

LAS VEGAS EDUCATIONAL FORUM 2002

We hope that you will join us in Las Vegas, Nevada at the IWMF Educational Forum on April 12 – 14, 2002.

As always, the IWMF Educational Forum is a place to learn about the latest in research developments and to hear world-class investigators discuss treatment recommendations. The IWMF Educational Forum is an annual event dedicated exclusively to helping patients understand the nature of Waldenstrom's Macroglobulinemia: the symptoms, the treatment options and treatment side-effects.

Highlights of the Educational Forum Professional Presentations

Dr. Robert Kyle of Mayo Clinic will deliver the keynote address. Dr. Kyle was a friend and colleague of Jan Waldenstrom and is arguably the world's best-known WM expert.

Dr. Steven Treon of Harvard and Dana Farber Cancer Institute will speak Friday evening on "Defining the Challenges in Waldenstrom's." Dr. Treon is known to many of us as the organizer of a WM symposium for physicians in Banff, Canada last April and the Boston conference in November.

Dr. Morie Gertz of Mayo Clinic will talk about how WM produces symptoms and how they are monitored. Dr. Gertz is a world-recognized authority on WM and the author of "Waldenstrom's Macroglobulinemia, A Review of Therapy," written specifically for IWMF for distribution to physicians.

Dr. James Mason, Director of the Blood and Marrow Transplantation Program at Scripps Cancer Center, will speak about bone marrow transplantation for WM patients. "Are Mini-transplants an Option?" is the title of his lecture. Dr. Mason will also

discuss stem cell harvesting in anticipation of a future transplant.

Carolyn Katzin, Certified Nutrition Specialist, President, American Cancer Society, will discuss the myths and misconceptions of nutrition and supplementation. She will also discuss things that can be of benefit to us.

Monica Myklebust, M.D, Program In Integrative Medicine, University of Arizona, will be speaking about her fellowship, which is teaching her how to incorporate complementary methods with standard medical practice. She will also explain how a plan might be set up for a WM patient who comes into the clinic in the Program of Integrative Medicine.

In addition to coping with cancer, many of us have problems relating to insurance companies, employers and, if we apply for disability benefits, the Social Security Administration.

Barbara Schwerin, Director of the Cancer Legal Resource Center, will help us through this maze with her talk "Cancer and the Law—A Look at Employment and Insurance: What You Need to Know."

Dr. Guy Sherwood will be our pre-session speaker. He is a family-practice physician and will speak about WM from the point of view of a physician who is also a WM patient.

Breakout Sessions

These sessions are small group meetings focused around a specific symptom or side-effect or treatment. Breakout groups provide an opportunity for everyone to share their experience with WM. Among others, these sessions will include groups for the newly diagnosed and for caretakers, as well as a session on spirituality and WM, headed by a WM patient, the Reverend Ronald Payne. Dr. Monica Myklebust will provide information in a

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WM PATIENT PROFILE PROJECT

We now have over seven hundred WM patient profiles in the WMPP Database. Edition 2 will be distributed to our Scientific Advisory Committee and other qualified researchers early in January, 2002.

Two active studies are in progress on Edition 1. Dr. Mary McMasters of the National Cancer Institute has selected approximately one hundred patients from the Database whom she is approaching for additional information about their family members with related cancers. The second study is underway at Dana Farber Cancer Institute in Boston under the direction of Dr. Constantine Mitsiades and will be a complete review of the data.

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DANA FARBER PATIENT/PHYSICIAN SUMMIT ON WALDENSTROM'S

By Jim Berg, IWMF Trustee

On Friday, November 9, almost three hundred Waldenstrom's patients and caregivers assembled at the Seaport Hotel in Boston for a physician-patient conference sponsored by the Dana Farber Cancer Institute, the first of its kind ever held by such an institution for this rare malady. Given the slate of presenters, and the tendency of professionals to speak over laymen's heads, we realized we were in for a rough ride. But that's why we had come; we wanted to be brought up to date. We looked forward to coming away with a far better understanding, both of the nature of the beast we fight and of the knowledge or ignorance of the medical profession about it. We would not be disappointed in any of those areas.

The evening began with a dinner and the usual introductions. Then Dr. Steven Treon of Dana Farber led us through the history of the disease from its discovery by Dr. Jan Waldenstrom (who didn't know he had found it until much later), to the development of standard treatments, to the prospect that in Athens in 2002 a summit conference of experts will try to define the disease, classify its stages and come up with recommended treatment regimens. Next, Dr. Marvin Stone of Baylor told us what standard symptoms and procedures are today, emphasizing that just as all that glitters is not gold, all high IgM is not Waldenstrom's.

