IWMF NEWSLETTER

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INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

INSIDE THIS ISSUE

Drs. Rafat Abonour, Irene Ghobrial, and Morie Gertz, the distinguished panel for the Ask the Doctor session of the 2009 IWMF Educational Forum held in Memphis, Tennessee. Coverage of the Ed Forum begins on page 5.

DR. ROBERT KYLE HONORED BY IWMF KYLE ENDOWMENT FUND ESTABLISHED

BY JUDITH MAY, IWMF PRESIDENT

In honor of Dr. Robert A. Kyle and Mrs. Charlene M. Kyle, Judith May, IWMF President, announced the first ever endowment program for the IWMF at the 2009 Memphis Educational Forum. The goal of this very important project is to raise one million dollars. The annual interest earned on the Kyle Endowment Fund will be used to sponsor research initiatives. Judith's presentation at the appreciation luncheon on April 25 read as follows:

I believe everyone in our WM community knows Bob Kyle. Bob is a presenter at every Ed Forum and he is featured in many issues of the *Torch*. Bob travels from one end of the globe to the other presenting lectures on WM and related cancers. From small support group meetings in church halls in Minnesota to the Stockholm research workshop – to the Memphis Ed Forum – he enlightens both the newest patients as well as the veteran medical researchers on subjects of interest. I cannot begin to describe the long list of national and international awards that Bob has received, as there are so many, from the most prominent sources in the field of cancer. In the WM world, it is safe to say that he is known as the godfather of WM, having mentored many doctors who are now involved in WM research and seeing WM patients.

Dr. Robert Kyle Honored, cont. on page 2

Dr. Robert Kyle Honored, cont. from page 1

Bob Kyle's friendship with Dr. Jan Waldenstrom, who discovered our disease, began in 1965 and lasted until Dr. Waldenstrom's death in 1996. He is a friend to Dr. Waldenstrom's son, Dr. Anders Waldenstrom, who spoke at the recent Boston summit. Dr. Kyle is a special advisor and friend to the IWMF Board of Trustees. He is a charter member of the IWMF Scientific Advisory Committee and has been the Chair of that committee for over five years. Not only has he treated many WM patients over the years, but he is also a pioneer researcher in WM. We owe Bob Kyle our highest respect and appreciation for his continued interest in our disease.

As a tribute to his outstanding contributions to the IWMF and all of its membership, the Board of Trustees of the International Waldenstrom's Macroglobulinemia Foundation has established the Dr. Robert A. Kyle and Mrs. Charlene M. Kyle Endowment Fund – the *first* endowed fund of the IWMF. The annual income from this fund will be used for activities, strategies, people and programs associated with the IWMF Research Fund as determined by the IWMF Board and in accordance with special guidelines.

Our goal is to raise one million dollars. The IWMF membership – patients, caregivers, medical personnel – all are encouraged to contribute as we strive to reach our one million dollar objective.

Arlene Hinchcliffe and Dr. Robert A. Kyle

To start the ball rolling, please use the 5-in-5 Research Fund return envelope in this issue of the *Torch*. Open it up and note the second entry on the bottom half with this language: "Establish a Named or Designated Fund." For those of you who wish to participate in the Kyle Endowment Fund with a check, pledge, or estate gift, check this box and write 'Kyle Fund' right after the line and complete appropriate directions at the top of the envelope. Or call the office for the numbers to contact me or Dick Weiland, Vice President for Fundraising.

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HAVE YOUR SAY

The *Torch* welcomes letters, articles or suggestions for articles.
If you have something you'd like to share with your fellow WMers,
please contact Alice Riginos at 202-342-1069 or ariginos@sy-thetis.org

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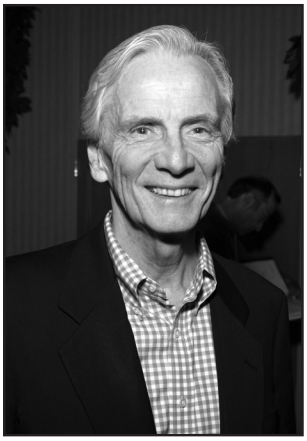
PRESIDENT'S CORNER

BY JUDITH MAY



Jim Bunton

Board Changes

It is with great respect and admiration for long-time Trustee Jim Bunton that I announce his retirement from the IWMF Board of Trustees. Jim has served on the Board for nine years, holding the executive positions of Treasurer and Vice-President for Administration, as well as Secretary. He served on the Executive Committee for all those years and was intimately involved in every aspect of member services and Board decisions that guided the growth of the foundation. Jim has been a strong and wise voice on the Board, and we have benefited from his many years of experience in the financial world and service on many other nonprofit boards. We will continue to seek Jim's advice, and he will remain active on the IWMF Investment Committee.

Two other Trustees have left the Board recently: Arlene Hinchcliffe and Roy Parker have completed their terms and we thank them heartily for their services and energy. Arlene, who is President of the Waldenstrom's Macroglobulinemia Foundation of Canada, will continue her efforts to establish more support groups in Canada and also her tremendous success with fundraising in Canada. We thank you both for all that you have done and may yet continue to do for WM patients everywhere.

Returning to the Board is Dr. Guy Sherwood, who is well-known to many of you. Guy will be holding the position of Chair of the International Committee and will continue to be very active as a senior writer for the *Torch* and a reviewer and writer of IWMF booklets. Guy is also on the Research Committee.

A recent new Trustee to the Board is Sue Herms. Sue is a microbiologist and has joined the IWMF Research Committee, a position for which she is very well qualified. You all have seen Sue's many medical articles in the *Torch*. She will continue to write for the *Torch* in the capacity of Medical News Editor. In addition to the Publications Committee, Sue will also serve on the Planning Committee for the next Ed Forum.

We warmly welcome Sue and Guy to the Board.

The Ed Forum

The Memphis Educational Forum was surprisingly well attended considering that there were two excellent patient conferences running almost back-to-back and that many members had to make a choice between the Boston Patient & Physician Summit and the IWMF Ed Forum. Some of you were able to attend both. DVDs will soon be available from both conferences. You can order the Ed Forum DVDs at our website or by contacting Sara McKinnie at 941-927-4963 or e-mail office@iwmf.com. She can also point you to the Boston Patient & Physician Summit DVDs as she worked at both conferences.

This year we accommodated a request from patient Bob Reeber and agreed that Bob and a group of patients (who participate in an online discussion group for WM patients with strong scientific backgrounds) could hold a science session at the forum. Bob was the organizer who sought out speakers on the topic of WM genetics and developed an agenda for a two-hour session, with lunch, for those who were in Memphis early Friday morning. The three speakers presented on the following topics: 1) New approaches & models for studying disease in humans through new and complex genetic studies in mice and rats; 2) Technologies and infomatics to support systems approaches to biomedical research; 3) A study of relationships between genetic variations in humans and individual variables in drug response. The session was very well received. Thank you, Bob.

We also want to send a big thank-you to Linda Heise, a professional with the Medicare system, for the information she shared and questions she answered in two breakout sessions for WM patients. This is very important information for many of us and was extremely well organized. Thank you, Linda.

And, of course, many thanks and much appreciation go to Cindy Furst and Roy Parker, the co-chairs of the Ed Forum this year for their hard work in staying focused on all the many details and working with the hotel to make this a very successful conference. Working with Cindy and Roy were Ed Forum Committee members Tom Myers, Bill Paul, Don Lindemann and myself.

Regarding the IWMF Ed Forum for 2010, we had announced earlier that the location would be Orlando, Florida. However, we recently made the decision to change the location to Las Vegas, Nevada. This we did to collaborate with Dr. Steve Treon and the Bing Center which will be holding the Patient & Physician Summit meetings every other year from now on. In 2011 the Summit will be held in Orlando. With the 2009 Summit held in Boston, and the Ed Forum for 2010 and the Summit for 2011 planned for Orlando, it seemed that holding major patient conferences in the East for three years was not fair to patients in other parts of the country. Las Vegas seems to be an appropriate and popular location for our 2010 Ed Forum. We will

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be collaborating with the DFCI Bing Center in planning future conferences so that they are held in different parts of the country and separated by a number of months to make it more likely that patients would attend both. The formats for these conferences are different from each other and serve different purposes. You can review the agendas for these conferences on the websites of the IWMF (www.iwmf.com) and the Bing Center (www.wmprogram.org). There will always be a need for patients to meet and mingle at Ed Forums. As long as members register and attend, the IWMF Ed Forums will continue.

Special Gift

I believe most of you received an e-mail from me in the form of a request for a Special Gift to the IWMF. As we all face the challenges of the current economic conditions, it is important for you to know that we appreciate your contributions that sustain the IWMF. We are working to further 'tighten the IWMF belt' without diminishing services. One way is through lowering our printing and mailing costs by making electronic versions of our materials available and downloadable on our website. If you would like to receive IWMF publications electronically instead of hard copy by mail, please let our office know and you will be placed on the electronic list. Just e-mail our office at office@iwmf.com.

Collaborations

We continue to appreciate the opportunities afforded us by the Lymphoma Research Foundation. The LRF holds regional workshops around the country as well as an annual Education Forum and invites the IWMF to arrange WM seminars wherever we are able to engage presenters and gather a group of WM patients to listen to experts on WM. On October 3 there will be a LRF workshop in San Francisco at which we will have a WM seminar. More details will be forthcoming on our website, or you can check the LRF website at www.lymphoma.org. We hope that as many IWMF members as possible will register for this seminar. It will be held at Hotel Nikko, and Dr. Ranjana Advani of Stanford University will be the Program Chairwoman.

