

## CLINICAL TRIALS SEEKING WALDENSTROM'S PATIENTS

The IWMF board would like to bring to your attention the opportunities presented by the National Cancer Institute's (NCI) latest list of clinical trials for Waldenstrom's (WM) patients. Of the 34 trials for which WM patients may qualify, 13 are seeking WM patients to include in their patient group. Four trials exclusively for WM patients are looking for 171 applicants.

Clinical Trials are the last step in the arduous process of research and development of new, more effective and safe drugs for difficult diseases such as WM. This process starts in the laboratory, proceeds to testing in tubes with cancer cells, to testing with mice, then to early tests on humans for safety, to final testing through clinical trials.

Most trials use a standardized protocol on carefully selected patients, so that results can be accurately interpreted without complications of other diseases or unusual situations. Patients must apply for a trial and only those who meet the entry criteria are admitted. Some trials use double-blind protocols where patients receive one of two treatments, and the researchers don't know which so as to not bias their interpretation.

Most trials listed below use currently approved drugs, and often conventional therapies, in new combinations or sequence, looking for the famed chemical cocktail of maximum effect and minimum side effect. All trials are exploring how to find the best possible treatment for a specific condition, such as first-time treatment, or treatment for those who have been treated but whose treatment did not work or now need re-treatment because the disease has returned.

It is extremely important to explore all possible treatment options in advance, since some treatments can have long-term negative side effects (such as permanent suppression of the immune system), and some will be more effective and safe for each particular condition. The question of whether a clinical trial is available for your treatment, and whether it might be more

effective and safe should be discussed in detail with your hematologist/oncologist and with the providers of the clinical trial.

There are potential benefits and some disadvantages to joining a clinical trial. Benefits include receiving new drugs and combination protocols, expert medical care from leading research physicians very closely monitoring your health and the results of treatment, and the knowledge that you are contributing to medical research in our rare disease. Disadvantages include unknown side effects or adverse reactions and the possibility that the new approach may not be effective for your unique situation.

Questions to ask your doctor and the trial providers include what drugs you will receive and their purpose, what are the benefits and risks, what are potential side effects, how long the study will last and the time and tests involved, your personal responsibilities, other treatment options, and the costs involved and whether insurance will cover the treatment.

In the past, patients had to travel to distant medical centers to participate in clinical trials. But now, through affiliations with the major cooperative groups supported by the NCI, patients may usually access the latest clinical trials in their home communities, with the cooperation of their own doctor and hospital. The list of cancer trials follows, with contact information for the research study's participating organization, which can refer you to locations close to your home town for nearly every trial.

The trials for WM patients only:

1. Phase II Study of rituximab in patients with WM. NCI sponsored. Seeking 12 - 25 patients. This is a multicenter study. Patients receive rituximab IV weekly for 4 weeks, repeated 2 months later. Patients are followed every 6 months for 2 years. Contact: Christos E. Emmanouilides, Jonsson Comprehensive Cancer Center, UCLA, Telephone: 310/206-0716. [Protocol: UCLA-9909016, NCI-G00-1709]

2. Phase II Study of antineoplastons A-10 and AS2-1 in patients with recurrent or refractory WM. (Antineoplastons are naturally occurring substances found in urine, and may inhibit the growth of cancer cells.) Seeking 20 - 40 patients. Patients will receive injections of antineoplastons 6 times a day. Treatment may be repeated for as long as benefit is shown. Patients will be evaluated every 2 months for 1 year, and then every 3 months for 1 year. Contact: Stanislaw R. Burzynski, Burzynski Research Institute, Houston, TX. Telephone: 713/335-5697. [Protocol: BRI-MW-2] (Privately funded)

3. Phase II Pilot Study of rituximab in patients with WM. Monoclonal antibodies such as rituximab can locate cancer cells and deliver tumor-killing substances to them without harming normal cells. Seeking 66 patients. Patients will receive an infusion of rituximab once a week for 4 weeks. Patients will receive follow-up evaluations every 3 months for 2 years, every 6

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## **CLINICAL TRIALS ...**

months for 3 years, and once a year thereafter. Contact: Morie Abraham Gertz, Eastern Cooperative Oncology Group (Morie Gertz is on the IWMF Scientific Advisory Committee). Telephone: 507/284-4102. [Protocol: E-3A98] (NCI-sponsored.)

4. Phase II Study of rituximab and fludarabine in patients with WM. [This is an approved study - not yet active] Seeking 40 patients. Patients will receive rituximab IV over 3-6 hours once weekly on weeks 1-4, 17, 18, 30, and 31, and fludarabine IV over 10-30 minutes once daily for 5 days on weeks 5, 9, 13, 19, 23, and 27. Patients are followed at least every 2 months for 2 years. Contact: Christos E. Emmanouilides, Jonsson Comprehensive Cancer Center, UCLA. Telephone 310/206-0716. Protocol: UCLA-010106301, NCI-G01-1960. (NCI-sponsored).

Remaining trials looking for WM patients:

5. Phase II Study of dolastatin 10 in patients with indolent lymphoma, WM, or chronic lymphocytic leukemia. Seeking 74 patients.. This trial will study the effectiveness of dolastatin 10 as a treatment for the above conditions.

This is a multicenter study. Patients are stratified by disease — chronic lymphocytic leukemia vs. indolent lymphoma vs. WM. Contact: Steven M. Grunberg, Vermont Cancer Center. Telephone 802/847-4446. Protocol: VCC-9802, NCI-T98-0007. (NCI-sponsored).

6. Phase II/III Study of standard and novel conditioning therapy and allogeneic blood or marrow transplantation in patients with severe aplastic anemia or hematologic malignancy. Seeking 405 patients over five years. Contact: Philip McCarthy, Roswell Park Cancer Institute, Buffalo, NY. Telephone: 716/845-8707. Protocol: RPCI-RP-9815, NCI-V99-1527. (Privately funded)

7. Phase I Study of UCN-01 and fludarabine in patients with recurrent or refractory low grade or indolent lymphoid malignancies. Seeking 20 patients. Contact: Wyndham Hopkins Wilson, Center for Cancer Research. Telephone: 301/435-2415. (NCI-sponsored) Protocol: NCI-99-C-0127, NCI-T99-0022.