Saturday's sessions lasted from breakfast at eight until ten at night. All the sessions convened in Anthony's Pier 4 Restaurant, across the street from the hotel. Drs. Meletios Dimopoulos (Athens), Veronique Leblond (Paris) and Donna Weber (M.D. Anderson) discussed the nucleoside analogues 2CdA and fludarabine. Then Drs. Kenneth Anderson (Dana Farber), Melitios Dimopoulos and Morton Coleman (Cornell) talked about thalidomide and other drugs that alter the environment in which cancer cells live. After lunch came Drs. Steven Treon, Christos Emmanuelides (UCLA), Stanley Frankel (U. of MD) and Nikhil Munshi (Dana Farber), discussing novel drugs and procedures in the pipeline.

At Saturday evening's banquet there were greetings by Dr. Edward Benz, President of Dana Farber, and an inspired presentation by Mrs. Harriett Fulbright, former chair of the National Endowment for the Humanities, on how she discovered she had Waldenstrom's. The banquet concluded with the presentation of an award to IWMF's founder, Arnold Smokler, who unfortunately was unable to be present.

Sunday morning began with a talk about the treatment of peripheral neuropathy by Dr. Todd Levine, a neurologist from Phoenix. Then, for three hours, came what many of us thought the high point of the entire weekend. The whole panel of doctors was presented with a series of actual case histories, and in each one the doctors were asked in turn what treatment they would recommend at a given juncture. They seldom agreed. In fact, for one patient the recommendations stretched from allogenic transplant at one extreme to hospice care and comfort at the other. (The patient, incidentally, is still very much with us nine months after treatment, and tried unsuccessfully to register for the conference, which was oversubscribed). Had the entire weekend consisted of these three hours alone, this conference would have been worth every penny.

Thus ended Boston, 2001. Though the hotel charges were horrendous (\$22.00 per night to park your car), one could if one wished stay elsewhere, and the almost universal opinion was that we'd go again. Preliminary plans call for a follow-up in 2003. Same time, same station, as they say.

LAS VEGAS...

smaller group setting for those who are interested. There will also be a panel of transplant survivors who will share their stories and answer your questions.

Side-Trips and Tours

Treat yourself to a combined learning experience and vacation. Take advantage of our low conference-priced room rates to add a few days of sightseeing. Among other exciting adventures, we will have group rates for a Vegas show and are planning a group tour for an overnight stay at the Grand Canyon.

So why should you attend?

If you have this disease, or if a loved one does, you will want to be here, learning, sharing and working together with other WMers. Past attendees say that one of the most significant benefits of the Forum is meeting other patients and caregivers. Friendships developed here

continue — who better can understand what you are going through than another patient or caregiver? Who better to tell you how a treatment feels than someone who has experienced it?

Lastly, the Forum is a chance to learn about the IWWMF and its programs and to pass on your suggestions for developing an ever better organization.

The IWWMF Educational Forum is funded only by your contributions and organized by unpaid volunteers. We need and invite your support and participation. You can volunteer to help out when you register for the Forum.

Come and join us! Sign up now for reduced registration rates. This promises to be the best Forum ever.

LAS VEGAS EDUCATIONAL FORUM – IWWMF REGISTRATION FORM

Las Vegas, Nevada: Friday – Saturday – Sunday April 12 – 14, 2002

Cost Per person U.S. Dollars: Postmarked by March 15, 2002 \$115
Afterwards, or at the door \$125

Name: _____ Telephone _____ Email _____

Name: _____ Telephone _____ Email _____

Name: _____ Telephone _____ Email _____

Please indicate if patient, caregiver or family member next to each name

Mailing Address _____

Payment Total: \$ _____ Check MasterCard VISA AMEX

Credit Card No. _____ Expiration Date _____

Cardholder's Signature _____

Registration fee covers dinner on Friday, breakfast on Saturday and Sunday, and lunch on Saturday.
Would you like your name/address/email listed in the roster of attendees to be mailed out after the event?

Yes _____ No _____ (information you want omitted) _____

Mail this form and your registration fee to:
IWWMF, 2300 Bee Ridge Rd. #301, Sarasota FL 34239

Or FAX this form with your credit card information to (941) 927-4467
Fees will be refunded ONLY if notified two weeks prior to event

You are responsible for making your own hotel reservations. The special IWWMF room rate is \$99 per night plus tax. Please reserve by March 13, 2002. This special rate is effective three days before and after the event. Rates return to \$150 per night plus tax outside of that period. Check in is at 3 p.m. Check out is noon. Your room will be held until 4 p.m. on date of arrival unless guaranteed by a credit card. Please contact Embassy Suites Convention Center, 3600 Paradise Road, Las Vegas, NV 89109. Call (702) 893-8000 or FAX (702) 893-0708. Do not call the toll free (800) number, as the IWWMF rate is not established through Embassy Suites main reservation site.

FROM THE IWMF TalkList

By Jeanne Pond

Keeping up with the TalkList enables patients to learn about their disease and how to deal with WM's symptoms and complications.