The LRF will hold its annual Educational Forum on Lymphoma in New York City, October 23-25. A WM seminar is in the planning stages, and we encourage you to consider attending. More information will soon be available through e-mails, IWMF-Talk, and the IWMF and LRF websites. You will receive more information about this also through e-mails, IWMF-Talk notices, and the IWMF and LRF websites.

Please feel free to contact our office with any questions you may have. I look forward to seeing you at these future events.

Stay well,

Judith

IWMF Trustees 2008-09 (l to r): Ron Yee, Bill Paul, Roy Parker, Cindy Furst, Don Lindemann, Robert Kyle, Judith May, Tom Myers, Sue Herms, Peter DeNardis, Arlene Hinchcliffe, Don Brown. (missing: James Bunton, Marty Glassman, Elinor Howenstein, Dick Weiland)

ED FORUM MUSINGS

BY SECRET WALLIE

The 2009 IWMF Educational Forum was held April 24-26 at the Memphis Marriott East. As in previous years, the Ed Forum provided three days of informative sessions focusing on Waldenstrom's macroglobulinemia and covering its pathogenesis, genetics, side effects, treatments – both established and novel – plus many strategies for coping with WM for patient and caregiver alike. And, as usual, there were plenty of opportunities for socializing, greeting old acquaintances and making new friends. In the past those who did not attend had to wait for a Special Bulletin to be prepared and the Forum DVDs to circulate before they too could access the presentations, and even then they missed the social moments that make these annual gatherings so special. This year, however, all who stayed tuned to IWMF-TALK were able to keep up with events as they unfolded, thanks to the energetic blogging straight from the Marriott Memphis East by the self-styled Secret Wallie. Emerging from the mists of Memphis, Secret Wallie announced his arrival Thursday evening on IWMF-TALK and kept up a lively report for the next three days, blending factual accounts of the presentations by medical professionals with the social buzz of the participants. The response to Secret Wallie's style of reportage was so enthusiastic that the Torch here prints selections from Secret Wallie's blog as testimony to the success of another terrific IWMF Ed Forum.

THURSDAY: It's the eve of the 2009 Ed Forum in Memphis, Tennessee. One feels a sense of anticipation in the air and a yearning to connect (and reconnect) with fellow WMers in the coming days. The schedule of events and activities for Friday and Saturday (and Sunday morning) is packed with a varied and exhaustive list of presentations by researchers and medical professionals and promises to be enlightening to WM veterans and first-timers as well.

For the next couple of days, I will try to post some highlights of Ed Forum activities and give you a sense of what it's like to be at an Ed Forum from the perspective of a fellow attendee. I won't be presenting specifics of each presentation (it's just not physically possible), but I will provide highlights. My intent is to give you a sense of both the tangible (educational) and intangible (fellowship) benefits of attending an Ed Forum and of the Memphis Forum in particular. It is hoped that these postings will help you feel as if you are here with us.

Someone spread a rumor that Ron Draftz, Guy Sherwood, and Tom Myers will be donning white jumpsuits and doing their best Elvis impersonations during Friday's dinner. But that's just a rumor, and it may be best for everyone if that's the extent of it! (No offense, guys!)

Until tomorrow . . .

Secret Wallie in Memphis

FRIDAY: For several IWMF staff, members, and volunteers, the day began quite early at 6 am. They were seen scurrying back and forth to ensure that registration tables, name tags, pamphlets, and IWMF merchandise (t-shirts, caps, etc.) were available and ready when folks started to arrive. And arrive they did, some participants appearing as early as 8 am, even though the official start of the Ed Forum wouldn't be until 2 pm. Evidently, many people had decided that they wanted to take advantage of the various early bird sessions that were set to begin at 10 am.

It was quite an experience matching faces with the names of the many folks we communicate with and/or read about on IWMF-TALK. Just as important as listening to the presentations by various researchers and experts, if not more so, was being able to see so many fellow WM'ers in one place, being amazed at how hale and hearty everyone looked, as they swapped symptom and treatment stories with each other. Truly a wonderful, educational experience!

Many first-timers attended the early bird session on Understanding Your Blood Tests, where they learned the relevance of things like Complete Blood Counts, Chemical Panel and Immunofixations, and the various components of each. Others attended parts I and II of Dr. Brian Van Ness' presentation on the genetics behind cancer and WM. These sessions were well attended with over 50 people in each session.

Dr. Van Ness did a great job of explaining the mechanics and importance of genomic analysis. He stressed the importance of genomics and genetic studies to assess not only one's predisposition to disease but also one's ability to respond to therapy. The study of genome variations among people can be used to predict disease risk, disease prognosis, disease complications, and drug responses. High Tech Device of the Day: Affymetrix GeneChip Array Device for DNA and RNA analysis of blood samples (see http://www.affymetrix.com). Interesting Fact of the Day: adverse drug response is the fourth leading cause of death in the US (ahead of even pneumonia)! According to Dr. Van Ness, not too far down the road will be the day when we will all be carrying identity cards that have an encoded bar code representing the unique sequence of our own genome.

The Ed Forum officially opened with the afternoon's two-track sessions–one for the first-timers and one for veterans. Dr. Kyle kicked off the first-timers' session with his insightful, instructive introduction to WM, followed by Dr. Ansell's explanation of conventional treatments for WM and by Dr. McMaster's report on the NCI's familial studies of WM. The veterans' session was

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initiated with Dr. Abonour's discussion of various complications of WM, followed by Dr. Stone's discussion of hyperviscosity syndrome and cryoglobulinemia.

Dr. Ansell's presentation focused on various treatment options (and suggested the conventional wisdom of waiting until symptoms are present to treat):

- Watch and wait (carefully)
- Single agent treatment
- Combination of drugs
- Plasmapheresis
- Clinical trials with new agents
- Stem cell transplant

He also mentioned the various drug classes currently used for WM:

- Alkylating Agents (chlorambucil, cyclophosphamide)
- Purine Analogs (fludarabine, pentostatin, cladribine)
- Antibodies (rituximab, alemtuzumab/Campath)
- Proteosome Inhibitors (bortezomib/Velcade)
- Other (thalidomide, lenalidomide)

Dr. Ansell presented the Mayo Clinic's consensus recommendations for first-line treatments, which did suggest using any of the above drug classes, but, darn it, my jotting lost speed here! (Look for the presentation on the Ed Forum DVD's)

For those who have relapsed after previous therapy, he stated Mayo Clinic's consensus:

- First, consider a clinical trial
- If beneficial response lasted 2 or more years, consider repeating your original therapy
- If beneficial response lasted less than 2 years, consider an alternative first line therapy (see above)

NOTE: at this time, Mayo does NOT recommend maintenance Rituxan–not necessarily because it is not useful or effective, but because there is still no definitive study that clearly proves that maintenance Rituxan is useful for WM (the delay in reaction to Rituxan makes it difficult to do so).

Dr. McMaster outlined interesting results of the NCI's familial study – they had initial expectations of finding only a handful of families that had parents, children, and siblings with WM but ended up with many more, the majority of such families displaying two people in a family having WM. She encouraged us all to participate in the study – and stressed that the results of the blood and saliva testing can be kept confidential if you wish (so that if they find that somehow your children are "predisposed" to WM, the children are not notified as such – because we tend not to treat until symptoms appear and because, moreover, children of WM patients may never even get the disease).

The importance of this study is not only to see whether there is a genetic inheritance involved in WM but also to assess what is the same and what is different between family members with similar genetic codes when one member has WM and another does not. Information about how to participate and contact information can be found at the clinical trial website: http://clinicaltrials.gov/ct2/show/NCT00052234 (note: you don't have to travel to participate in this study).

Dr. Abonour discussed the various complications that can occur in patients with WM and how to address them (including peripheral neuropathy, fatigue, anemia, etc). He also stressed the importance of exercise in dealing with our disease. Avoiding exercise becomes a vicious cycle . . . the less you exercise, the more your muscles atrophy and the more sedentary you become, making you want to exercise less, and the cycle continues. And he stated something to the effect of "Just telling cancer victims that having a good attitude will help you manage your cancer is pure rubbish." He emphasized that the important thing is to maintain a "mindfulness-based stress reduction mechanism" and to use your willpower to overcome stress. He cited an article about "mindfulness-based stress reduction" in *Psychosomatic Medicine* (65: 571-581 (2003)).

The evening concluded with a reception and dinner for all attendees and a keynote address by Dr. Scott Howard of the St. Jude Hospital in Memphis. Much resveratrol was consumed during the reception (purely for medicinal purposes, of course). Also, participants were treated to a slideshow of pictures taken from past Ed Forums – so, if you were at a previous Ed Forum, chances are we still saw you on the big screen at this year's Forum!

The evening concluded with the President recognizing the Trustees and IWMF member volunteers who work tirelessly in a variety of roles to further the mission of the IWMF. Judith gave special thanks to this year's Ed Forum co-chairs, Roy Parker and Cindy Furst. Judith particularly wanted to recognize the caregivers in the audience and wished them well by way of a

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Ed Forum Musings, cont. from page 6

quote from former US First Lady Rosalyn Carter: "There are only four kinds of people in the world – those who have been caregivers, those who currently are caregivers, those who will be caregivers, and those who need caregivers."

Judith also welcomed those who had traveled the furthest to get to Tennessee – Veikko Hoikkala, a support group leader from Finland, and Marlies Oom, representing the MM & WM Patient Association of the Netherlands (CKP), along with the several members in attendance from Canada.

A reported sighting of Elvis's ghost in the hallway before dinner evidently convinced our would-be impersonators not to don their spandex jumpsuits. There was no singing either. We'll see what tomorrow's river cruise may bring in this regard... perhaps Elvis's ghost will whisper in the ear of Judith May or Sue Herms or Sara McKinnie to give us their rendition of "Hunk of IgM – er, Burning Love."