8. Phase I/II Study of pentostatin with cyclophosphamide for previously treated patients with intermediate and high risk chronic lymphocytic leukemia and other low grade B-cell malignancies. Seeking 3 - 30 patients for Phase I, and 14 - 30 patients for Phase II. Contact: Mark Adam Weiss, Memorial Sloan-Kettering Cancer Center, NY. Telephone: 212/639-5827. (NCI-

sponsored). Protocol: MSKCC-98083, NCI-G98-1482.

9. Phase II Study of myeloablative therapy with autologous hematopoietic stem cell transplantation in patients with multiple myeloma or other B-cell malignancies. Seeking 10 patients minimum. Contact: David H. Vesole, Medical College of Wisconsin. Telephone: 414/805-4646. (Privately funded). Protocol: MCW-96110, NCI-V97-1368, MCW-HRRC-29196.

10. Phase II Study of oxaliplatin in patients with relapsed or refractory non-Hodgkin's lymphoma. Seeking 72 patients. [New drug]. Contact: Anas Younes, University of Texas, M.D. Anderson Cancer Center. Telephone: 713/792-2860. (NCI-sponsored). Protocol: MDA-ID-99406, NCI-1652.

11. Phase II Study of rituximab and vinorelbine in patients with relapsed B-cell non-Hodgkin's lymphoma following autologous peripheral blood stem cell transplantation. Seeking 18-25 patients. Contact: Christos E. Emmanouilides, Jonsson Comprehensive Cancer Center, UCLA. Telephone: 310/206-0716. (NCI-sponsored). Protocol: UCLA-990302901, NCI-G99-1545.

12. Phase II Study of PS-341 in patients with low grade lymphoproliferative disorders. Seeking 36-70 patients. Contact: Owen A. O'Connor, Memorial Sloan-Kettering Cancer Center, NY. Telephone: 212/639-8889. (NCI-sponsored). Protocol: MSKCC-01049, NCI-2795.

13. Phase III Randomized Study of involved-field radiotherapy with or without low-dose total body irradiation in patients with previously untreated, stage I or II low-grade non-Hodgkin's lymphoma. Seeking 344 patients over six years. This is a European study which will be available to patients in Belgium, Egypt, France, Germany, Netherlands, South Africa and Turkey. Contacts: J.H. Meerwaldt, EORTC Lymphoma Group. Telephone: 31-53-4872751. And, Volker Gustav Budach, EORTC Radiotherapy Group, Telephone: 49-30-450527021.

This is a non-U.S. clinical trial which our international members may be interested in exploring. Protocol: EORTC-20971.

In addition, there are 21 more trials that do not specifically mention WM, but we are eligible to enroll if we meet their entry criteria as they are looking for low-grade B-cell lymphoma patients which covers a number of different diseases. The website for this list is on the NCI site, and the address is: <http://cancernet.nci.nih.gov>.

Warmest regards,  
Judith May, V.President, IWMF

## IWMF TO SPONSOR THE SECOND INTERNATIONAL WM WORKSHOP

Here's some exciting news! The Second International Workshop on Waldenstrom's Macroglobulinemia, a meeting of the world's experts on WM, will convene in Athens next September. IWMF is thrilled to be one of the sponsors of this important conference. We have promised to fund approximately one third of the expected cost.

The inspiration for this workshop was born in a 1998 meeting attended by IWMF's president, Ben Rude, our former president, Arnie Smokler, and the IWMF Scientific Advisory Committee. A decision was made to assemble a "think tank" of the world's WM experts. Judith May, IWMF's vice president, convinced both the NIH Office of Rare Diseases and the NCI of the importance of such a meeting.

The following December, an exploratory meeting was attended by a dozen WM experts and IWMF trustees. The workshop was approved. In September 2000, nineteen doctors met on the NCI Campus at Bethesda, Maryland. This workshop was the first ever convocation of WM experts to share ideas and research.

The response was so positive that IWMF promised support for a follow up meeting. Dr. Robert Kyle of Mayo Clinic, Dr. Steven Treon of Dana Farber Cancer Institute, and Dr. Bruce Cheson of the National Cancer Institute agreed to jointly chair the meeting, and Dr. Meletios Dimopoulos of the University of Athens offered to host it in Athens in September 2002.

Among the goals of the Athens meeting:

- *Establish diagnostic criteria:* Currently, there are no well defined, agreed upon criteria for diagnosis.
- *Recommend when to treat:* The initial treatment for WM is often just to watch and wait. There is little agreement as to when to intervene: whether to wait for specific symptoms or for hemoglobin or IgM numbers to reach certain levels.
- *Evaluate treatment protocols:* There is no standard treatment for WM, and there have been no head-to-head comparisons made of the many options available. From this meeting will come information to help clinicians and their patients select appropriate treatment.
- *Establish response criteria:* There are no agreed upon definitions of response to treatment, whether it is defined as a reduction in IgM, tumor burden, or in the level of anemia. This makes it difficult for researchers to compare one study with another.
- *Review ongoing research and suggest directions for future research:* We are proud that all four recipients of IWMF research grants have been invited to contribute, as have nine of the twelve members of our scientific advisory committee.

The Second International Workshop represents a solidifying of the world's researchers behind a common goal that of improving the treatment and seeking a cure for Waldenstrom's macroglobulinemia.

We cannot imagine a goal more worthy of our support.

## WE GET LETTERS

The World Trade Center tragedy brought forth an outpouring of messages of sorrow and condolence on the IWMF Talklist. Here are just a few:

After today, how can I feel bad about my condition? I was 6 years old when the attack on Pearl Harbor happened. Now I can get some sense how my parents felt at the time. My own troubles are not very important right now. God Bless the United States.

*Steven French, Rochester NY*

The terror attacks on your country, your city, your home?? has filled our lives here in Holland with great sorrow. The many victims among my fireman-colleagues are hurting me personally.

*Leo and Magda de Bruin,  
The Netherlands*

This is a heartfelt message of sympathy to all the members of the IWMF who may in some way be touched by the terrible attacks on your beloved country. God Bless you All.

*Betty Reed, United Kingdom*

It was with great shock and dismay that I watched the horror happening in New York and Washington yesterday. My thoughts and prayers are with all of you who may have loved ones who were killed or injured.