STAYING INFORMED

One member reported that a WM expert at Mayo Clinic advised drinking three liters of water daily to help counteract potential kidney damage due to excessive protein. This is also excellent advice for anyone during and following chemo. (Although three liters may be a bit much for those of us with the usual golden-years bladder problems.)

* * *

Members continue to ask about their low cholesterol levels. Dr. Susan Leclair commented: "The current theory is that since cholesterol is used in making cell membranes, the low cholesterol level found in many malignancies is a reflection of cellular activity. Levels vary widely among patients; it is believed that this reflects a combination of cellular metabolism and the liver's ability to make cholesterol. Over 85% of your cholesterol comes from your liver, not from your diet.

* * *

Some Wmners were puzzled about the term *tumor*, believing it meant "a single lump." One response was "any abnormal growth is a tumor, even when it is extensive and involves many different cells." Our fellow WM patient, Dr. Tom Hoffman, wrote that "if you look at a WM patient's bone marrow, abnormal plasma cells form little

masses of cells from excessive cell division. These little clumps are called tumors."

* * *

Dr. Hoffman also answered a question about Schnitzler's Syndrome, an itchy rash seen in some .05% of WM patients. It results, he said, from a deposit of immunoglobulin in the skin.

* * *

Our patient/Doctor Guy Sherwood answered another TalkList query: Why does the IgM level often rise after plasmapheresis? Dr. Sherwood replied that "if you have aggressive disease your IgMs will rise after plasmapheresis (PP). The cancer cells keep producing IgMs. Remember, PP treats hyperviscosity and elevated IgMs—it doesn't do a thing to reduce the amount of cancer cells producing IgMs." If you have an indolent disease, you will need infrequent PP. Also, if you've had therapy, be it Rituxan and/or chemo, your IgMs may be on a downward spiral and you will require less PP.

* * *

Another exchange concerned Rituxan. A TalkList member was concerned that after four Rituxan infusions his IgM was about where it was when he started—at 6,000. His oncologist wanted him to have another round of Rituxan. A "second opinion onc" suggested the Rituxan didn't and wouldn't work and wanted him to move on to 2CdA or fludarabine. Which treatment to follow was his dilemma.

A member responded by posting the results of a study by four researchers at Sloan-Kettering in New York. All of the study's subjects experienced no immediate drop in IgM levels with Rituxan, but the study concluded that "the reason for this observation is unknown. The complement-mediated cytotoxicity and/or apoptosis [death] of tumor cells induced by rituximab may be associated with a release of intracellular IgM, thus causing a transient rise in serum IgM levels. Thus, an increased IgM level during or shortly following treatment should not uniformly be interpreted as treatment failure."

* * *

STAYING THANKFUL

Ben Rude posted this Thanksgiving Day message:

"...I am thankful that if I had to be given a cancer, that it was WM, a cancer that, while not curable, is treatable and one that has permitted me to lead a very full life or the five-plus years since diagnosis. I am thankful to have gone through three separate treatment protocols with no side effects and each resulting in a remission which I continue to enjoy. I am thankful to be able to run, hike and ski as well as any seventy-year-old I know. I am thankful to have found IWMF, an organization that has given me inspiration, support, many new friends, and has become a vital part of my own ongoing treatment. And I am thankful for this wonderful TalkList and the 520 members...who are standing by with support, encouragement and advice."

HOW TO JOIN THE TalkList

Subscribing: Send an e-mail to: 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

PATIENT ADVOCATE FOUNDATION

By Jim Berg

Having trouble with your HMO? Do they question the treatment your oncologist recommends? Are they telling you a treatment is “experimental,” or that it’s not approved for your disease? Don’t know whether you can get a new drug covered by your prescription plan? Does your employer discriminate against you because of your illness?

Everyone with medical insurance at some point will have a claim the company wants to disallow. Some breadwinners will find that they’ve been let go or denied advancement because they require medical care. Some physicians won’t recommend certain procedures lest the HMOs for which they work brand them as being too loose with money. What do you do? To whom can you turn?

There are remedies. Most insurers have appeals processes. Doctors frequently go to bat for patients if they know trouble is brewing. State insurance departments have the responsibility of protecting consumers against fraud or unfair treatment by their insurers. And then there are those lawyers whose TV ads say they can help (provided, of course, they think you’ve got a good case, and – oh, what a fee!)

But each of these remedies takes expertise to use effectively. And not all of us are prepared to go it alone against “the company.” Who can tell you that the company is refusing payment because they aren’t up-to-date on FDA approvals or because the physician’s billing service is using the wrong codes for the illness or the procedure? (More than one WM patient has discovered that denied bills are paid once the disease is described as a “lymphoplasmacytic lymphoma.”)

An organization that can help you is the Patient Advocate Foundation, based in Newport News, Virginia.