Oh yes...and Tai Chi is scheduled for Saturday morning at 6:30! Until tomorrow...

Your Secret Wallie in Memphis

Saturday: Believe it or not, I decided not to jot down all the notes I had taken throughout the day and only give you the highlights. It is unbelievable how much information is provided at these Ed Forums! Some casual "elevator conversation" I overheard included: "Gee, I feel so energized and have a renewed sense of how to deal with WM now" and "I'm on information overload – can't wait for the dinner cruise to unplug my brain." So here's a "brief" summary of the day's activities.

For some, the morning began bright and early at 6:30 with Tai Chi (you guessed it – that did not include yours truly). Breakfast was available for all at 7:15, and a full day of sessions and activities ensued.

The first session was "How Chemo Works" presented by Dr. Morie Gertz. Dr. Gertz encouraged us all to put on our high school chemistry and biology thinking-caps as he led us through the origins and mechanics of the primary types of chemotherapy that are used for WM. He discussed treatment mechanisms such as antibodies (rituximab), alkylating agents (melphalan, Leukeran, and Cytoxan), and nucleoside analogs (fludarabine).

Did you know rituximab originates from the fusion of human cells with mouse cells? Or that alkylating agents had their origin in mustard gas used in war time to kill enemy soldiers? Or that nucleoside analogs are used to halt the cell duplication process?

Questions posed to him included those about transformation due to the use of alkylating agents. The response was that about 5% of patients HEAVILY exposed (doses today are much smaller and shorter) could have transformation within 2-12 years, where the red and white blood cells become incapable of dividing further and myelodysplasia is the result. There is no simple therapy for this. This also explains why, when Cytoxan is doing good things against our bad cells, we're not left on Cytoxan treatments indefinitely. With regard to fludarabine/cladribine, transformation is much lower, but it is still a possibility. In his practice, Dr. Gertz doesn't let risk of transformation drive the treatment decision because it's so important to treat very active WM versus the very low chance of transformation. One final note he made regarding transformation was the hypothesis that it may not be the treatment itself that leads to transformation but possibly the fact that we are living longer and may be starting to exhibit the "natural" tendency for some WM'ers to have their disease transform – regardless of treatment type. But there have not been studies to prove this.

Next up was Dr. Levine, who discussed peripheral neuropathy. The process by which PN is diagnosed involves assessing whether the patient truly has PN, what type of PN it is, and how to treat the PN (or how to treat the symptoms). PN can affect either the central nervous system (brain, spinal cord), or the peripheral nervous system (when it leaves the spine to go to the extremities). Common symptoms include numbness/tingling, balance problems, tremors, muscle weakness, and pain. Dr. Levine ran over a long list of potential therapies and ways of managing neurological pain. Once again, the DVDs will have recorded all he advised.

The day also included morning and afternoon "breakout sessions"– five sessions taking place simultaneously–on topics such as: Rituxan and WM, Nutrition and Cancer, Caregivers, Newly Diagnosed, Medicare Questions related to WM, Disability Options, Estate Planning for WM Patients, and Support Group Leaders. (Unfortunately, many of these sessions may not have been taped for the Ed Forum DVD's – simply not enough video cameras to go around)

As is traditional at the Ed Forums, Saturday lunch provided the opportunity to present appreciation awards, introduce the Trustees, and make special announcements. The afternoon then began with a presentation by Dr. Ghobrial about novel agents used to treat WM, followed by a panel of WM patients discussing the mechanisms and benefits of participating in clinical trials.

Dr. Ghobrial discussed the exciting early results of ongoing clinical trials (many of them are specific to WM – which hasn't happened very often in the past) with such agents as perifosine, RAD001, Velcade/Rituxan combination, and enzaustarin and upcoming clinical trials with a proteosome inhibitor (like Velcade) called carfolzimib that should not have the PN issues

Ed Forum Musings, cont. on page 10

2009 IWMF EDUCATIONAL FORUM

Photos courtesy of Jack Whalen

2009 IWMF EDUCATIONAL FORUM

Photos courtesy of Jack Whalen

associated with Velcade. She also discussed the possibilities for individualized therapy and research that is ongoing, especially with regard to microRNA (miRNA) – and how, if one has high expression of miRNA 155, one would get treated in a certain way. Future challenges will involve finding the best combination that targets critical pathways regulating WM growth and resistance.

Questions were raised as to age limits for participating in clinical trials (there are no age limits) and logistical issues with regard to participating in trials in Boston at Dana-Farber (one does have to travel at his/her own expense to Boston on several occasions during the trial). Dr. Ghobrial did mention that they are working on getting a partnership with US Oncology to open up trials to multiple centers at different locations (and not just Dana-Farber in Boston). Another question was raised regarding FDA approval of drugs specifically for treatment of WM. DFCI is trying to pursue this also and is talking to the FDA, especially with regard to Velcade and RAD001. The issue is that most times the FDA only does such approvals with large phase 3 trials that involve 300 to 400 people – for rare, orphan diseases such as WM this is quite difficult. Fortunately, the FDA does have other provisions for diseases such as ours.

The last presentation of the day before the afternoon breakout sessions was the panel discussion regarding clinical trials organized by Dr. Guy Sherwood. The panelists were our fellow IWMF members/patients Marcia Klepac and Tom Howenstine, who discussed their experiences with clinical trials. Guy has participated in several clinical trials, as has Marcia–and both did so primarily because their disease was not responding well to various forms of treatment. Tom relayed his experiences with the RAD001 trial at Mayo. Many in the audience had also participated in clinical trials, and they encouraged all of us to participate in future trials. Travel costs can be an issue, along with health insurance considerations, but one can discuss these with the institution running the trial. In many cases, there are resources available and other arrangements that can be made to make this a little or no cost proposition for trial participants. (Many times arrangements have been made to do the treatment at the trial center – Boston, for example – and then have several subsequent blood tests performed at your local hospital rather than traveling to Boston for each test). One can view the current trials for WM at a website: http://www.clinicaltrials.gov – type in waldenstrom and search for it.

The afternoon breakout sessions came next, and then members were free to go out on the town in Memphis or join in the riverboat cruise for dinner and dancing with fellow members. It was an opportunity for many healthy activities for WM patients – taking in safe quantities of Vitamin D on a warm, sunny day in Memphis, ingesting resveratrol in a cup or two of red wine, and exercising while tripping the light fantastic on the decks of the riverboat. Participants had a great time, sharing the evening with each other and enjoying a relaxing evening under the stars on the Mississippi river. On one of the boats several members engaged in an impromptu dance competition of sorts with high school students from Ontario on a band trip to Memphis, and it was great to see some of our "more experienced" members school the students on the fine art of "free style" dancing. Unfortunately, Elvis was NOT sighted on either cruise, although we did have the opportunity to sing and dance to a couple of Elvis tunes...but no jumpsuits were donned at this time.

One more musing to go...gotta get a nap now.

Your Secret Wallie

Sunday: This will be the last of this year's Ed Forum Musings. Sunday, the last day of activities for the Forum, began much like Saturday with 6:30 am Tai Chi (nuts – missed it again!) followed by breakfast provided for all attendees. The day's activities included an optional breakfast meeting to discuss ways to raise money to help find a cure for WM, an Ask the Doctors session, and the annual IWMF Business Meeting, along with saying heartfelt goodbyes to the many fellow Wallies you encounter over the few days you're at the conference.

The "main attraction" of the morning was the Ask the Doctor session. The panel of doctors was introduced – Dr. Robert Kyle (the moderator and question-asker), Dr. Rafat Abonour, Dr. Morie Gertz, and Dr. Irene Ghobrial – and everyone in attendance gave them a standing ovation for everything they have been doing on our behalf with their research and in their clinical practices. Throughout the weekend attendees were encouraged to write down questions on small note cards and place them in a special collection box. The doctors would then review those questions and select a large number to respond to during this session. The doctors actually responded to 30 or so questions on a wide range of topics – Rituxan, Rituxan maintenance, causes of WM, familial risk, aggressive WM, transformation to DLBCL and MDS, linkage between IgM and cholesterol levels, light chains, auto-immune disease/immunodeficiency and WM, herpes zoster (shingles), average survival statistics, chemo brain, mental fogginess, and peripheral neuropathy.

Note: what impressed me most about these doctors (besides the fact that they continue to do valuable research for WM patients) is that they are so approachable when they are at the conference. Each day that they are there, they are quite receptive to patients introducing themselves to them and asking personal medical questions. It amazes me that these doctors are so courteous and caring, even when they are "off the clock", so to speak. I know I can't thank them enough for *everything* they do on our behalf, and *everything* speaks volumes about their dedication to our cause.

Ed Forum Musings, cont. on page 11

Ed Forum Musings, cont. from page 10

The Forum ended with the annual IWMF Business Meeting. President Judith May led the Board of Trustees in presentations regarding various activities that the IWMF is spearheading: IWMF financial report, publications, support groups, website redesign, patient database, fundraising, and research projects. Attendees were invited to ask questions.

After having sat through all the activities and events, I must say that I truly appreciate that the IWMF goes to the expense and tremendous effort of hosting such an event each year on behalf of all WM patients, families, and caregivers. After attending the Forum, one can only imagine the amount of coordination that must take place behind the scenes to put on such a wonderful event stretching over three days. It was a tremendous effort on the part of all the many, many volunteers who planned and worked on the spot.

Did I mention the sound and video crew? To help keep costs down, the IWMF has volunteers on hand to manage the sound system and the video recording system. They are all WM patient volunteers who painstakingly set up all meeting rooms so that microphones work properly, major sessions are caught on video, and projectors are available to all presenters. My hat's off to them for doing such an effort when they could just have easily been sitting back with the rest of us instead!