*Helen Kelm, Canada*

Taylor Grace (named after her grandmother who passed away in July from WM) turned 9 years old this year. In lieu of a birthday celebration, she and her parents asked friends and family to send money to be donated in memory of Lois Grace Slaski. Taylor received \$60 in birthday money, donated ALL of it to "Grandma's Cancer Fund" with IWMF and sent us the following letter:

August 26, 2001

Dear Mr. Rude,

Hi. My name is Taylor Grace Hawn. I am 9 years old. My grandma, Lois Grace Slaski, died on June 30, 2001. My birthday is on July 9, 9 days after my grandma died. For my birthday I received \$60. I decided to donate the money to my grandma's cancer fund. I know that it will make Grandma happy. I will continue to collect money for I. W. M. F!

Love,  
Taylor Hawn

*Further, a generous memoriam gift from the Mario Morino Fidelity Charitable Gift Fund is forthcoming.*

## FROM THE IWMF TalkList

By Jeanne Pond

*Find a doctor. Ask a doctor. Request information from other members. Learn how to read your medical tests. Share your own experience with fellow patients.*

*The IWMF TalkList provides all these opportunities. Here are some recent TalkList exchanges.*

### CLARIFYING TERMS

The term *sedimentation rate* caused a flurry of postings. **Julio Freire Andrade** emailed from Spain that the sedimentation rate is the rate at which erythrocytes settle out of anticoagulated blood in one hour. A high rate is found in all collagen diseases, in infections, pneumonia, syphilis, in inflammatory diseases and in Waldenstrom's. Julio had a high rate for years that his doctors couldn't explain, but after his other blood figures became abnormal, WM was recognized.

\* \* \*

The *SPEP test* is frequently mentioned on the TalkList. It stands for serum protein electrophoresis. The Merck Manual calls it "the most useful diagnostic test, along with immunoelectrophoresis, to detect large quantities of macroglobulins in the blood." Many oncologists prefer it to the regular IgM test.

\* \* \*

Serum 2m refers to beta 2 microglobulin present in the blood. It is a biological marker present on the surface of cells. When blood cancers become more aggressive, more beta 2 microglobulin shows up in the blood. A normal or low beta 2 microglobulin level at diagnosis indicates a good prognosis. **Bert Visheau** sent along this explanation.

### ASK THE DOCTOR

Some questions raised on the TalkList are referred to one of the doctors on IWMF's Scientific

Advisory Committee. Here are some recent questions and answers.

*Question:* My cholesterol is lower these days than it used to be and I wonder if WM has anything to do with it?

*Doctor:* That is a very good observation. I have noticed this connection for years, do not believe it to be coincidental, but have no explanation for it.

[Note: **Drs. Tom Hoffman** and **Guy Sherwood**, both WM patients themselves, believe that WM nutritionally depletes our bodies so that they cannot make enough cholesterol. Also, high amounts of IgM in the blood may render traditional methods of assaying lipid levels (cholesterol and triglycerides) not entirely accurate.]

\* \* \*

*Question:* My IgM is 8500 and I have a marked decrease in sexual activity. Do you think there's a connection with WM?

*Doctor:* Erectile dysfunction is likely from anemia and fatigue or viscosity affecting penile blood.

\* \* \*

*Question:* Is it possible to develop leukemia as a result of taking the chemotherapy chlorambucil (Leukeran)?

*Doctor:* The possibility is very slight and results, usually, from years of use. It is wise to stop using it when it is no longer needed.

\* \* \*

*Question:* I've had lymph fluid in my pleural cavity for years. It has an IgM level of 5000 while my blood measurement is only 3200. Does IgM show up in all body fluids?

*Doctor:* Not necessarily, but malignant pleural effusions have been described, particularly if there is lymphomatous involvement in the lung.

### FIND A DOCTOR

Graham Taylor wrote hoping for the name of a WM specialist in South Africa. Our IWMF doctor

panel responded with the name of a specialist in Cape Town. Graham was delighted to make an appointment—even though the doctor's office is eight hundred kilometers from his home.

### LIVING WITH WALDENSTROM'S

The TalkList gives WM patients around the world a change to share their stories with other patients.

### A RECOVERY FROM SEVERE PERIPHERAL NEUROPATHY

**Jim Kerch** began experiencing peripheral neuropathy in 1989 at the age of sixty-three. His palms and the soles of his feet became super sensitive to pain and later became numb. Muscles in his feet and legs became so weak that the joints loosened, letting bones in his feet and ankles slip out of place.

Diagnosed with WM, Jim was treated with oral Cytoxan and prednisone over a period of months. Three years of remission followed. When he had a slight increase in the neuropathy, the treatment was repeated. Today Jim has been without treatment for three years. In remission the damaged nerves began to grow back!

Jim wrote, "You can recover from severe neuropathy caused by WM if the nerves involved have not been completely destroyed. They will regrow. You must eliminate the high IgM count, have patience, an optimistic point of view, and follow your doctor's orders. During treatment I used a wheelchair on and off for over a year, then a walker for about three years. Today my WM is in complete remission and I get around quite well, wearing braces on my feet and ankles and often using my cane. I'm 75 and I can drive, operate a farm tractor, type, and do a lot of other things, but I still can't play the piano. (I never could!)."

### A NEW MEMBER FROM FINLAND

A posting from **Elias Jarvineva** evoked visions of quiet lakes nestled amid forests crisscrossed by ski trails. It also reminded us that Finland has socialized medicine. Elias said he was a healthy seventy-five-year-old in 1996, walking one to two hours a day and skiing in the in winter, when a new health station was established in his district with designated doctors. His wife thought they should see their new doctor.

Blood work revealed that his IgM was 4300, and Elias was started on chlorambucil and allopurinol. A short time later a suspicious looking cyst was found in his left kidney. A needle biopsy indicated that in addition to WM, he had an adenocarcinoma in the kidney. After kidney surgery he continued the chemotherapy. It was stopped in June 1997 but started again a year later when his IgM count rose.

Elias is still on the regimen, with an IgM of 1650. He has very few symptoms. He still walks one to two hours daily and swims with his wife on summer mornings in the lake. No more skiing, however, as “my balance is not sure enough on the slopes. I feel extremely lucky: diagnosis of WM by accident and of carcinoma in the kidney at an early phase. Hospital checks regularly three to four times a year. Good doctors and excellent hospitals. My life has evidently been blessed with some additional years.”