Founded a dozen years ago in memory of a cancer patient, the purpose of this organization is to help patients get the services and drugs they need. Their mission statement reads:

“Patient Advocate Foundation is a national non-profit organization that serves as an active liaison between the patient and their insurer, employer and/or creditors to resolve insurance, job discrimination and/or debt crisis matters relative to their diagnosis through case managers, doctors and attorneys.”

The foundation has a series of excellent publications on matters such as understanding managed care, dealing with job discrimination, and handling the crisis of debt. Titles like “The Managed Care Answer Guide,” “Your Guide to the Appeals Process,” and “First my Illness, Now Job Discrimination” are full of helpful strategies for dealing with the financial issues faced by patients and caregivers.

Through the organization’s web site, www.patientadvocate.org, or by calling their toll-free number, 1-(800) 532-5274, you can request information or assistance. They maintain a legal resources network to provide “legal consulting and referral services for patients confronting denial of insurance coverage, employment discrimination and/or need for negotiating support with public assistance programs through both state and federal agencies.”

The Patient Advocate Foundation is supported by medical societies, patient organizations, cancer clinics and upwards of a dozen well-known drug companies. If you are having insurance, job or financial problems due to WM, try giving them a call. And let “The Torch” know what treatment you receive, and how they were or were not able to assist you. We think they will come through.

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WM PATIENT PROFILE PROJECT...

The WMPP Committee regularly posts statistical reports and responses to queries on the WMPP Website at http://geocities.com/WMPP_data/. Starting this month, we will post a message on the IWWMF Talklist when we post a new item to the site. If you have a specific query or report you would like to see from the Database, send an e-mail to Jim Johannsen with the specifics.

The WMPP is an ongoing project. If you haven’t sent your profile, please do so. If you have only partial data, send what you have and send the rest later. You can get a profile form from Sara McKinnie at the IWWMF

office (e-mail iwmfl@juno.com). The form is also available for downloading on the WMPP Website.

The profile includes a provision for maintaining the confidentiality of your identity. The researchers would prefer that you waive confidentiality so you can be contacted for clarification or future study, but we will abide by your wishes. If you previously submitted your profile and did not waive confidentiality but would like to do so now, please let us know.

If you have any questions about the WMPP project, contact Jim Johannsen, Chair at jjohannsenwm@aol.com.

The word *January* comes from *Janus*, the Roman god of doors, who has two faces, one looking forward, one back, an appropriate metaphor for a look back at the year 2001 and forward to 2002.

IWMF PATIENT ADVOCACY

During 2001 we were involved in a number of important programs in our nation's capital. I was proud to represent WM patients as a member of the Leukemia, Lymphoma, Myeloma roundtable, which met in December, 2000 in Washington D.C. and reconvened in 2001 with recommendations to the NCI for future research in these diseases.

In April, former IWMF treasurer John Renshaw, trustee Jack Gelber and his wife Carol, and I participated in the annual Lymphoma Advocacy Day. We visited senators, representatives and their aides to stress the importance of increased funding for research.

June 20 and 21, at another event in Washington on behalf of blood diseases, we joined several leukemia, lymphoma and myeloma groups. The IWMF was represented by Janet Stanton from Idaho and Cindy Leinonen from Wyoming, both RNs. They also participated in lobbying activities and sat in on a Senate subcommittee hearing.

By joining with other blood disease organizations, we have become part of a larger voice with assurance of being heard in our nation's capital. We expect to be even more involved with patient advocacy issues in the coming year.

IWMF SUPPORT GROUPS

The year just past saw the birth of five support groups — in San Francisco, Los Angeles, Chicago, Philadelphia, and western Ohio. All are flourishing. But there are still too many areas of the country without a group, and our goal for 2002 is to fill those gaps.

IWMF PATIENT CONFERENCES

Our Educational Forum last April in Miami was a great success, and the one coming up in Las Vegas promises to be even more successful. In the past year we have established partnerships with other organizations to publicize activities of interest to WMers. IWMF members have attended workshops and meetings throughout the country sponsored by the Lymphoma Research Foundation of America, the Cure for Lymphoma foundation, the Multiple Myeloma Foundation, M.D. Anderson Cancer Center, the Wellness Community and the Goldman Partnerships. We hope to bring even more such events to our members' attention in 2002.

IWMF PUBLICATIONS

New publications in 2001 included *How to Read Your Blood Test*, by member Barbara Hauser; *What Now? Stories of Hope and Courage*; a French translation of *Treatment Options, a Handbook for Patients*, and *Waldenstrom's Macroglobulinemia, a Review of Therapy*, by Dr. Morie Gertz of Mayo Clinic. We are particularly excited about this work, which we plan to make available to physicians throughout the world to assist them in making treatment decisions.

Plans for 2002 include a revision of *Treatment Options* and *Waldenstrom's Macroglobulinemia, What It Is!* and translation of selected documents into French and Spanish.