Overall, the entire event was amazing and (at times) mind numbing–but I learned a lot, and, just as importantly (if not more so), met many, many fantastic and interesting people who share in the WM journey that I find myself on. May we all continue on that journey together, hale and hearty, for many, many years to come!

And so farewell to Secret Wallie. Was he just another spectral illusion in the land of Elvis or will we hear again in 2010? Time alone will tell. But, in the meantime, members of the IWMF can look forward to receiving a Special Bulletin, now in preparation, with expanded details of the Ed Forum sessions. The Special Bulletin will be available electronically or mailed directly, and DVDs of the Ed Forum will soon be available for purchase. See insert to order your copy.

2009 BEN RUDE HERITAGE SOCIETY MEMBERS RECENT INDUCTEES DISPLAY AN INTERNATIONAL THEME

BY DICK WEILAND, VICE PRESIDENT FOR FUNDRAISING

During the appreciation luncheon at the Memphis Educational Forum, Judith May extended a warm welcome to members of the Ben Rude Heritage Society, both the founding members of 2008 and the new members of this year. Ben Rude, who was the second IWMF President, passed away in 2005, but his legacy of leadership is remembered and continues through the Ben Rude Heritage Society and through the Chairperson of the Society, his spouse, Laurie Rude. It was Laurie's pleasure to announce the 2009 members of the Ben Rude Heritage Society.

By way of introduction, Laurie noted that the program was initiated in 2008 with gifts totaling over one quarter of a million dollars. She was particularly pleased to announce that the accumulated intentional gifts from the donor families of 2009 now bring the total to $750,500!

Of the eleven families participating this year, one of the donors is from England, one from France, one from Canada, three from Florida, three from California, one from New York, and one from Arizona. Once again, the IWMF demonstrates an international profile.

One honoree prefers to remain anonymous, but we can tell you that he hails from the west and has named the IWMF in his government retirement account. (Incidentally, for those of you who prefer the role of a quiet benefactor, this is a great way to remember the IWMF)

Not all of the international honorees or family representatives could make it to Memphis for the presentations, but you may be interested in learning a bit about their backgrounds.

Jean-Marc Audibert's spouse, **Sarah**, shared this touching note with us from Vincennes, France: "My husband…was a very quiet person and I don't think he would have been comfortable in having any of his biographical information presented. Still, I would rather propose that you [share] his own words in French as we found them in his will, regarding a donation to IWMF:

> Cette association m'a aidé à comprendre ma maladie et mes traitements; je souhaite qu'elle poursuive ses efforts dans ce sens, en particulier auprès des patients de langue française. [This foundation helped me understand my illness and treatments. I wish that it can continue with its efforts for that purpose, especially towards French speaking patients.]

Sara Audibert adds, "It also seems important to point out that even if my husband felt constantly tired because of his illness, the treatments … [kept]… it under control over 12 years."

2009 Ben Rude Heritage Society, cont. on page 12

2009 Ben Rude Heritage Society, cont. from page 11

The third set of donors is **Martin** and **Marguerite Baer.** Martin's biography continues the international flavor. He was born in Germany, moved to Switzerland in 1941, and immigrated to the US in 1960 where he settled in New York City. Through a mutual friend he met Marguerite on a skiing trip in Illinois, and the rest is history. Martin started an international company making products used in film for the Kodak Company. His niece now runs the company while the Baers enjoy sunny Florida.

Norman W. Crandall, Jr., was born in Pasadena and lived in Arizona for 25 years. After a distinguished career with the 3M Company, he retired and earned a divinity degree. Norman is remembered by his friends for his many philanthropic works, including the gift from his estate to the IWMF.

Jan Dye – the spouse of **Tony Dye** – is pleased to be a part of this international recognition program as it perpetuates the memory of her late husband. She extended her regrets from Bromley, England, regarding her absence at the appreciation luncheon and added this note: "I shall never forget our IWMF 'family' and all the support and information we received from all of you over the years of Tony's illness."

Jed Gelber could not be in Memphis, but the spirits of the Gelber family certainly were. Jed's father, **Jack Gelber,** was a well-known Broadway playwright and former IWMF Board member. **Carol Gelber,** Jed's mother, served as the *Torch* editor for some time before succumbing to thyroid cancer. Jed's bequest from his IRA is in memory of his parents, both of whom knew Ben personally.

Stanley Kaufman was not in Memphis either, but he sent warm greetings to one and all, along with hearty thanks to the IWMF, which is "a wonderful organization." He appreciates the IWMF being on top of recent research with "timely reports on medical advances." Stan was diagnosed with WM one year after retiring as a policy analyst at the White House for government contracting. He is doing very well now.

Kathleen L. Miner is the founder of "A Miner Miracle," a San Francisco-based nonprofit, and, more recently, the Miner Miracle SHOP – both providing famous-maker clothing and accessories at deep discounts, professional clothing tips, image counseling, and presentation skills to low-income people seeking to enter the work force. Kathy has lots of experience with event fundraising and is currently helping the IWMF as a resource person for events.

Sam and **Gail Murdough** are no strangers to the IWMF. Sam worked at Polaroid and Bell & Howell before owning a marina in New Hampshire for 20 years. Gail worked in insurance before helping Sam at the marina. In 1997 Gail was diagnosed with WM; she is doing well, however, and is now active in nonprofit work with their church.

2009 Ben Rude Heritage Society, cont. on page 40

THE BEN RUDE HERITAGE SOCIETY INQUIRY FORM

I would like to support IWMF in one of the following ways. Please contact me about:

❑ A Bequest in my Will or making a Codicil
❑ A Charitable Remainder Trust
❑ A Gift Annuity
❑ A Life Estate or Real Estate Gift
❑ A Charitable Lead Trust
❑ Life Insurance
❑ Other _____

Signature

Name (please print)

Address/City/State/Zip

Telephone Number

E-mail Address

IWMF RESEARCH GRANT UPDATES

EDITED BY RONALD DRAFTZ

Understanding the formation and then the control of WM requires understanding which genes in our chromosomes are mutated. This may lead to understanding how these mutation processes can be blocked or modified to prevent the progression of WM. A technique known as array-based Comparative Genomic Hybridization (aCGH) or, more simply, microarray analysis, allows identification of genes and gene segments that are defective or have been deleted from chromosomes. The completed study summarized below was conducted under a grant from the IWMF and utilized high resolution microarray analysis to uncover various gene defects found in marrow samples from a group of WM patients. This information is part of a growing body of knowledge essential for studying what may control these defects and, in turn, control WM.

Since 2006 Dr. Esteban Braggio holds the position of Research Fellow in Dr. Rafael Fonseca's laboratory, Mayo Clinic Arizona, Scottsdale, AZ. Following completion of undergraduate studies in genetics at the Faculty of Chemical and Natural Sciences of the Universidad Nacional de Misiones, Posadas City, Argentina, Dr. Braggio received the degree of Master of Science from the Genetics Division, Faculty of Biological Sciences, Universidade Federal do Rio de Janeiro, Rio de Janeiro City, Brazil, and his Ph.D. in Science from the Faculty of Medicine, also at the Universidade Federal do Rio de Janeiro.

Tom Myers, IWMF Vice President for Research

Genome-Wide Characterization of DNA Copy Number Changes Using Array-based Comparative Genomic Hybridization in Waldenström Macroglobulinemia and Delineation of the Minimal Region of 6Q Deletion

BY ESTEBAN BRAGGIO

Dr. Esteban Braggio

Waldenström macroglobulinemia (WM) is an incurable, low-grade B-cell lymphoproliferative disorder characterized by bone marrow (BM) infiltration of a clonal population of small B-lymphocytes, plasmacytoid lymphocytes and plasma cells that secrete monoclonal IgM antibody.

The genetic basis of WM remains poorly understood. Few chromosomal abnormalities have been reported, reflecting the difficulty in obtaining enough cells for karyotypes (chromosome analysis). This test requires large numbers of dividing cells in metaphase, a stage of cell division when the chromosomes are highly condensed, thus their morphology can be analyzed and abnormalities can be identified. Because tumor cells are relatively slow growing in WM, compared to other tumor types, it can be difficult to obtain WM cells in this metaphase condition

Instead of studying karyotypes, we performed a comprehensive, array-based, comparative genomic hybridization analysis. In this method, tumor and normal DNA are labeled with different fluorescent dyes and then both DNA's are hybridized against an array composed by DNA probes complementary to 243,000 sequences spread all around the 23 pairs of chromosomes. The amount of tumor and normal DNA that hybridizes with each of those probes will reflect the relative amount of each DNA type in that specific region of the genome, thus identifying gains or losses in the tumor genome. This approach has two main advantages when compared with karyotype analysis: a) does not require cells in metaphase, thus allowing the analysis of all patients; and b) has a significantly higher resolution, making possible the study of chromosomes at the gene level.

Reading a Chromosome Address

Humans have 23 pairs of chromosomes that are numbered from the largest to the smallest. For example, the "11" in 11q22-23 indicates the 11th largest chromosome of the 23 chromosomes. Additional numbers are used to describe specific bands of that chromosome which can be distinguished by staining. These other numbers after the letter q provide a more specific address on a chromosome arm.

There are two pairs of arms: two identical long arms, q, and two identical short arms, p joined at a center (the centromere). The numbers following the letters p or q refer to the band location. For example, the "22-23" in an 11q22-23 deletion indicates that the deletion occurs within the range of 22 to 23 bands away from the centromere where the arms are joined. The numbers separated by a decimal point indicate a sub-band providing an even more precise address.

Think of the first chromosome number as the street, the second (band number or range) as the building number and any additional numbers as the apartment unit.

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Terminology Tips

Hybridization is the joining of two complementary strands of DNA which in microarray analyses identifies gene segments based on using known fluorescently labeled DNA probes that react with the DNA strands from patients.