### BEATING THE ODDS

One posting on the IWMF TalkList may inspire many more.

**Dave Lively** mentioned that he was diagnosed in 1989 “with a poor prognosis, but I’m still here.” This prompted **Emil Parente** to write that when he started down the WM road (in 1980 when he was fifty) he learned that the median survival rate was

fifty months. “Well, I’m still here and still kickin’ and have lived a very full life thanks to 2CdA and plasmaphoresis.” **Peter Sussman**, twelve years from diagnosis, calls himself

“The Energizer Bunny.” **Larry Q.** says he was fifty when diagnosed and his IgM was 5000+. He’ll be fifty-eight this year and his IgM is 2000 with serum viscosity in the normal range. He wonders what the longest survival record is for WM because it is the goal he’ll shoot for.

**Jack Middendorf** thought his diagnosis meant he had only four to seven years left, so he quit his job and took stock of his life. A woodworker by avocation, he began building his coffin out of some “rather nice red oak. It turned out just great and was ready for that fancy lining they install.” Then Jack realized that new treatments had changed the picture. The coffin is now a unique liquor cabinet. Jack plans to live a good long time—and empty the cabinet many more times.

### LEG CRAMPS

Many patients have complained on the IWMF TalkList of severe leg cramps, especially at night, and several have told us how they cope. Here are some of the suggestions:

Especially in hot weather, we can lose a lot of potassium when exercising. Low potassium levels may cause cramping. A fast, cheap fix is to eat a banana, drink orange juice, or take an over-the-counter potassium pill.

- Drink quinine water.
- Grip the space between your nostrils very firmly. It looks weird but it works.
- If you take a calcium supplement, be sure you take magnesium in half the amount.
- Leg cramps very definitely go away with chemotherapy.

## HOW TO JOIN THE TalkList

**Subscribing:** Send an e-mail to: [join-iwmf@iwmf.talklist.com](mailto:join-iwmf@iwmf.talklist.com)  
Include your full name in the subject line and leave the message field blank.

**Unsubscribing:** Upon joining the TalkList, you will receive a welcome message with instructions to unsubscribe. It is recommended that you print out this message for future reference.

**Posting Your Message:** Send a message to [iwmf@iwmf.talklist.com](mailto:iwmf@iwmf.talklist.com)

# New Treatments In Waldenstrom's Macroglobulinemia

By Raymond Alexanian, M.D.

At a breakout session held in connection with MD Anderson's annual "Living Fully with Cancer" Conference September 6-8, Dr. Raymond Alexanian, M.D., Professor of Medicine at Anderson, presented an overview of the characteristics of WM, then went on to discuss and respond to questions regarding new developments in treatment of WM.

With respect to treatment, Dr. Alexanian noted that some years ago there was little controversy over the best treatment because there were few choices. Now that the choices in treatment are greater, so is the debate over which is best, including issues relating to the best drug combinations, how long to continue a course of treatment to maximize benefits while minimizing toxicity and side effects, and the role of transplants. At Anderson, the current preferred treatment (generally two courses for previously untreated patients) is the three drug combination of 2CdA, cyclophosphamide (cytoxan), rituximab (Rituxan). This program has achieved a 90% rate of remission among previously untreated patients, and 80-85% recontrol after an average three-year unmaintained remission.

In response to a question regarding comparison of the Anderson treatment program to that of other centers, Dr. Alexanian said the largest American study involved fludarabine delivered as a single agent, achieving a 40% response rate. Another study about to be reported involves rituximab as a single agent, and that will indicate a 40% rate of remission. The Anderson approach has for some years involved a combination of drugs because he believes there is biological support for the position, that there are synergistic benefits to the combination of drugs; and the combination of drugs also achieves

## PRESIDENT'S C O R N E R

By Ben Rude

My column for this issue is being written on a plane at 30,000 feet, en route from Houston to my home in California after two days of education and entertainment at the annual M.D. Anderson "Living Fully with Cancer" conference.

I rubbed elbows with nearly a thousand, fun-loving and inspiring patients and caregivers, including perhaps two dozen IWMF members, from our Houston area support group, as well as out of state.

The foundation has been a supporter of this conference for several years, and the specific WM breakout sessions this year were provided through the fund-raising efforts of John and Barbara Manouso, leaders of the Houston group. Barbara also arranged reserved tables for us for the general sessions and mealtimes.

The conference began officially on Friday morning with three inspiring talks. Dr. Jerri Nielsen narrated her struggle with breast cancer while serving with a scientific expedition on the south pole. She not only diagnosed herself but also did her own breast biopsy and self-administered air-dropped chemo until she could be flown out. It was an amazing story, told with humor and vivacity. She was followed by CNN newsman, Bob Losure, a survivor of testicular cancer, who also served as M.C. that evening, and by Hamilton Jordan, chief of staff under Jimmy Carter, and three-time cancer survivor (lymphoma, prostate, and melanoma). All three have written books dealing with their experiences with cancer.

As inspiring and interesting as these speakers were, I had not come for them; I had come to learn. From the 18 breakout sessions, I selected four. M.D. Anderson's vice president, Dr. Martin Raber, supported by his caregiver/wife/physician, Dr. Adele Raber, discussed their ongoing struggle with Waldenstrom's. Despite immediate access to the world's best medical care, they deal with the same issues, such as fatigue, as many of us. My particular interests also took me into "Good News for Clinical Trials" and "Allogeneic Mini-transplants," details of which I am saving for a future issue.

Two presentations impressed me so much that I bought the authors' books. Karyn Buxman, RN-turned humorist, gave a simultaneously hilarious and fascinating presentation of laughter as therapy. Her book, *This Won't Hurt a Bit*, is a treasury of doctor, nurse, and hospital jokes.

The second speaker, Mark Moyad, spoke on "Nutrition, Vitamins, Minerals, Herbs, and other Supplements." Moyad is a highly entertaining speaker, but more importantly, a careful scientist who emphasizes that supplements should be subject to the same rigorous testing as drugs. His conclusion, that we should depend more on a healthy diet and exercise than on supplements, struck a responsive chord with me. Although initially put off by his book's title, *The ABC's of Nutrition and Supplements for Prostate Cancer*, after hearing the talk I bought it and discovered that one needn't be a patient or even a prospect for prostate cancer to benefit from it. It is one of the best sources on complementary medicine I have seen.

