes. Most of our chemos target B lymphocytes, so all the Ig's go down with treatment.

IWMF President **Judith May** reports that a message from the American Society of Hematology informs us that it has included a link to IWMF on its website in the past and a review of links resulted in us being included again. The message also congratulated us on "the high quality of patient information available on our site." Judith said we have added this link to the Resource tab of our website.

Jerry Fleming reminds us again that people who served in the US military in Vietnam are qualified for disability compensation from the Veterans Administration. You don't have to prove a cause and effect relationship between Agent Orange and WM or that you were exposed to it. Be ready to prove you were stationed in Vietnam before you apply, however. Jerry says, "Do not delay in applying, even if you are now in remission. You should receive disability compensation and the amount is significant. The effective date is the date you submit your application so delaying it will cost you." Jerry's phone number is 972-867-5102 if you want more information.

ELECTION OF IWMF TRUSTEES

By James Bunton

In the last *Torch* we indicated that the three year term of Jim Berg was expiring, leaving a vacancy on the board, and we asked anyone interested in becoming a trustee to submit a resumé. No applications were received.

Fortunately, Jim Berg has indicated his enthusiasm to remain on the board for another term. As he is a major author and editor for board publications, we are delighted. Since a single name fills the vacancy, and Jim Berg is endorsed and unanimously recommended by the board, and as no other candidates applied, he is acclaimed as an elected trustee for another three year term.

SUPPORT GROUP NEWS

MICHIGAN

COLORADO

The Rocky Mountain Support Group gathered in February to hear a great presentation from a representative of “Navitas,” a care facility that provides rehabilitation services in the area. The topic was “how to reduce fatigue, pain and depression.” Participants also discussed symptoms management and how to improve quality of life. In addition, the two coordinators (**Roy Parker** and **Bill Bass**) and others who have attended previous IWMF Forums discussed the format of these national gatherings and what attendees can look forward to this May. Several new members hope to go.

The group has 25 active members, and meetings usually attract 12-15 patients along with spouses and/or adult children. The next meeting is planned for June.

FLORIDA

Southwest Florida

Herb Kallman reports that the SW Florida Support Group met in Sarasota in January to hear from Dr. Steven Treon and two of his researchers, Chris Patterson and Jacob Soumerai. About 100 people attended—the largest support group meeting ever in this area.

Tampa

As of press time, the Tampa Area Support Group was planning a March meeting at Pa Pa Joe’s Restaurant in Brooksville. Mr. Charles Donley, a physical therapist, was invited to make a presentation on neuropathy.

Group correspondent **Eunice Johnson** says that a special thanks is due to Herb Kallman of the Sarasota group for inviting Tampa members to the January presentation by Dr. Steven Treon. “We also want to say an extra special thank you to Pa Pa Joe’s Restaurant for hosting so graciously our last three support group meetings!” The next meeting of the Tampa Area Support Group (covering west and central Florida) is scheduled for a Saturday afternoon in late October—specifics to be announced by email at a later date.

GEORGIA

For its first meeting of the year, the Georgia support group invited Dr. Leonard Heffner from Emory University Hospital, according to group leader **Mal Roseman**. “Dr. Heffner provided us a line by line explanation of the blood test that Waldenstrom patients frequently receive, utilizing the IWMF blood test form found on the website.”

The Michigan support group plans a meeting on April 22nd at Beaumont Hospital in Royal Oak. “We will be listening to a speaker from Infectious Disease speak on how to prevent infections,” reports **Heather Grzemkowski**. “Also, we will be having a potluck and catching up on how everyone is doing.”

NEW ENGLAND

As of press time the Boston/New England area support group was scheduled to have an early March meeting to hear about research on familial connections among WM patients. The group meets every other month except in summer, and has a speaker at every other meeting. For the past five years they have sponsored a golf tournament to raise money for research into familial incidence in Waldenstrom’s. The next tournament will be August 28. If you are interested in playing or helping to organize it, contact Lynne Mara at 781-749-0204 or jmara@nordic-group.com

NEW YORK

Western & Central New York

As the *Torch* is readied for printing, this group was scheduled to meet March 25 at Gilda’s Club. “We are particularly pleased and excited to have two outstanding Treatment Center staff members from The James P. Wilmot Cancer Center address our group,” writes **Gail Burgie**. The meeting was to include a roundtable discussion among members about health status, treatments, nutrition and insurance, etc., concluding with a social hour and refreshments. The next meeting is planned for mid-summer.