Genes are DNA segments of a chromosome that are the physical and functional units of heredity.

Micro RNA's are short strands of ribonucleic acid that regulate genes and their formation of proteins.

Transcription is the copying or synthesis of RNA under the direction of DNA.

Overall, we analyzed 42 WM patients and we found copy number abnormalities (more or less than the normal two gene copies per genome) in 83% of them, with a median of three abnormalities per patient. The most common chromosomal abnormality, identified in 40% of patients, was the deletion of chromosome arm 6q. Other recurrent abnormalities identified were deletions on 13q14 (10%), 7q22, 8p, 11q22-23, 11q23.2-24, and 17p11.2-13.3 (7% each). At 13q14, the area deleted was similar to that described in chronic lymphocytic leukemia (CLL) patients and includes the microRNA genes MIRN15A and MIRN16-1, which have already been described as playing a key role in CLL pathogenesis. On the other hand, partial or whole gains of chromosome 18 and 6p were the most common gains (16.6% each), followed by gains of chromosome 4 (11.9%), and chromosomes 3, 8q and Xq27-28 (9.5% each). In our studies, a gain of 6p was always accompanied by a deletion of 6q.

At the gene level, we identified deletions and gene mutations affecting the genes TRAF3 and TNFAIP3. These two genes have tumor suppressor function that protects cells from developing into cancer. These two genes are part of a cellular pathway called nuclear factor kappa B (NF-kB) signaling pathway, which regulates the transcription of hundreds of genes into proteins involved in several cellular processes, such as inflammation, innate immunity, cell growth, and cell death. Both genes are described as "negative regulators" of the pathway, meaning that when they are inactivated, regulatory controls are lost, leading to improper regulation of immune response, cell growth, and cell death.

Such mutations affecting regulators of the NF-kB pathway highlight its biologic importance and suggest a therapeutic role for inhibitors of this pathway, such as bortezomib (Velcade), in the treatment of a subgroup of WM patients harboring mutations in that molecular pathway.

The characterization of WM and the identification of pathways to treating and curing WM could be greatly advanced by the use of animal models. To date, no WM animal model has been established for research. The study conducted by Dr. Tsingotjidou is one of the first attempts sponsored by the IWMF to develop a mouse model. The study has been completed and the following summary indicates that it was possible to induce WM in mice using bone implants from WM patients. The summary below was taken from the abstract of the paper that was published in the research journal Experimental Hematology (2009) 37(4):469-76. This study, with further work, may lead to a method for producing mice with WM for research and testing.

Anastasia S. Tsingotjidou is currently Lecturer in Anatomy, Histology and Embryology at the Faculty of Veterinary Medicine at the University of Thessaloniki, Greece. She received her Ph.D. in Neuroanatomy from the University of Thessaloniki, Greece, and was a postdoctoral fellow in the Department of Neurobiology and Orthopaedics at the School of Medicine and in the Section of Oral Radiology at the School of Dentistry of the University of California at Los Angeles. Her postdoctoral research interests focus on bone biology and the establishment of an animal model to investigate human bone metastasis of prostate cancer cells.

Tom Myers, IWMF Vice President for Research

Establishment of an Animal Model for Waldenström's Macroglobulinemia

BY ANASTASIA S. TSINGOTJIDOU

The present study was undertaken with the aim of developing a mouse model of WM using mice with the novel characteristics of being nonobese diabetic/severe combined immunodeficiency (NOD/SCID). Pairs of bone particles derived from adult humans with and without WM were successfully implanted intramuscularly in these NOD/SCID mice. Each mouse was implanted with a bone fragment taken from an adult without WM into one hind limb. A different biopsy chip taken from a WM patient was implanted in the other limb of the mouse.

All mice implanted with the WM bone marrow core biopsies had increased levels of serum IgM after just 1 month following the bone chip implantation. Histopathologic (microscopical exam of bone or tissue specimens) and immunohistochemical (monoclonal IgM proteins) analysis showed that in approximately half of the mice WM cells metastasized from the WM bone implant to the distantly implanted non-WM bone chip. Serum IgM value records of all mice correlated with histopathological observations and immunohistochemical analysis for neoplastic cell density and metastatic growth that was consistent with WM.

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Results obtained in the present study suggest that IgM-producing WM cells not only retained viability in the bone marrow of the WM bone biopsy but also developed in the normal bone marrow chip implanted into the mouse. The mouse model reported here improves on existing models of WM by essentially reproducing the adult human bone marrow microenvironment of abnormal WM tumor cells.

COOKS' HAPPY HOUR

BY PENNI WISNER AND NANCY LAMBERT

The other day, enjoying a salad lunch outdoors on a day as warm as I remember summer days in Connecticut (no, these are infrequent in San Francisco, no matter what your Beach Boy views of CA are), I had this sudden, visceral thought: "Summer! Corn! Tomatoes! Strawberries! Raspberries!" (I know, visceral thoughts come frequently to those of us obsessed–only in a healthy way, of course–with food.) And so, it is time to prepare and review our salad making skills, especially vinaigrette, so that we can fully utilize and enjoy summer's bounty.

Two, or maybe three, equipment notes before we launch into the actual food idea part of our *raison d'être*. In my work as a kitchen coach, I've noticed several important kitchen omissions that are very easy to rectify and will speed and improve your cooking enormously: make sure your knives are sharp! Then they do the work, not you. If you feel comfortable with one, invest in a small, inexpensive, hand-held mandoline. These make amazingly quick work of slicing anything from strawberries to cabbage. If you do not have a peppermill, buy one ASAP and keep it on the counter to use all the time. Oh yes, one more equipment tip: during this season, if you have one, move your mini-prep food processor to the counter top from whatever corner it has been occupying. Use it to chop shallots, garlic, ginger, etc., then add your other dressing ingredients. Make more dressing than you need and store it in a glass bottle in the fridge. Homemade convenience food.

Okay. The secret(s) to creating delicious salads is variety, a result of investing in a wide range of the highest quality fruits, vegetables, cheeses, nuts, and such. That means buying from local, organic, or biodynamic farmers at your farmers' markets that are flowering all over now. Check out http://find.mapmuse.com/interest/farmer-markets to find a market near you.

The second most important way to build variety into your salads is your dressing. You do not need to buy bottle after bottle of dressing. Nope. It takes how long to make your own, thirty seconds? Despite the gazillions of "recipes" for salad dressings you can find on the Internet, in magazines, and newspapers, you don't need one. All you need to know is this: one part acid (vinegar/lemon and/or citrus juice) and two to three parts oil. Salt and *freshly ground pepper*. Mix. Taste. Adjust balance with more oil or vinegar. Use your salad spoon as a measure and your salad bowl as your mixing bowl. Pile your salad ingredients on top. Cover with a dish towel and store in the refrigerator until serving time. Toss. Bingo.

Refinements: add salt and pepper to the vinegar and stir before you add the oil. Oil makes it harder for the salt to dissolve. Add a spoonful of prepared Dijon mustard (flavored with herbs, perhaps tarragon, is an easy way to add a different taste) to the vinegar and stir well. Then when you stir in the oil, the mustard creates an emulsion that keeps the oil in suspension and prevents your vinaigrette from separating. Vary your vinaigrette with different vinegars–apple cider, unseasoned rice vinegar (seasoned only means sugar has been added), balsamic, sherry vinegar, white and red wine vinegar, lemon, orange and grapefruit juice. Or use a combination. For stronger citrus flavors, you can simmer orange juice until reduced by half. Or roast or grill the fruit before squeezing it. For a touch of creaminess, add a dollop of thick, Greek yogurt or a teaspoon or so of mayonnaise.

Using various oils singly or in combination also creates variety. When my French godmother taught me to make vinaigrette, she used corn and vegetable oil. You can, too. Try extra-virgin olive oil made from different olive varieties and/or those made in different parts of the world. Add a small splash of toasted sesame oil. (But not truffle oil; save that to drizzle straight on fish or polenta.) If you love Caesar salad, crush some anchovies into the dressing and/or use the oil the anchovies were packed in. I sometimes add a bit of soy and fish sauce to my vinaigrettes. These add an undertone of savory pungency. You could also add a taste of Worcestershire for the same effect. To cut calories, you can add some good chicken stock or yogurt. I'm not one to suggest adding water to salad dressing. To me that just seems to dilute the flavor.

A few other notes: remember to use fresh herbs in your salads. Sometimes, to bite into a whole mint leaf, for instance, can seem overwhelming, so rough chop the herbs. And flowers! As long as they are garden grown away from pesticides, etc., many flowers are edible and make salads look so pretty. Incorrigible and invasive borage is in my garden, but I forgive it because I love the cucumber taste of its bright flowers. And the nasturtiums are also running wild (they are climbing the

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jasmine right now and trying to get onto the deck). They add a bright, spicy note. You can eat fuchsia, forget-me-nots, violets, bachelor buttons, calendulas and many more.

Ah, let's not forget cheese. I tend to prefer cheese grated or crumbled into salads versus blended into the dressing. Use a fine grater for light dustings of hard cheeses or use a vegetable peeler for thin curls. And crumble feta, goat, and blue cheeses. Give yourself permission to go to the market with the widest cheese selections and then ask for tastes. Bring home several new-to-you selections and add them to your salads. And then there's crumbled bacon, prosciutto slivers, crispy pancetta, maybe even leftover salmon skin or duck skin crisped in a skillet . . .

Got the idea?

Our motto: Eat Well to Stay Well

AN INTEGRATIVE PATH TO WELLNESS

BY JO CAVALLO

The spring 2009 issue of Lymphoma Today, the Lymphoma Research Foundation's newsletter, contained portions of this article by Jo Cavallo. The full article (including additional resources such as what you should know before getting a massage and taking another look at Vitamin C and cancer) is found below. The article is printed with the permission of the LRF.