Audio tapes of individual sessions are available at \$8.00 each. For a list of tapes, contact Sound on Tape, Inc., toll free 866-222-8273.

A unique feature of the annual conference is a "Spirit Wall," where one can post any message at all. The one that impressed me most was this: "I didn't start to live until they told me I was going to die. (That was six years ago.)"

Unfortunately, my flight schedule did not permit me to stay for the conference wrap-up, the "Celebration of Life!" It is always a highlight worthy of Las Vegas. Maybe next year.

Stay well, Ben

the greatest possibility of remission at the earliest point in the greatest number of patients rather than moving through various single agent therapies

that have less likelihood of achieving early remission and consequently achieving good quality of life for sustained periods.

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## **New Treatments In...**

In response to another question regarding the “triggers” for treatment, Dr. Alexanian stated generally that treatment is indicated when individual or a combination of symptoms begin to threaten a patient’s general health and quality of life. These may include internal lymph nodes larger than 5 centimeters, hemoglobin less than 10 grams per deciliter, impending transfusion dependence, or moderately enlarged spleen. The absolute level of IgM that may indicate treatment appears less important, provided that serum viscosity is at an acceptable level. Some patients can live comfortably for protracted periods with modestly high but constant level of IgM, others have difficulties despite a relatively low level if other clinical features are threatening. With respect to the hyperviscosity

syndrome as a trigger, a level four times normal was cited as a benchmark problem level, but this complication occurs in only about 15% of patients.

With respect to future treatment alternatives, Dr. Alexanian expressed the view that the role of transplants will likely be limited to cases of very short remission or with resistance to chemotherapy because of the long remissions currently achieved with the various chemotherapy alternatives. The most promising new treatments are likely to involve the new generation of monoclonal antibodies (Bexxar and Zevalin) in which radioactive isotopes are added to “Rituxan like molecules” to kill tumor cells more effectively by honing in on the CD20 antigen expressed on the malignant cells.

## **VITAMIN C, DIET AND WM**

Should WM patients take “therapeutic” amounts of Vitamin C? Researchers at Sloan-Kettering Cancer Center say “probably not.” Vitamin C is a powerful anti-oxidant that consumes free radicals or toxic substances that can be generated from chemotherapy to destroy cancer cells. Large amounts of the vitamin could interfere with the effects of chemotherapy. Earlier it was discovered that cancer cells need large amounts of Vitamin C to keep them healthy. Why feed cancer cells?

To those wondering if any specific diet or exercise regimen is effective in controlling WM, our doctor says “no” but recommends a low meat, high vegetable and fruit diet with some tofu, plus exercise.

## **STANDING ROOM ONLY AT L. A. AREA SUPPORT GROUP MEETING**

Dr. Christos Emanouilides’ presentation at the UCLA Medical Center Saturday, September 15, 2001, attracted over 50 patients and caregivers. The following is a brief summary of his presentation. Following an explanation of WM, “Dr. E,” as he is affectionately known, listed the common symptoms: fatigue (85%), bleeding (60%), peripheral neuropathy (17%), bone pain (10%), anemia and hyper-viscosity syndrome.

Less common symptoms are the enlargement of the lymph nodes, liver, and spleen. He then covered available treatment options with their response rates and side effects. In his opinion, fludarabine and cladribine (2CdA) are the chemos of choice over alkylating agents such as chlorambucil, cytoxan, etc., in that the response rates seem to be higher. He regards Rituxan as promising and suggests that it may sensitize malignant cells to chemotherapy. The side effects of Rituxan are mainly infusion related.

He explained that the use of interferon is somewhat effective but is avoided in the U.S. because of the numerous side effects (flu symptoms) and the inconvenience of 3 weekly injections. He is also cool on thalidomide because of the low response rate of 25% and it has a lot of side effects (somnolence, sometimes irreversible neuropathy, rashes, constipation and sometimes blood clots).

Bone Marrow Transplants are extremely risky. Autologous stem cell transplant, in which the patient’s own stem cells are used, is not effective. At this time there is no way to cleanse the stem cells of all malignant cells. It is possible that one or more WM cells could be reintroduced. Allogeneic transplants for patients over 40 years carry a mortality rate over 30%. Mini-transplants, in which low-dose therapy is followed by infusion of stem cells, may hold some promise, particularly for

WM patients who have run out of options.

Dr. “E” does not see an imminent cure, but he is optimistic that the disease will prove to be amenable to long-term control with the right combination of drugs. He gave a detailed explanation of how Rituxan is believed to work and spoke about radioactive monoclonal antibodies Zevalin and Bexar. At this time he is preparing a dose related clinical trial for WM patients using Zevalin. Zevalin is about to be approved in the next few months.

Following his presentation, Dr. E answered questions from the audience. We are grateful to him for sharing his time and expertise. Congratulations to Dr. “E” on the recent birth of twin boys!

# TREASURER'S REPORT

By James Bunton

My special thanks to those of you who responded to the request in the summer Torch for a special contribution. While the response was gratifying, our receipts to date are still behind last year. We will be hard pressed to meet the need for member services.

Some members have asked for an account of how the IWMF spends its funds. The financial statements for last year are on our website in great detail. However, as an accountant with over forty years experience, I know that financial statements are not easy to understand or the best way to communicate information. I thought it would be helpful to set out in narrative form how IWMF's money is spent.

One of our largest expenditures is the cost of printing and mailing the Torch, our quarterly newsletter. The Torch keeps our members up-to-date with information about IWMF as well as with news from the medical world, such as new treatments and clinical trials. IWMF volunteers write and edit the Torch, leaving us with only the cost of printing and postage, approximately **\$21,000** for the year.

This year we reduced the Torch mailing list by asking people to let us know if they didn't want to receive the newsletter. At the same time, under the direction of Neil Massoth, IWMF has initiated a program to try to reach more people affected by WM. Right now we probably reach less than 20 percent of WM patients. If this new program succeeds we will have more members, and our newsletter costs will increase.