IWMF TALKLIST

Our e-mail list server, IWMF TalkList, grew from a handful of members at the beginning of 2001 to over five hundred today. Each week brings new members. We are particularly pleased with our feature "Ask the Doctor," by which selected questions are referred to our Scientific Advisory Committee for expert opinion. We are grateful to Drs. Mary Varterasian, Stanley Frankel, and Morie Gertz for their participation.

Looking back on the year 2001, it clearly was, as Frank Sinatra put it, "a very good year." With your continued support, 2002 will be even better.

Keep well,
Ben

THAD RAUSHI'S NEW BOOK IS A VIEW FROM WITHIN

Thad Raushi, the author of *Waldenstrom's Macroglobulinemia, What It Is!* has written a new book about living with early onset Alzheimer's. Thad says that although *A View From Within* focuses on the dementia of Alzheimer's, it also "includes reflections on living with WM and a brain tumor as there is no way to entirely separate the different health issues we may live with." The back cover calls the book "a reflection of the author's inner thoughts and feelings about living a high quality life with a low quality disease. He writes about intimate trials and tears...and about joy and peace. The book moves beyond the adventure of surviving to the art of celebrating all of life as a gift to be lived well each day, doing the best we can with what we have."

IWMF Trustee Michael Luttrell writes that "Thad has faced challenges that would fell most of us, and, with a triple whammy of medical problems, like the Energizer Bunny has just kept on ticking. I've treasured Thad's words and contributions and I'm convinced that his book is going to be another source of strength and inspiration."

To order *A View From Within* send a check for \$14.95 to: Alzheimer's Disease and Related Disorders Association, Northeastern New York Chapter, 85 Watervliet Ave., Albany, New York 12206. Make check payable to: Alzheimer's Association, NENY Chapter.

In Gratitude...

THANKS FOR COMPUTER

In the spring issue of the *Torch* we appealed for a donated laptop computer that would be used at medical conferences and meetings. Sure enough, an IWFMF member came through. Eric Lamp, a resale manager for Compaq computers, donated his own laptop. It has proved to be indispensable for recording notes at three conferences so far. Thank you, Eric!

JOHN D'ANGELO MEMORIAL FOUNDATION CONTRIBUTES TO IWFMF RESEARCH FUND

On June 18, 2001 the John D'Angelo, Sr. Memorial Foundation held their first annual golf tournament at the Rancocas Golf Club in Willingboro, New Jersey. John D'Angelo was an avid golfer who died in December 2000 after a long battle with WM.

Ninety-seven golfers participated, raising \$7,500 for WM research. The tournament was organized by John D'Angelo, Jr. with the help of family and friends. His sister, Christine Allen, persuaded her employer, Princeton Consultants, Inc., to donate \$2,500 as a sponsor of the event. A cousin found a second corporate sponsor, Mercedes Benz USA, who donated \$8,000 worth of gift bags for the participants.

Participating golfers paid \$100 to enter the tournament and played for sponsor-donated prize trophies. Half of the money raised went to IWFMF's research fund; the other half paid for the event's expenses: golf fees, a casual lunch and a formal dinner after the day's golfing. The tournament was such a success that it is slated to be an annual event.

We all thank the John D'Angelo Memorial Foundation for their contribution to the search for a cure for Waldenstrom's Macroglobulinemia.

IWMF MILLION DOLLAR CLUB RECEIVES GENEROUS DONATION

A golf tournament, the "Steve Lipkowitz Mixed Scramble," held last July in Grand Ledge, Michigan resulted in a \$4,000 donation to the Million Dollar Club. The donation was arranged by Jim and Ann Lipkowitz in honor of Ann's father, Dr. John C. Bernloehr, who has been diagnosed with WM and who agreed to match the tournament proceeds with his own contribution. Dr. Bernloehr writes that in 1995 he was given five years to live. But, he adds, "the other day my oncologist informed me something else would get me before Waldenstrom's does. If I get Tiger Woods to show up at our next outing I would be a real happy camper. Anyhow, I am in my 89th season!" Our congratulations to John for his wonderful attitude.

FREE AIR TRANSPORT FOR CANCER PATIENTS

Thanks to IWFMF member Norm Spector for this tip: An organization called Corporate Angel Network can help cancer patients who need to fly to and from approved treatment centers. Over five hundred major corporations participate in the organization's program. The Corporate Angel Network matches corporate jet schedules with those of participating patients. If a match is not available, they can obtain deep discount fares on commercial airlines. There are some restrictions—for example, they can't accommodate patients in wheelchairs and they require a doctor's statement that the patient is able to fly safely.

For details, call the Corporate Angel Network at (914) 328-1313.