Introduction

Although the practice of using a holistic approach to treat disease, relieve symptoms and promote healing dates back to the fourth century, B.C., when the Greek physician Hippocrates first advocated natural remedies to combat illnesses, holistic medicine really came into vogue in the 1960s and 1970s. The concept of holistic medicine is rooted in the belief that when one part of the body or mind is not functioning properly, the health of the whole person is affected and, therefore, therapies that treat the mind, body and spirit are necessary to make the person well.

Over the years, holistic medicine has morphed into two general categories: alternative and complementary, commonly identified by the acronym CAM (complementary and alternative medicine). However, medical experts say the term is problematic for cancer patients because, while there are distinct differences between the categories, patients often confuse the two approaches. Alternative therapy refers to unproven or disproven treatments that are used in place of standard or proven therapy, and complementary therapy is used in conjunction with standard medicine to help improve a patient's quality of life and relieve chemotherapy and radiation side effects.

"The term CAM is an obstacle for my colleagues and for the public because people think of alternative medicine, they don't hear the word complementary. Alternative means instead of conventional therapy and we're not talking about that. We're talking about using the best evidenced-based complementary therapies alongside conventional-based therapies to improve quality of life and the effects of chemotherapy and lessen the side effects of cancer therapies and the disease," says David Rosenthal, MD, past president of the Society for Integrative Oncology and medical director of the Leonard P. Zakim Center for Integrative Therapies at Dana-Farber Cancer Institute in Boston.

"When you're talking about cancers, there are no viable alternative treatments," says Kathleen Wesa, MD, assistant attending physician in the Integrative Medicine Service at Memorial Sloan-Kettering Cancer Center in New York City. Rather than CAM, oncologists prefer the term "integrative medicine," which they say more accurately describes therapies that complement conventional cancer treatments. "The term integrative medicine is becoming more popular and we're hoping that it's looked on more sincerely and not looked upon as alternative medicine," says Dr. Rosenthal.

Integrative medicine combines traditional cancer care with a vast array of unconventional therapies, including biologically-based products like herbs, botanicals and vitamins; special diets; chiropractic care, acupuncture and massage; mind/body relaxation techniques such as Reiki, yoga, meditation and guided imagery; and health-related prayer to alleviate treatment side effects and, in some cases, to even improve disease outcome.

The Role of Integrative Medicine in Lymphoma

While the use of unorthodox remedies to treat illness has a long history in this country, it was not until 1992 when the National Institutes of Health launched the Office of Alternative Medicine, now called the National Center for Complementary and Alternative Medicine (NCCAM), that the study of alternative and complementary therapy gained real legitimacy in traditional medicine. Since 1999, NCCAM has funded more than 2,200 research grants, including 370 that involved the treatment of

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An Integrative Path to Wellness, cont. from page 16

cancer. Besides NCCAM, many major academic cancer centers, including Memorial Sloan-Kettering, Dana-Farber, MD Anderson Cancer Center and the Mayo Clinic, have also launched clinical studies in complementary therapies. And some are showing benefits in the treatment of lymphoma patients.

"I think that the role of integrative oncology in lymphoma patients is to help them with disease symptoms and with the treatment of the cancer, but not to cure the lymphoma," says Donald Abrams, MD, chief of hematology/oncology at San Francisco General Hospital and director of Integrative Oncology Research at the University of California, San Francisco Osher Center for Integrative Medicine.

In fact, complementary therapies are proving to be so beneficial in relieving the treatment side effects of patients suffering from various blood cancers, Dr. Rosenthal says, that the number of physician referrals to integrative medicine specialists he sees is second only to those for patients combating breast cancer.

"What many lymphoma and leukemia patients are looking for is relief from symptoms and improving their quality of life and outcome of the disease. We know that some treatments for cancer cause nausea and vomiting and we know that acupuncture reduces nausea and vomiting and the need for [antiemetic drugs like] Ondansetron (Zofran), which can also cause side effects," says Dr. Rosenthal.

There is also evidence that body-based practices such as massage therapy can be instrumental in reducing pain and producing a sense of well-being in cancer patients. "We know that patients' pain scores as well as other symptoms such as anxiety, depression, insomnia and fatigue were decreased by 50 percent following a massage and that relief lasted for 48 hours," says Dr. Wesa. "There are also many calming effects from massage therapy such as an increase in the sense of serenity." However, Dr. Wesa cautions, before lymphoma patients decide to get a massage they should check with their oncologist to make sure their blood counts are normal and that they do not have lymphedema, localized fluid retention caused by a compromised lymphatic system, and that they go to a qualified massage therapist. (See "What You Should Know Before Getting a Massage")

Caution: Not Everything That is Natural is Good for You

While some complementary therapies like meditation, acupuncture and therapeutic massage have been found to be safe and effective in providing symptom relief from cancer treatment, others, such as the use of botanicals, herbs, vitamins and antioxidants, may actually be harmful, rendering some chemotherapy agents and radiation therapy less effective and more toxic. At the forefront of the controversy is the high-dose use of over-the-counter antioxidant supplements like vitamins A, C and E. Even antioxidant-rich drinks like green tea and pomegranate juice have come under scrutiny.

"Many chemotherapies like the alkylating agents cyclophosphamide (Cytoxan) and nitrogen mustard act by interfering with the oxidative process around the cells and there is some literature to suggest that if you give antioxidants you're preventing that oxidative process, so you're interfering with the overall aspects of radiation and chemotherapy," says Dr. Rosenthal.

Until more definitive research is done, say experts, it is best for lymphoma patients to avoid using antioxidants and dietary supplements, even in low doses. "Antioxidants are probably acceptable for people who don't have cancer because they help protect the cells. But if you have cancer and you're undergoing chemotherapy, are you protecting the cancer cells as well? You don't want to be drinking juices that are high in antioxidants such as cranberry, pomegranate, acai, goji or mangosteen because they have the potential to interfere with chemotherapy or radiation therapy. Having one cup of green tea per day is probably okay, but we don't know that for sure," says Dr. Wesa. "It is safest to avoid consuming large quantities of high-antioxidant containing foods and beverages during chemotherapy and/or radiation therapy. The antioxidant dietary supplements are definitely contraindicated."

One area of complementary medicine that is getting a lot of study is the efficacy, safety and toxicity of combining botanicals and herbs with conventional chemotherapy. "I don't think we know as integrative oncologists the extent to which certain things interact," says Dr. Abrams. "We have researchers at the National Cancer Institute (NCI) that do very elegant pharmacokinetic interaction studies between botanicals and chemotherapeutic substances and report seeing changes in the concentration of the chemotherapy when taken in the presence of a botanical. For example, I don't think a patient getting chemotherapy should be taking St. John's wort because it seems to decrease the area under the curve for most chemotherapeutic agents that are metabolized by the same liver enzyme system, [making the treatment less effective]."

The Importance of a Healthy Diet and Exercise

Although taking over-the-counter dietary supplements should be avoided during lymphoma treatment, eating a nutrient-rich diet is essential to maintaining stamina, boosting immune function and reducing the side effects of treatment. "If you have a malignancy that involves your immune system, down ramping inflammation in the body is desirable. And there are nutritional approaches for non-Hodgkin lymphoma patients that can be done both for the impact of inflammation on angiogenesis (the

An Integrative Path to Wellness, cont. on page 18

growth of new blood vessels), apoptosis (cell death) differentiation and immune competence," says Dr. Abrams. "You can minimize inflammation by eating an anti-inflammatory diet high in Omega 3 fatty acids and limiting the intake of animal-source fats to avoid Omega 6 fatty acids, which are pro-inflammatory."

Experts also recommend following the USDA Food Guide Pyramid (mypyramid.gov) to maintain a healthy diet while undergoing cancer therapy, including eating plenty of fruits and vegetables—at least two to four servings of fruits and three to five servings of vegetables a day—whole grains and chicken. Maintaining a regular exercise program most days of the week is also recommended to help reduce fatigue and stress and build muscular strength. However, before starting or resuming any exercise program, talk with your doctor to see how much and what types of activity are most appropriate for you.

The Bottom Line

The good news for lymphoma patients is that many lymphomas are treatable and curable with conventional medical care and patients should never consider alternative medicine alone for treatment, despite the "natural" cancer cure claims found on the Internet and elsewhere.

If you are interested in developing an integrative treatment plan, talk to your healthcare team about what might work best for you based on medical evidence and experience. And be sure to tell your medical team about any dietary supplements and vitamins you are taking and ask about potential conflicts or interference with your treatment.

"Doctors should ask their patients about their use of complementary therapies," says Dr. Abrams. "But if patients are not asked, they should tell their providers what they're taking."

Where to Find Help

To learn more about integrative medicine and the research that is being done, visit these websites.

- **American Cancer Society Complementary and Alternative Methods for Cancer Managemen**t (www.cancer.org/docroot/ETO/content/ETO_5_1_Introduction.asp) This page of the American Cancer Society contains a primer on alternative and complementary approaches to cancer care, questions to ask your healthcare provider and how to spot quackery and fraud.
- **MD Anderson Cancer Center's Complementary/Integrative Medicine Education Resources** (www.mdanderson.org/departments/cimer) This website provides links to research studies on a variety of complementary/integrative and alternative cancer therapies and clinical trials in integrative oncology at the cancer center.
- **Memorial Sloan-Kettering Cancer Center** (www.mskcc.org/aboutherbs) Here you will find evidence-based information and current research on herbs, botanicals and dietary supplements.
- **National Center for Complimentary and Alternative Medicine** (www.nccam.nih.gov) Published by the National Institutes of Health, this website provides a list of clinical trials, information on complementary and alternative therapies and how to be an informed consumer.
- **Quackwatch** (www.quackwatch.org) This comprehensive site contains information about questionable cancer treatment claims and tips on how consumers can protect themselves against fraud.