Another major expenditure is the cost of printing and mailing the package of material we send to people who call our office for information about WM. We get about fifty such inquiries per month. The amount budgeted for this service is \$8,000.

We have budgeted for, but not yet committed to, the printing of three booklets. Two of them, *Waldenstrom's Macroglobulinemia—What It Is!* and *Treatment Options—A Handbook for Patients*, need to be brought up-to-date. The third is a new booklet written for the medical profession. We are fortunate that Dr. Morie Gertz volunteered to prepare it, and it is almost ready for publication. **\$15,000** has been budgeted for the production of these three booklets.

We budgeted for, and have spent,

about **\$3,000** reprinting the small IWMF pamphlet which is sent to all WM inquiries and is distributed at medical conferences.

The April 2001 Educational Forum was originally budgeted at **\$18,000**. However, due to efficient management and the low cost of the Miami hotel, the cost was about **\$10,000**. For the first time we broke even on this annual event.

We allocated **\$6,000** for attendance at medical conferences. At these events we distribute our literature, inform the medical profession about IWMF, and learn about the latest treatments and research. Several of our members and trustees travel to these conferences at their own expense. They spend many hours at our booth, answering questions from doctors and others.

A weekend meeting of the Board of Trustees costs about **\$6,000**. We budgeted for two meetings this year, at a cost of **\$12,000**. We need such face-to-face meetings to set long-term policy, to develop member services programs, and to determine which research proposals IWMF will fund. Most of the trustee's work is done by email, telephone, and teleconferences. The next board meeting is tentatively set for January, so we may not need all the amount budgeted for 2001.

IWMF's office in Sarasota is run very effectively by our part-time office manager, Sara McKinnie, and a part-time assistant. They take care of our correspondence and banking, mail the information packages, newsletters and booklets, and perform all the miscellaneous tasks necessary to run an efficient office. The budget for their services is **\$21,000**. In addition, we allocate about **\$3,000** annually for bookkeeping, accounting, and tax return services. The annual rent for our Sarasota office is **\$6,000**. Miscellaneous expenses such as office supplies, telephone charges and insurance are budgeted at **\$8,000**.

At the beginning of 2001 we budgeted **\$8,000** for the expansion of the WM Patient Profile. So far we have not spent any of this amount, and it may be deferred to 2002.

A majority of new members discover IWMF through our website, and one of our most useful services is the IWMF TalkList. Yet these services are not included in our budget

## IWMF OFFICERS SELECTED FOR NCI BOARD

The IWMF Board of Trustees is pleased to announce that President Ben Rude and Vice President Judith May have been invited to join the National Cancer Institute's Consumer Advocates in Research and Related Activities (CARRA). The CARRA program is designed to increase the involvement of people affected by cancer in NCI activities. Through CARRA, NCI incorporates the cancer survivor's viewpoint into their programs and activities.

Some of the activities CARRA members are asked to participate in are:

- Serving on NCI's Progress Review Groups to establish research priorities for specific types of cancer;
- Participate in early design efforts of clinical trials to improve quality of care for cancer patients;
- Advocate for and evaluate clinical trials;
- Assist in identifying gaps in current cancer research;
- Develop and review information for the public regarding trials, and the NCI website;
- Advocate for and participate in activities to address national issues. Both Ben and Judith will serve three-year terms on the CARRA board.

because they are maintained by dedicated volunteers. The minor costs involved are included in the miscellaneous category.

Our total budget for the year adds up to **\$121,000**. Some of these costs can be postponed until next year, but it would be a shame to do so because of a lack of funds. We need every dollar in order to deliver services to our members.

Finally, we must point out that in addition to our member services, this year IWMF has allocated **\$155,000** for medical research that, we hope, will help improve the treatment of (and someday cure) our disease.

# SUPPORT GROUP NEWS

By Jack Gelber

There is a great sense of renewed energy in the local support groups around the country.

IWMF support groups provide patients and their families an opportunity to meet face-to-face with others who share their experience and hope. If you want to start a group in your area, call or write me for help. Jack Gelber (212) 995-9613 or [jackgelber@msn.com](mailto:jackgelber@msn.com).

Here's some news from IWMF regional groups:

## New York City Area

On September 9, the internationally acclaimed clinician and researcher, Dr. Morton Coleman of Cornell Weill Medical Center, spoke to our group for two hours and then answered questions from an audience of over fifty WMers. Dr. Coleman and his associates are in clinical trials of BLT-D, a nonmyelosuppressive treatment that combines Biaxin, low-dose thalidomide and Dexamethasone. Dr. Coleman believes that BLT-D has a place in the arsenal in the fight against WM. And, excitingly, he and his team are investigating a monoclonal agent for CD-22, which is often associated with Waldenstrom's B cells.

Dr. Coleman stressed the need for WMers to participate in clinical trials. A later issue of the Torch will include a detailed account of Dr. Coleman's research.

## Rochester, New York

Group leader Stephen French writes that the last meeting "had eight members, including a new member. We urged her to register with IWMF and ask for material for the newly diagnosed. We all reviewed our state of well-being. Most everyone is either in remission, heading to remission or holding their own... Rituxan seems to be the drug of choice right now with our local "oncs." I myself have received it twice, but it did not seem to work.

"Our youngest member is forty-four, our oldest is near seventy. We are planning a dinner, hosted by a member, on November 17. Two members hope to attend the Boston conference and give us a report.

"I said a few words about putting our troubles in perspective when compared to the terrorist incidents in NYC and Washington... We all agreed to continue to support IWMF because one important activity of the foundation is to publicize our disease and keep it before the public, particularly legislatures.

"Our next meeting will probably be in February and we will try to get a physician to speak to us about peripheral neuropathy or new WM protocols."

## Eastern NY/Western New England

Thad Raushi writes that on January 25, 1997 this group met for the first time, attended by four people with WM and three spouses.

"On September 15, 2001 the group held its twenty-eighth bi-monthly meeting, six of the original seven people attending along with numerous others.

"Over these four and a half years, the group has met in both New York and Massachusetts, in a community college, medical college, local church, and hospitals. For the past two years we have met at the Cancer Resources Center of the Albany Medical Center in Albany, New York.