LYMPHOMA FOUNDATIONS MERGE

Donna Shu, Executive Director of the Lymphoma Research Foundation of America (LRFA) announced at their Educational Forum held in Chicago in October the merger of the LRFA with the Cure For Lymphoma (CFL). The new organization will be known as the Lymphoma Research Foundation and will maintain the LRFA office in Los Angeles and the CFL office in New York. Both organizations believe that this merger will avoid duplication of effort and result in better service to members and more effective targeting of research funds.

The IWFMF has worked closely with both organizations for several years and lauds this joining of forces.

HELP WANTED!

We need fundraisers. Our Trustees work hard, but hard work is not always enough. There is an art to fundraising, and none of the Trustees has experience in this important area.

A few creative volunteers have held local fundraising events. And we need the small and local, like one member's jazz party and another's long hike down the Sierras. But we also need people who know how to approach pharmaceutical companies, public agencies and private philanthropic organizations.

This is your foundation and we need your help. If you have fundraising experience and would like to help, please contact Ben Rude at bdr@tminet.com.

SUPPORT GROUP NEWS

New IWWMF support groups have flourished this past year, yet there are still many Wmners who don't have access to a nearby group. If you'd like to start a group in your area, let IWWMF help. Call or write Jack Gelber (212) 995-9613 or jackgelber@msn.com.

Here's news from some local group leaders:

California

Sacramento and San Francisco Groups Join Hands. Join us for a potluck lunch at our next combined support group meeting at Bethany Church in Fairfield on January 26 at noon. Or, if you prefer, just attend the meeting which will start at 1:00 p.m. We will not have a speaker as we will be busy getting to know one another. Trustees Michael Luttrell and Davell Hays will share news of the IWWMF Board meeting to be held the week before. Please e-mail Davell at Davell1@pacbell.net or Penni Wisner at Penniw@pacbell.net for directions and ideas on what to bring for the potluck. The church is one mile off Highway 80. You may call either leader (see support group phone numbers.)

Illinois

Twenty-eight Wmners attended the Lymphoma Research Foundation's Educational Forum held in the Chicago area on October 12 – 14. Ben Rude, IWWMF president, and Jack Gelber, support group coordinator, addressed our group in a breakout session. On October 28 thirteen of us met at Lutheran General Hospital in Park Ridge, Illinois. It was our group's second meeting. We shared our experiences and discussed future meeting agendas. Some Chicago area Wmners attended the conference in Boston and will talk about it at a future meeting. Contact John Hynes for information (see list following.)

Kentucky, Ohio, Indiana

The first two gatherings of the WOEINK Support Group were held in July and October 2001 at the Upper Valley Medical Center, Troy, Ohio. At the July session, Dr. Pierluigi Porcu, member of the staff headed by Dr. John Byrd at The James Cancer Center of Ohio State University offered a most helpful presentation on WM and its

treatment options. At the October meeting, Dr. Guy Sherwood, physician and WM patient, shared with the group from his unique perspective as a doctor with the disease.

Four members of our group who participated in the Boston conference will talk about it at our next meeting on Saturday, January 19, 2002. At this meeting we anticipate having more time for sharing our individual stories and for discussing the focus of future meetings.

For details, contact Ron Payne at (937) 349-4344 or revron@bright.net.

Albany, New York

In 2002 meetings will be held on Saturdays from 11:00 a.m. - 3:00 p.m. at the Cancer Resources Center of Albany Medical Center on New Scotland Avenue. Meeting dates are: January 26, March 9, May 18, July 20, September 14 and November 9.

Our group is changing coordinators. We welcome Melvyn Horowitz as Support Group Coordinator and Claire Wengraf as Coordinator of Programs. Mel and Claire are long-time members of the group. We thank them for their willingness to serve and look forward to their leadership. The group will remain a support group in nature, with the inclusion of an educational component of several speakers. We will hear tapes from conferences and forums to keep up-to-date on topics related to WM.

Sylvia and I have coordinated the group since our first meeting in January 1997. We have grown close to the wonderful, supportive members of the group and look forward to continuing our participation.

If you have questions regarding the support group, please contact Mel at (518) 449-8817 or horowmel@hvcc.edu

Best wishes,
Thad (WM) & Sylvia Raushi

New York City

Forty-five people attended our November 18 meeting. New members were given a chance to ask questions and explain their current WM status.

Thirty of our members attended the Boston conference. We heard reports from several of them—one of the most interesting was the recounting of individual case studies presented at the conference and the responses of the doctors who analyzed them.

We plan to meet six times in 2002. Jack Gelber (see following list) has details.

Rochester, New York

The next meeting will be on February 16 at 1:30 p.m. in the Fairport Village Library. Call Stephen French (see following list) for more information.