What You Should Know Before Getting a Massage

Anyone who has had a massage can testify to its relaxing and rejuvenating benefits. And for lymphoma patients undergoing treatment, having a therapeutic massage can be especially helpful in relieving pain, fatigue and anxiety. However, experts caution that there are some inherent risks in getting a massage that patients should know about before having one done.

"For lymphoma patients, the massage has to be performed by someone who is familiar with working with cancer patients," says Kathleen Wesa, MD, assistant attending physician in the Integrative Medicine Service at Memorial Sloan-Kettering Cancer Center. "You can't go to any massage therapist. There are some considerations, for example, if someone's blood counts are low, if the patient has had surgery or lymphodema. You don't want to be doing deep tissue massage on someone who has low platelets or on someone who is frail."

Because the needs of cancer patients and survivors are so unique, some spa facilities are now offering services specifically designed for them. Although, once again, some precautions should be taken to ensure that the facility and therapist are qualified to treat cancer patients.

"When a patient contacts a spa facility, she should always ask what type of specialized training the therapists have," says Barbara Stirewalt, director of The Spa at Mohonk Mountain House in New Paltz, New York, which began offering spa services to cancer patients two years ago. "If the spa facility doesn't offer clients a health questionnaire to fill out before getting a massage, clients should inform the spa about their treatment status. It's especially important to know whether lymph nodes

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have been removed. In addition, clients should ask questions about the therapists' qualifications in treating cancer patients or survivors."

Another important consideration, says Stirewalt, is to be sure that the massage therapist has received advanced training, preferably endorsed by the National Certification Board for Therapeutic Massage and Bodywork or by the American Massage Board Association.

To ensure your safety, check with your medical team before getting a massage and ask what you should be aware of regarding any potential complications or restrictions from your treatment.

Taking Another Look at Vitamin C and Cancer

Thirty years ago, Nobel laureate Linus Pauling made headlines with the publication of his book *Cancer and Vitamin C*, which suggested that vitamin C supplements could lengthen survival times of terminally ill cancer patients. Although Pauling's findings were later contested, new research on vitamin C and it is anti-tumor effect on non-Hodgkin lymphoma and other cancers may vindicate Pauling's earlier work.

A phase II clinical trial using intravenous high-dose vitamin C for patients with refractory non-Hodgkin lymphoma was recently launched at the Jefferson-Myrna Brind Center of Integrated Medicine at the Thomas Jefferson University and Hospital in Philadelphia to determine whether the treatment can slow the disease from progressing after first-line treatment has failed.

"We decided to do the study based upon the positive laboratory data in mice models as well as anecdotal data in human studies showing that high-dose vitamin C can be helpful for certain cancer types," says Daniel Monti, MD, executive and medical director of the Myrna Brind Center and lead investigator of the trial. "The reason that it's helpful is because we're giving it in doses you can only take intravenously. It does not work orally. Taken intravenously, vitamin C diffuses into the extra cellular space outside the blood stream and a conversion to hydrogen peroxide takes place, which causes apoptosis, or cell death, in certain types of cancers."

Preliminary data is showing that one of those cancer types is non-Hodgkin lymphoma because, says Dr. Monti, NHL cells do not process hydrogen peroxide. A phase I study of intravenous high-dose vitamin C in patients with various types of cancer has already been completed and showed that the treatment is safe and nontoxic. "We're starting with refractory non-Hodgkin lymphoma patients because we want them to get first-line care that's been proven to help. For patients who are no longer responding to first-line care or who never responded to it, this is worth a try because it's not going to hurt them," says Dr. Monti.

Despite Dr. Monti's early findings, the controversy surrounding vitamin C and its potential cancer benefits has not subsided. A recent laboratory study by researchers at Memorial Sloan-Kettering Cancer Center of the effects of vitamin C on cancer cells found that the supplement reduced the effectiveness of chemotherapy drugs. In another set of experiments in which mice were implanted with cancer cells, the researchers found that the tumors in mice implanted with cancer cells pretreated with vitamin C grew more quickly than tumors in mice not pretreated with vitamin C. However, says Dr. Monti, "in this study dihydro ascorbic acid, a form of vitamin C that is toxic to humans, was used making the generalization of the results difficult to interpret."

While Dr. Monti's FDA-approved study is using vitamin C in large intravenous dosages that function like a drug, until more is known about the role vitamin C and other antioxidants have on cancer and cancer treatment, your best bet is to stick to a healthy diet to get the nutrients you need rather than rely on dietary supplements. "Vitamin E, C and beta carotene are ones that people get over the counter, but you can get all those nutrients in the pulp of a glass of orange juice. So it behooves us to be very careful until we have seen what's going on [with the research]," says David Rosenthal, MD, medical director of the Leonard P. Zakim Center for Integrative Medicine Therapies at Dana-Farber Cancer Institute.

FROM CANADA: WMFC NEWS

BY ARLENE HINCHCLIFFE, WMFC PRESIDENT

The Waldenstrom's Macroglobulinemia Foundation of Canada is a branch of the International Waldenstrom's Macroglobulinemia Foundation serving our Canadian members. Established 10 years ago as the first WM support group in Canada, in 2003 we became a charitable foundation to assure tax-exempt status for the generous donations of our Canadian members.

Members of the WMFC are automatically members of the IWMF. The IWMF is dedicated to ensuring that its members receive the most current information available concerning treatments for and research on Waldenstrom's macroglobulinemia through booklets, the *Torch* newsletter, support groups, and the annual Educational Forum. All of the materials and services provided by the IWMF are available to WMFC members.

This year, as President of the WMFC, I will be focusing on promoting awareness of this rare cancer and creating more support groups across our country. Support groups are the foundation of the WMFC/IWMF. They provide a gathering of people who understand the challenges of living with WM, and participation in a support group provides comfort to family and friends during a difficult time. Currently there are five support groups across Canada: in Halifax, NS; Montreal, QC; Ottawa, ON; Oakville/Toronto, ON; and Vancouver, BC. Support groups or regional contacts are still needed in Calgary, Edmonton, Northern Ontario, New Brunswick, Saskatchewan, Manitoba and P.E.I. I hope Canadian WMFC members will join me in filling this need. Together, we can make a difference!

In this issue of the *Torch* the Canadian Lifeline is printed on page 37. The Lifeline is a list of WM veterans who are available by telephone and by e-mail to discuss specific issues related to Waldenstrom's macroglobulinemia. We are looking for more Canadian members who would be interested in joining our Lifeline list, which will be printed in future issues of the *Torch*.

If you are interested in reaching out and starting a group or volunteering on the Lifeline contact list in your community, please contact me for more information.

On a personal note, I have just concluded a three year term as a Trustee on the IWMF Board and would like to take this opportunity to say thank you to each and every member on the Board as well as to our support staff, Sara McKinnie and Gail Macdonald, for their outstanding efforts over the years to the IWMF.

I will end by reminding you that donations to the WMFC membership and research funds are welcome. To receive a tax receipt valid in Canada, go to our website www.wmfc.ca for a donation forms. Please forward all donations to WMFC, 260 Dalewood Drive, Oakville, ON L6J 4P3. Note: all donations from Canada sent to the IWMF are forwarded to the WMFC, and a Canadian tax receipt is automatically mailed in return.

I hope you are all having a great summer.

Arlene Hinchcliffe can be reached at: wmfc@noco.ca and 905-337-2450

THE ABC'S OF ANEMIA

BY SUE HERMS

The simplest definition of anemia is a condition that occurs when you don't have enough healthy red blood cells (also called erythrocytes or red corpuscles). Anemia is not a disease in and of itself but is rather a sign of an underlying disease process.

Red blood cells (RBCs) are the transporters of oxygen and carbon dioxide to and from your lungs and your tissues. They are made in the bone marrow through a series of complicated steps requiring several nutrients and interaction with a hormone called erythropoietin produced by the kidneys, which monitor the oxygen level in the body. As RBCs mature, they are released into the bloodstream. The part of each RBC that binds to oxygen and carbon dioxide is the red-pigmented protein called hemoglobin. One of the interesting things about red blood cells is that mature cells no longer have a nucleus or many other typical cell structures and cannot reproduce themselves. Basically, they are not much more than a container for hemoglobin. They last for about 120 days in the circulation and constantly need to be replaced because of the wear and tear they go through while traveling throughout the body.

The general symptoms of anemia may range from very mild to severe. Commonly, affected people complain of weakness or fatigue, dizziness, cold hands and feet, headache, poor mental concentration, and shortness of breath. Pale skin, lips, gums, and nail beds can indicate more severe anemia. Very severe anemia can lead to palpitations, sweatiness, and heart failure.

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Some types of anemia also have their own fairly specific symptoms, which can be helpful in the diagnosis.

The starting point for the diagnosis of anemia is usually the Complete Blood Count (CBC), and the tests that the physician examines are red blood cell count, hemoglobin, and hematocrit. Normal ranges for these values vary somewhat by age and gender: normal RBC count is approximately 4-6 million cells per cubic millimeter, normal hemoglobin is generally 12-18 grams per deciliter, and normal hematocrit is usually 35-45%. Instruments also measure the size of the RBCs (the mean corpuscular volume or MCV), which can be an important tool in distinguishing among the causes of anemia, since some anemias will cause RBCs to be either smaller or larger than normal. An experienced medical technologist or pathologist can look at red blood cells under a microscope and see clues that point to a particular cause – in addition to size variations, certain kinds of anemia will result in changes to the shape or intensity of color of the RBCs. Another measurement that can be helpful is the reticulocyte count. Reticulocytes are immature RBCs that are released into the bloodstream; a certain amount is normal in order to maintain a steady RBC turnover, but large numbers of reticulocytes may indicate that the bone marrow is attempting to replace excessive losses of RBCs.