"The primary focus has remained member support. Additionally, the group has had speakers on a variety of issues, including a hematologist on WM, a professor of biological sciences on blood and the circulatory and lymphatic systems, an oncology nurse on understanding blood counts, a psychiatrist on living with disease, a nurse on complimentary therapies, a nutritionist, and our own members leading discussions on IWMF conference tapes.

"Group meetings have been open to all, informal, and always upbeat! The next meeting is scheduled for November 17."

## Philadelphia

Karen Pindzola tells us that the Philadelphia area group held their second meeting on September 16. An oncology nurse practitioner spoke about understanding blood tests. She described the different types of leukocytes (white cells), both granular which mainly fight bacteria and non-granular which mainly fight viruses. In lymphoma, some leukocytes never mature and are non-functioning. She also covered erythrocytes (red cells) and the tests for volume, color and the amount of hemoglobin, that are part of the CBC, and why these tests are done. She discussed the immunoglobulin types M, A, D, G, and E, pointing out that IgM has a molecular weight of 900,000 while the others average about 170,000 — thus our macroglobulinemia.

Everyone was very enthusiastic about this informative meeting. It really helped to tie together things that some of us had heard but didn't fully understand. The meeting ended on an up note with a communal meal.

## Western Pennsylvania

Bob Shaffrey writes that Dr. Agha, his oncologist, will address the group on November 2. It will be an "open format" with Dr. Agha taking questions from members about their own WM status. A buffet dinner will precede the evening's presentation. Contact Bob Shaffrey for details. (See the support group list.)

## Ohio

Dr. Guy Sherwood will speak to the W. Ohio/ E. Indiana/ N. Kentucky IWMF group on October 20 in Troy, Ohio. His talk is titled "A Novel Perspective: A WM Patient Who Happens to be a Physician. Or is it a Physician Who Happens to be a WM Patient?" The meeting will be at the Upper Valley Medical Center. For details contact Ron Payne. (See the support group list.)

## Chicago

Ridge, Illinois. There will be a review of information from the October 13-14 Lymphoma Research Foundation Forum. Anyone interested in attending should contact John Hynes. (See the support group list).

## Sacramento

Davell Hays writes that the highlight of the September 16 meeting was a presentation by Dr. Jonathon Hake, a doctor who adds complimentary practices to standard medical care. He focused on becoming one's own advocate and on becoming engaged in all parts of treatment. Dr. Hake emphasized that attitude, exercise, and eating right may be as important as actual medical treatment in increasing longevity. He stressed that supplements may be called for, but not at random, and suggested ways to find information about supplements and how to find reputable doctors who use them.

There was a great turnout for this meeting, with four brand-new members, recently diagnosed, expressing gratitude for the information they got at the meeting. Three members discussed their first-line, stand-alone treatment with Rituxan. Three others talked about successful results from tandem stem-cell transplants. (Two of these members now have normal IGM and other blood levels.) The importance of the WM Patient Profile was also discussed.

## San Francisco Bay Area

The second meeting of this new group was held on September 24 at the home of Norm and Colleen Marks in Oakland. They write that "we will continue to get to know each other and discuss ideas for future programs and activities." (See the support group list if you wish to contact this new group.)

## LOCAL SUPPORT GROUP LIST

### *California*

Los Angeles area:  
Lynn Bickle (805) 492-4927  
Sacramento, CA:  
Davell Hays (530) 295-1344 or  
Darlene Aniasco (916) 542-4428  
San Diego, CA:  
Norm Spector (619) 454-6313  
San Francisco area:  
Penni Wisner (415) 552-6579

### *Florida*

Gainesville, FLA:  
Jim Townsend (352) 376-3664  
Tampa, FLA:  
David Cowart (813) 961-3201

### *Georgia*

Atlanta, GA:  
Laura or Bob Bailey  
(770) 664-8213

### *Illinois*

Chicago area:  
John Hynes (847) 729-2093

### *Kentucky, Ohio, and Indiana*

Ron Payne (937) 339-3627

### *Massachusetts*

Boston, MA:  
Lynne or Joe Mara (781) 749-0204  
or  
Judy Christensen (781) 335-5698

### *New York*

Albany, N.Y. & vicinity:  
Sylvia or Thad Raushi  
(518) 393-1760  
New York City area:  
Carol or Jack Gelber  
(212) 995-9613  
Rochester, N.Y.:  
Stephen French (761) 621-3317

### *Pennsylvania*

Philadelphia area:  
Karen Pindzola (610) 647-2931  
*West PA, East Ohio, North VA and  
West MD:*  
Bob Shaffrey (412) 443-2284

### *Texas*

Houston, TX: Barbara or  
John Manoussou (713) 840-0828

### *Washington*

Seattle area:  
Peg Horton (253) 874-8820

### *Washington D.C.*

Washington, D.C., Maryland and  
No. Virginia:  
Catherine Naylor (301) 229-0319

## INTERNATIONAL

### CANADA:

Arlene Hinchcliffe (905) 337-2455

### UNITED KINGDOM:

Nigel Pardoe and Cheryl Luckie  
0208 840 9812 or  
[Pardoenc@aol.com](mailto:Pardoenc@aol.com)

### THE NETHERLANDS:

Leo de Bruin  
00317 93415666 or  
[leo.magda@hetnet.nl](mailto:leo.magda@hetnet.nl)

## THE LIFELINE

If you can't get to a local support meeting, use our IWMF telephone lifeline to call a WM veteran. Or, if you'd like to volunteer, call or write to me: Jack Gelber (212) 995-9613 or [jackgelber@msn.com](mailto:jackgelber@msn.com)

### NEWLY DIAGNOSED

Norm Spector (617) 454-6313  
Stephen French (716) 621-3317  
Sallie Moore (516) 795-3746

### RITUXAN

Neil Massoth (201) 444-6253  
Charles Vassollo (201) 947-6977  
Allen Weinert (603) 863-5347

### 2-CdA

Norm Spector (617) 454-6313  
Ben Rude (661) 821-1904  
(with Cytoxan or Rituxan)  
Bernard Swichkow  
(305) 665-5303

### FLUDARABINE

Peg Horton (254) 874-8820  
Jack Gelber (212) 995-9613  
(with Rituxan)  
Marty Kopin (310) 390-1546

### STEM CELL TRANSPLANT

Howard Donley (916) 422-9562  
Davell Hays (530) 295-1344  
Gregg Jarrett (630) 243-8121