W. Pennsylvania, E. Ohio, N. Virginia, W. Maryland

The group met on November 2 at St. Francis Hospital in Cranberry, PA. The evening began with a covered-dish dinner. Our guest, who explained WM in detail, was Dr. Mounzer Agha from the Oncology Hematology Association, University of Pittsburgh Cancer Institute. He asked each of the Wmners to describe his/her history, beginning with diagnosis and including all treatments received. This format allowed everyone to ask questions about his/her own situation. Twenty-eight people attended, including both Wmners and their caregivers. This was the largest meeting we have ever had! Kudos go to Bonnie O' Shell (caregiver to WMer Gary O'Shell) who worked many hours to coordinate all the arrangements for the dinner. Others who assisted were Lydia Davis, Shariann Hall, Bill Serfaty and Gladys Stander. Interested in joining the group? Call Bob Shaffrey (see list following.)

Washington, D.C.

Our group has some twelve to fifteen members who meet every other month. We exchange information and update new people about current treatments for WM. We are hoping to have guest speakers at some future meetings. If you'd like to join us, contact Catherine Naylor (see list following).

LOCAL SUPPORT GROUPS

California

Los Angeles
Lynn Bickle (805) 492-4927
Sacramento
Davell Hays (503) 295-1344
Darlene Aniasco (916) 542-4428
San Diego
Norm Spector (858) 454-6313
San Francisco
Penni Wisner (415) 552-6579

Florida

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

Georgia

Atlanta
Laura or Bob Bailey (770) 664-8213

Illinois

Chicago
John Haynes (847) 729-2093

Kentucky, Ohio, Indiana

Ron Payne (937) 349-4344

Massachusetts

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

New York

Albany
Mel Horowitz (518) 449-8817
New York City
Jack or Carol Gelber (212) 995-9613
Rochester
Stephen French (585) 621-3317

Pennsylvania

Philadelphia
Karen Pindzola (610) 647-2931
W.PA, E. Ohio, N. VA, W.MD
Bob Shaffrey (412) 443-2284

Texas

Houston
Barbara or John Manouso
(713) 840-0828

Washington

Seattle
Peg Horton (253) 874-8820

Washington, D.C.

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

THE NETHERLANDS

Leo de Bruin
00317 9341 5666 or
leo.magda@hetnet.nl

THE LIFELINE

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

NEWLY DIAGNOSED

Norm Spector (858) 454-6313
Stephen French (585) 621-3317
Sallie Moore (516) 795-3746

RITUXAN

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

2CdA

Norm Spector (858) 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
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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RITUXAN

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FLUDARABINE

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CHLORAMBUCIL

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jpovall@mmm.com

OPHTHALMOLOGY

Terry Betts 01992 583643
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FRANCE AND

FRENCH SPEAKERS

Freddy Bastin 332 54 37 8952
nicbastin@aol.com

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

In memory of Mary Lou Bachman:

Robert & Marlene Reiter
Joseph & Rose Marie Morelli
Douglas & Linda Krantz

In memory of Marie Bonsack:

Jandeen Youngren

In memory of Carol Cochrane:

Sonja Fischer
Ann & Noyce Strait
William Born
Aron & Janice Lipshy
Christopher Pero
Kristin Born
Virginia Wygast
Barbara Grashoff
Jeffrey & Patricia Evans
Philip Kubik
Patrick & Jance Ziemba
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Jeffrey Evans
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Phyllis Klann
Christine Miller
Rebecca Spiro
Theresa & Arthur Kowalski
Hannah Loeffler
Robert Gorman
Albert & Patricia Stahl
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Philip & Patricia Miller
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In memory of Bill Crissey:

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In memory of Steven Dale Gastel:

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Ellen Goldman
Alberta Gearhart
Martha Ellen Anderson
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The Solid Rock
John & Mary Sullivan

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Robert & Kathryn Smith
Ara Johnston

In memory of Celila Landy:

Kathleen Carvin

In memory of Billye Lindsay:

J. Wayne Sellers
Emma Carter Circle
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Pauline & Billy Hyman
Joseph & Helen Solomon
Mary Margaret Rogers

In memory of Robert Putterman:

Rita Spira

In memory of Lois Slaski:

Ann Slaski

In memory of George Williams:

Lois Williams

In memory of J. Ronald Windsor:

Ian & Julie Windsor Mitchell

In memory of Robert Wisner:

Sally Hills

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

In honor of Vivan Boas:

Susan and Jeffrey Wilkinson
Travis & Dee Pubmire

In honor of Jill Burt:

Jewell Halle

In honor of Deborah Derdy:

Jean & Jeff Metzler

In honor of Joy Dulin:

Michael Dulin

In honor of Noah Fitzpatrick, M.D.

Michael Dulin

In honor of Linda Fox:

Ruth Fuhlbrugge

In honor of Pam Glossi:
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*In honor of Sandy & David
Greenberg:*
Mary & William Schlichtman

In honor of Dolores Hermsdorf:
Stephen Hermsdorf

In honor of Jennifer Hoegerman:
Helen Mitchell

In honor of Sarah Murray:
Jean & Jeff Metzel

In honor of Judith May:
Lois Ezell

In honor of Ronald Reimer, M.D.:
Clark W. Biedel, M.D.