Eastern New York/Western New England

Mel Horowitz reports that a large group gathered at Albany Medical College in January for an excellent presentation about changes in bone marrow and cell structure by Dr. Vernon Pilon, Chairman of the Department of Pathology at Albany Memorial Hospital. As of press time the group was anticipating its annual luncheon outing in March. Additional meetings this year are scheduled for May 13, June 15 (annual picnic), Sept. 16 and Nov. 4.

PENNSYLVANIA

Central PA and Northern MD

The speaker at the November meeting was Carol Clelland, a dietitian and nutritionist, who gave tips on healthy eating for WM patients. Group leader **Nancy Lambert** says she has printed information from Carol for those who were unable to attend.

The February meeting was hampered by a winter storm that swept the eastern coast “but provided most of us with lots of exercising in the way of snow removal.” The next meeting will be held May 7 at Messiah Village.

Philadelphia

The Philadelphia support group meeting in February was cancelled due to the blizzard that hit the Northeast that weekend! However, as of press time, members were anticipating an April 9th meeting with guest Dr. Steven Treon. He was invited to speak about the latest research that he and his team have been doing at Dana Farber.

TEXAS

The North Texas Waldenstrom’s Macroglobulinemia Support Group celebrated its second anniversary at the January 21 meeting, according to group leader **Jerry Fleming**. David Faris and Fred Berliner provided a birthday cake, and former IWMF trustee Ron Payne spoke on “While We Wait for a Cure.” Members took home copies of the new support group brochure to take to their cancer centers and oncologists for ultimate distribution to new patients. The speaker at the May meeting will be **Wendy Harpham, MD**. Dr. Harpham is a non-Hodgkin lymphoma survivor, a nationally acclaimed speaker and has published five books on the importance of hope in surviving cancer. For more information about the group, see mysite.verizon.net/res04akn/ntwmsg/.

WASHINGTON D.C./No. VA

Dr. Edward Gorak of Walter Reed Medical Center was a guest speaker at the January meeting of the DC area group, according to coordinator **Catherine Naylor**. He spoke and answered questions about his clinical experience with WM and related blood cancers. On May 21 Dr. Mary McMaster of NIH is scheduled to speak about her familial WM study, in which a number of IWMF members participated.

CANADA

Montreal

Sandra Proctor writes that a group in Montreal recently held its first meeting with 13 people—8 patients and five “others.” Of the 8, 5 were French, so most of the meeting was conducted in French. “One person spoke only in English but everyone was patient and it worked.” Another meeting is planned for early July.

“Il me fait plaisir de vous annoncer que la première rencontre du groupe de support de Montréal a eu lieu tel que prévu au debut février. Nous prévoyons tenir la prochaine rencontre dans quatre mois et il nous fera plaisir d’accueillir tout nouveau membres.”

2006 UNITED KINGDOM ANNUAL MEETING

This year's annual UK support group educational meeting is scheduled for June 10, 2006 and will be held at the Royal Air Force Club, 128 Piccadilly, London, Telephone +44 020 87399 1000. Professor Rohatiner will be the main speaker, and an IWMF trustee will also make a presentation. For details, contact Cherly Luckie or Nigel Pardoe at Cheryl.luckie@septemberservices.com or +44 020 8579 8120.

Aside from the usual reports on support group meetings, we recently received two testimonials to the value of support groups. Betty McPhee of Toronto writes:

I was diagnosed about 3-1/2 years ago. My doctor gave me a diagnosis and a prescription for chlorambucil in practically the same breath. If it hadn't been for the support group and the information that I received, I would have gone on taking it. I was actually quite healthy (as a WM patient with low numbers) and continued on with out any real symptoms for at least 3 years. Last year, I developed a pleural effusion and again, if it wasn't for my support group and the individual feedback I received from members, I wouldn't have been in a position to go ahead with treatment. It was very important for me to be well informed and confident that I was doing the right thing. From my (limited) perspective, I felt that there was a level of communication, understanding and just simply, the right kind of support that I have needed.

I have felt very fortunate that I have access to a support group which is only an hour away. I know that most Canadians don't have this so easily available to them, and for this reason, I would strongly encourage any of you WMers out there to organize a group near you. Even if you can find 3 or 4 people, it's worth it.

Finally, I would like to say a personal thank you to **Arlene Hinchcliffe** for all the work she puts into getting our meetings together. We appreciate it.