### SPLENECTOMY

Kathleen Ugenti (631) 427-8265

### ORAL CYTOXAN

Lou Birenbaum (314) 961-5591

### PLASMAPHERESIS

Fred Bickle (805) 492-4927  
Arlou Brahm (203) 264-7995

### WATCH AND WAIT

Reg Morgan (509) 633-1579  
Renee Paley-Bain (914) 277-7851  
Mel Horowitz (518) 449-8817  
Polly Oldberg (513) 932-7486

### YOUNG WM

Nobby Riedy (650) 879-9104  
Bob Bailey (770) 664-8313

### LATEST RESEARCH

Bert Visheau (CANADA)  
(905) 528-1789

### CAREGIVING

Lynn Bickle (805) 492-4917  
Brad Alexander (972) 529-2002

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### OPHTHALMOLOGY

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### FRANCE AND FRENCH SPEAKERS

Freddy Bastin 332 54 37 8952  
[nicbastin@aol.com](mailto:nicbastin@aol.com)

**Since June, 2001 the following contributions to the International Waldenstrom's Macroglobulinemia Foundation were made in memory of:**

*In memory of Ken Berman:*

Dr. & Mrs. Theodore Levine  
Edwin & Frances Landis  
Yung & Jane Tang

*In memory of Elizabeth Crawford:*

Marilyn Worth

*In memory of John De Angelo, Sr.*

John De Angelo, Jr. and  
the JDA, Sr. Memorial Foundation

*In memory of Ann Jackson Dyson*

Margaret Zehner

*In memory of George Farrier:*

Charles & Chris Rowe  
Jill Summerville  
Karen Lott  
Betty Kearney  
Joanna Walker  
Leslie Sakai Nesley  
Luciane Zanella  
Sarah Thamer Hallford  
John Terrible  
L. Robin Brody  
James & Marie Demera  
A. L. Jane Ferdinandi

*In memory of James H. Gapinsky:*

Victoria Garland

*In memory of Annette Giles:*

Kay Jones  
Anona Jones

*In memory of Daniel Gorski:*

Jane Hurst

*In memory of Chris Hole:*

Virginia Hole

*In memory of Raymond Ioele:*

Rebecca & Anthony Ioele

*In Memory of Betty Jackson:*

Richard & Ann Fitzgerald  
Carlene Merrill

*In memory of Gary Kincaid:*

Peggy Eastep

*In memory of Ray Perez:*

Alexis J. Perez

*In memory of Sam & Mollie Rozentman:*

Martin L. Rozenman

*In memory of Paula Saks Zellhofer:*

Gregor Zellhofer

*In memory of June Schubel:*

Marvin Paul

*In memory of Lois Slaski:*

Janet & Mitch Arnowitz  
Joseph & Sylvia Gibbons  
Taylor Gunn

**Since June, 2001 the following contributions to the International Waldenstrom's Macroglobulinemia Foundation were made in honor of:**

*In honor of Dr. Reim Androde:*

Melba & Alan Howenstine

*In honor of Frances Berg:*

United Way of Wyoming Valley

*In honor of Vivian Boas:*

Jesusa McLellan  
Samuel & Janet Shertzer  
Thomas & Linda Wilkinson

*In honor of Walter Biddle:*

Thomas Harren  
Bruce Hetrick  
L. B. Smith Cultural Foundation, Inc.  
L. B. Smith Medical Foundation

*In honor of Terrance Cherry:*

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*In honor of David Connor:*

Glennon Steik

*In honor of Joy Dulin:*

Michael Dulin

*In honor of Genie Gard:*

Melba & Alan Howenstine

*In honor of Kenton Howenstine:*

Melba & Alan Howenstine

*In honor of John Hynes:*

Margaret & Scott Watson

*In honor of Kathy and Tom Klewin:*

John & Barbara Peckinpugh

*In honor of Barbara Manouso:*

Annunciation Greek  
Orthodox Cathedral

*In honor of Judith May:*

Sharon Byous

*In honor of Claire Price:*

Judith Danziger

*In honor of Mark Thompson:*

United Way of Tri State

*In honor of Edward Wolf:*

Chicago Tribune Foundation

*In honor of Ying Yang:*

Jian Shen



International Waldenstrom's  
Macroglobulinemia Foundation  
2300 Bee Ridge Road, Suite 301  
Sarasota, FL 34239-6226

## IWMF RESEARCH GRANT AWARDS

*By Judith May*

The IWMF Board at its August 2001 meeting voted to fund a research study proposed by Dr. Raphael Fonseca at Mayo Clinic, and one proposed by Dr. Ayad Al-Katib at Wayne State University, Karmanos Cancer Institute. Both studies will begin in November 2001. Following is a summary of the studies:

Dr. Fonseca, Mayo Clinic - this proposal is entitled "Genomic Aberrations In the Clonal Cells of WM" and is a continuation of his work which we funded last year. Dr. Fonseca is pursuing studies into the origin and evolution of WM. This study will seek to characterize some of the potentially important chromosomal and molecular abnormalities in B-cells of WM patients in hopes this will translate into a better understanding of prevention and treatment of the disease.

Dr. Ayad Al-Katib, Karmanos Cancer Institute, Wayne State University" - this study builds on the results of the research by Dr. Al-Katib which we funded last year. The hypothesis is that a combination of Rituximab and 2CdA, following prior exposure of Bryostatins 1 to

the WM cells, will kill more if not all the tumor cells since Bryostatins 1 makes the CD20 of these cells more sensitive to the treatment of Rituximab and 2CdA.

In addition, the Board voted to fund \$26,000 to partially cover the costs of the second International Workshop on Waldenstrom's Macroglobulinemia, to be held September 27-30, 2002 in Athens, Greece. This would be a follow-up to the Workshop convened in Washington D.C. last year which was funded by the National Cancer Institute and IWMF. The 30-plus research physicians will divide into committees and work on various WM issues during the coming year, in preparation for reaching consensus in Athens.

Research funds in the amount of \$3,000 have also been awarded to purchase a computer for the Dana Farber Cancer Institute at Harvard, which will be used by a biostatistician who will analyze the Waldenstrom's Macroglobulinemia Patient Profile Database. Dr. Steve Treon will oversee this work.