In honor of LaDonna Stockstill:
Paul & Lynn Whitt

In honor of Mark Thompson:
United Way of Tri State

LYMPHOMA FOUNDATIONS MERGE

Donna Shu, Executive Director of the Lymphoma Research Foundation of America (LRFA) announced at their Educational Forum held in Chicago in October the merger of the LRFA with the Cure For Lymphoma (CFL). The new organization will be known as the Lymphoma Research Foundation and will maintain the LRFA office in Los Angeles and the CFL office in New York. Both organizations believe that this merger will avoid duplication of effort and result in better service to members and more effective targeting of research funds.

The IWFM has worked closely with both organizations for several years and lauds this joining of forces.

RESEARCH NEWS

By Bert Visheau

Thalidomide

Thalidomide, banned in the late 1950's for causing birth defects, has rekindled clinical interest due to its unique anti-inflammatory and moderating effect on the immune system. Good results have been observed recently in plasma cell malignancies such as multiple myeloma and WM.

A publication by Dimopolous et al. in the *Journal of Clinical Oncology* (August 15, 2001) presents results from a phase II study assessing the activity of thalidomide in patients with WM. Twenty patients (median age 74) were given increasing amounts, from 200mg to 600mg. A partial response in 25% of patients was reported. Reversible adverse effects were common, including constipation, drowsiness, fatigue and mood changes. Peripheral neuropathy occurred in five patients. No patient developed deep vein thrombosis.

The study concluded "Our data indicate that thalidomide has activity in WM but only low doses were tolerated in this elderly patient population. Confirmation studies as well as studies that will combine thalidomide with chemotherapy or with rituximab may be relevant."

Small molecule derivatives or analogs of thalidomide are being developed and trialed. The hope is these analogs will be more effective with fewer adverse effects. One such analog, CC-5013, developed by Celgene, exhibits these characteristics.

Thalidomide seems to have activity in WM and merits further study though caution must be exercised to avoid use during pregnancy.

Stem Cell Research

Embryonic stem cells are able to remain in culture indefinitely while keeping their ability to differentiate into any of the body's more than two hundred different cell and tissue types. Wisconsin researchers, with Dr. Kaufman as lead author, in *Proceedings of the National Academy of Sciences* (September 2001) report having coaxed human stem cells to differentiate into blood-forming or hematopoietic precursor cells. This work could potentially advance efforts to develop new sources of blood. The next step is to prod hematopoietic precursors to form colonies of red blood cells, white blood cells, and platelets. Potential application includes transplants to treat cancers of the blood and bone marrow.

Though the clinical promise of embryonic stem-cell-based therapies is great, the authors are quick to state these therapies will be entirely novel, and serious concerns about safety and effectiveness will need to be addressed. Of particular concern is malignant transformation of cells that have been in culture for extended periods. Many years of research remain.

Reading of Interest to WMers

*Dr. Folkman's War: Angiogenesis
and the Struggle to Defeat Cancer.*

By

Robert Cooke. Random
House, NY

Dr. Judah Folkman's war on cancer and struggle with the scientific community goes back four decades. His efforts have opened up a new front on the attack on cancer by targeting the blood supply to tumors. Highly recommended.



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IWMF MEMORIAL FOR CANADIAN HOCKEY STAR

When Bill Harris, a legendary center for the Toronto Maple Leafs, died in Toronto this past September his family requested, in lieu of flowers, that donations be made to IWMF.

Eight hundred people attended Harris's funeral where he was recalled as "a man who meant a lot to the city of Toronto." A Toronto newspaper called him "one of the Maple Leafs' most popular and classy players."

A member of Leaf teams that won three consecutive Stanley Cup championships from 1962 to 1964, Harris often joked that he was born with the club's insignia etched on his body. In the mid 1960s he was traded to the Detroit Red Wings and he also played for the Oakland Seals and the Pittsburgh Penguins. In 1969 he retired as a player. Later he coached both the Canadian and Swedish national hockey teams.

Harris was diagnosed with WM about seven years ago. Complicating matters, he developed diabetes two years ago and was diagnosed with brain cancer six months before he died.

Bill Harris is survived by two sons, Robert and William, Jr., two daughters, Wendy and Patti and his companion, Antonie Simpson. To date, more than \$1,600 has been donated in Bill Harris's name to IWMF's research fund to support the search for a cure for WM.

A CORRECTION

In the last *Torch*, one article was headed "New Treatments in Waldenstrom's Macroglobulinemia by Raymond Alexanian, M.D." The intent was to indicate the topic of Dr. Alexanian's presentation, not that he was the author of the article.

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 e-mail Carol Gelber at jackgelber@msn.com.