Finally, we received this from Rod Anderson, another member of the Toronto group:

Our Toronto WM Support Group meets one evening every second month and I must say I have found the meetings extremely useful. This is such a rare disease that it is very valuable to be able to have other patients and caregivers to share experiences with... It can also be useful to be able to compare side effects, alternative treatment options, etc. with the group. It makes all the difference between being alone with one's problems and having a group to receive advice and support from. I urge any WMers who do not presently belong to a Support Group to find the one nearest to you and join it.

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President, cont from page 2

One of our most important endeavors is fundraising. Waldenstrom's research is limited only by the amount of funds we can raise each year to support the search for better treatments and advancement toward a cure. Trustee Dave Lively is heading the 2006 IWFM fund raising campaign, as Tony Brown has recently resigned to take on a major renovation project for his church in California. During 2003-2005 Tony worked part time overseeing the renovation of smaller buildings, and is now focused on the sanctuary and landscaping which needs his full-time attention. Tony developed a very successful fundraising campaign last year and we are extremely appreciative of his hard work, and especially the great result. New research projects that need our funds in the coming years will be announced in the very near future.

We continue to seek people who can volunteer to help distribute IWFM leaflets to the hospitals and clinics in their areas. This is an effort to reach WM patients who may be attending support groups offered by their clinics and hospitals for all cancer patients, and who may not know about our organization. We would like to make access to the IWFM easier for them. Every year there are approximately 1500-2000 newly diagnosed WM patients in the U.S.; the Sarasota office may hear from perhaps 10% of them, often because they do not have access to computers or our literature. Our new outreach effort is under the direction of Trustee Elinor Howenstine. If you are willing and able to do this short-term, one-time activity in your town or city, please contact Elinor at: 415-927-1536 for specifics. Or email her at laraellie@aol.com

Stay well, Judith

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	805-492-4917 972-529-2002
CLINICAL TRIALS	Tom Hoffmann Guy Sherwood	501-868-8305 765-282-4377
CRYOGLOBULINEMIA	Fay Langer	973-731-1654
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
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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
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Since December, 2005 the following contributions to the International Waldenstrom's Macroglobulinemia Foundation were made in memory of:

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In memory of John G. Boniface:
Frank O. Barrett
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In memory of Wilbur Brown:
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Olga & Christ Theodore

Since December, 2005 the following contributions to the International Waldenstrom's Macroglobulinemia Foundation were made in honor of:

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Nickie & Richard Imprescia

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In honor of Frankie King:
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*In honor of the MN/Western Wisconsin
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The IWMF Washington D.C. Area
Support Group

In honor of Elaine Van Bloom:
Mark Mc Carthy
Donald & Carol Pickles

In honor of Bob Zehmer:
Jeanette & James Traylor



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DR. ROBERT A. KYLE RECEIVES LIFETIME ACHIEVEMENT AWARD

Dr. Robert A. Kyle, an IWMF trustee and Chairman of the Scientific Advisory Committee, was recently named as the recipient of a Lifetime Achievement Award by the Celgene Corporation.

In granting the award, Celgene noted that Dr. Kyle is a tireless educator and physician-researcher. In his 40 years as a Mayo Clinic consultant in Internal Medicine and Hematology, he has trained and mentored more than 200 hematologists including Dr. Morie Gertz (a member of the IWMF Scientific Advisory Council) and Dr. Rafael Fonseca (recipient of an IWMF grant to study WM genomics).

“Dr. Kyle allows people to shine,” said Dr. Vincent Rajkumar, one of Dr. Kyle’s protégés and a leading myeloma investigator. “This is rare in medicine: in most places, the senior investigator is the only one who gets credit. It is very rare to see many people individually known in the same field as the senior member of the team.”

Dr. Kyle was named Professor of Medicine at the Mayo Clinic in 1975. In 2001, he was the first recipient of the Waldenstrom’s Award at the first International Workshop on Macroglobulinemia. Among his nearly 100 other honors in medicine, he has received the Mayo Clinic’s Henry S. Plummer Distinguished Internist Award and Distinguished Mayo Clinician Award.

Dr. Kyle has been coeditor of four editions of *Neoplastic Diseases of the Blood* and three editions of *Myeloma, Biology and Management*. He has published nearly 2,000 papers and abstracts in medical literature about his research.

In addition to his service on the IWMF Board, Dr. Kyle is a member of the Board of Directors and chairman of the Scientific Advisory Board for the International Myeloma Foundation.

PARA NUESTROS MIEMBROS E AMIGOS DE HABLA HISPANA

El folleto "Macroglobulinemia de Waldenstrom: Repaso de su terapia" por el Dr. Morie Gertz está disponible en español ahora. Favor contactar a la oficina de la IWMF si quisiera recibir una copia del mismo.