Additional tests are usually required to establish a firm reason for the anemia. It is important for patients to have these additional workups rather than assume the cause of the problem. Occasionally, there may be more than one reason for anemia; for instance, a poor diet can cause one to be anemic due to several dietary deficiencies. Also, one should not take dietary supplements without establishing that they are necessary or beneficial since overdosing of some supplements can create problems.

Because of the complex process involved in the development and maintenance of the proper amount of RBCs in our bodies, a problem in any part of this process can lead to anemia. Believe it or not, there are more than 400 different anemias. A description of every anemia is beyond the scope of this article, but this discussion will include some of the most common ones and/or the ones most closely associated with diseases such as WM. Anemia can be classified into four broad categories: anemia due to excessive blood loss, inefficient or faulty hemoglobin or red blood cell production, anemia of chronic disease, and anemia due to excessive destruction of red blood cells.

Anemia Due to Excessive Blood Loss

Anemia through excessive blood loss can occur in many different ways. Obviously, an acute hemorrhage can cause anemia, but chronic blood loss is an often-overlooked reason because it can be difficult to detect. Chronic blood loss can occur because of bleeding ulcers, hemorrhoids, colon cancer, parasitic infestation, menstruation, pregnancy, or the use of nonsteroidal anti-inflammatory drugs (NSAIDS), just to name a few of the most common examples. A physician who suspects anemia from chronic bleeding might test for occult blood or parasites in the stool or perform endoscopy, colonoscopy, X-rays, CT scans, etc., to look for the sources of the bleeding.

Anemia Due to Inefficient or Faulty Hemoglobin or Red Blood Cell Production

Inefficient or faulty red blood cell production can be due to many different factors. The most common cause, and the one that we are probably most familiar with, is iron deficiency. Iron is a key component of hemoglobin, so if you don't consume enough in your diet, you will be anemic. After absorption into the bloodstream, the iron is transported by a carrier protein called transferrin to the bone marrow where it is incorporated into the red blood cells. Excess iron is stored as ferritin and hemosiderin in the liver, spleen, and other places. Therefore, if your doctor suspects that you have an iron deficiency, he will do tests to measure the amount of iron in your system, both circulating and stored, by tests called serum ferritin, serum iron, serum transferrin, and total iron binding capacity. Obviously, the treatment for iron deficiency anemia is to increase your iron intake.

There are other nutrients that can affect red blood cell production, and these include primarily Vitamin B12 and folate. Megaloblastic anemia is caused by a deficiency of B12, folate, or both. A subtype of megaloblastic anemia, called pernicious anemia, occurs primarily from the lack of intrinsic factor, which is produced in the stomach and is required for absorption of B12 from food. Patients with pernicious anemia may have additional symptoms of peripheral neuropathy, balance problems, and a very red, smooth, swollen tongue. Levels of B12, folate, and intrinsic factor can be tested. If diet is the problem, then one needs to increase the intake of the particular nutrient involved; if it is an absorption problem, then regular injections of B12 may be necessary.

Sideroblastic anemia is a disorder in which the body has adequate iron but is unable to incorporate it into the hemoglobin. The iron accumulates in the RBCs and gives the inside of the immature cells a characteristic appearance, which can be viewed by special staining under a microscope. These immature RBCs develop poorly and anemia is the consequence. Sideroblastic anemia may be inherited or may be acquired due to nutritional imbalances or prolonged exposures to toxins such as alcohol, lead, or drugs. Iron overload accompanies sideroblastic anemia because iron accumulates in the tissues rather than being used

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in the synthesis of hemoglobin. Repeated blood transfusions to relieve the resulting anemia will contribute significantly to the iron burden and may require chelation therapy to reduce the iron.

There are several genetic conditions affecting the formation of the red cell or of the hemoglobin protein. Probably the one most familiar to us is sickle cell anemia. In this case, a genetic defect in the hemoglobin causes the red blood cells to assume a crescent or sickle shape instead of the normal round shape. These red blood cells break down rapidly, so that sufficient oxygen does not get to the body's tissues, and the red blood cells can get stuck in the tiny blood vessels, causing pain and tissue damage. Thalessemia, another genetic defect, occurs when the protein chains that make up hemoglobin are produced at a decreased rate. Hemoglobin electrophoresis is a useful test for diagnosing these hereditary hemoglobin disorders. Other acquired or genetic defects in the RBC membrane can cause changes in the shape or size of the cell that lead to a shorter span of life in the circulation. Some diseases, called porphyrias, result from problems in the various enzyme pathways involved in production of the hemoglobin protein.

Aplastic anemia occurs when there is a marked reduction or absence of the stem cells that produce the blood-forming cells. This can be an inherited condition or can be acquired as a result of exposure to radiation, toxins (such as lead), certain medications, chemotherapies, or infections. Bone marrow biopsies are useful in diagnosing aplastic anemia, and therapy might include bone marrow transplantation.

Anemia of Chronic Disease

Many long-term medical conditions can cause anemia. One that we are all aware of is cancer, particularly the blood cancers such as leukemia or lymphoma. Anemia can be one of the earliest indicators of blood cancer and frequently initiates the process leading to the cancer diagnosis. In this situation, the tumor cells increase and crowd the normal blood-forming cells in the marrow so that they cannot adequately supply the body's need for RBCs. Some cancers may produce chemokines, or substances that may interfere with the normal mechanisms for blood cell formation. Chronic kidney disease can lead to anemia because the kidneys cannot produce enough erythropoietin to stimulate adequate red blood cell production. In these cases, transfusions or administration of erythropoietin agents such as Procrit or Aranesp may help with red blood cell production. Obviously, improvement of the underlying conditions with appropriate treatments can improve production as well.

Anemia Due to Excessive Destruction of Red Blood Cells

When red blood cells break down normally, most are removed by macrophages, particularly macrophages in the spleen. The iron in the hemoglobin protein is recycled to the bone marrow, the amino acids are returned to the liver, and another portion of the original hemoglobin protein is converted to bilirubin and transported to the liver, where it is further broken down and small amounts are excreted in the stool and the urine. Excessive destruction of red blood cells in the spleen, sometimes resulting from an enlarged spleen, will result in more bilirubin, possibly causing jaundice (yellowing) of the skin and eyes. Occasionally, removal of the spleen (splenectomy) may help to alleviate this problem.

When red blood cells are fragile and cannot withstand the stress of the circulatory system, they may rupture prematurely, causing hemolytic anemia. Some conditions causing hemolytic anemia are inherited. Others can be acquired as a result of certain infections, medications, or autoimmune diseases. In rare cases of WM, the cancerous B-cells produce an IgM protein which initiates an antibody attack on the body's own red blood cells at cold temperatures, causing them to break down. This condition is called cold agglutinin disease or cold hemolytic anemia. If this occurs in the bloodstream, large amounts of hemoglobin are released into the blood rather than going through the destruction process in the spleen and liver. Some of this hemoglobin may be recycled, but it may also overwhelm the body's usual mechanisms and be excreted by the kidneys, resulting in pink or red urine (hemoglobinuria). Hemolytic anemias can be treated with steroids, immunosuppressant drugs, or gamma globulin to help suppress the immune system's attack on the red blood cells.

MEDICAL NEWS ROUNDUP

BY SUE HERMS

Topical Menthol May Relieve Neuropathy from Velcade Treatment – Bortezomib (Velcade) treatment has been reported to lead to neuropathy in approximately 35% of multiple myeloma patients, with up to 15% suffering from severe pain, often requiring cessation of treatment. The University of Edinburgh in Edinburgh, Scotland, has reported a case study of a multiple myeloma (MM) patient with severe neuropathy induced by bortezomib who did not receive relief from standard treatments for pain. Based on preclinical studies, researchers applied topical 0.5% menthol in calamine cream to the area of pain and to the skin over the area of the spine where the affected nerves originated. After 5 days of twice daily applications, the patient reported sustained improvement in pain control, sleep, mobility, general function, and mood.

Turmeric and Green Tea Extracts Active Against CLL Cells – Both M. D. Anderson Cancer Center and the Mayo Clinic in Rochester have studied curcumin, the active ingredient in the spice turmeric, and the green tea extract epigallocatechin-3-gallate for the treatment of chronic lymphocytic leukemia (CLL). Curcumin induced apoptosis (programmed cell death) in CLL B-cell lines in a dose-dependent manner, and when the green tea extract was administered sequentially, there was a synergistic response. Additional evaluation of curcumin as a potential therapeutic agent appears to be warranted.

Oral Drug Decreases Adhesion of MM Cells in Bone Marrow – Researchers at Dana-Farber Cancer Institute and the University of Torino in Italy studied an oral drug called defibrotide for treatment of multiple myeloma (MM). Defibrotide enhanced the sensitivity of tumor cells in animal models to chemotherapies such as melphalan and dexamethasone and decreased the adhesion of MM cells to the bone marrow stroma. The data suggest that using defibrotide in combination with conventional and novel therapies can potentially improve patient outcome in MM and other malignancies.

Sequential Drug Administration of FCR Reduces Toxicity in CLL Patients – Rather than administering combination therapy of fludarabine, cyclophosphamide, and rituximab together in the treatment of chronic lymphocytic leukemia (CLL) patients, Sloan-Kettering Cancer Center evaluated the sequential delivery of the same drugs, in order to reduce some of the toxicity that occurs when the drugs are co-administered. Thirty six previously untreated patients participated in the study: 89% achieved a response and of these, 61% were complete responses. The five-year survival rate for the entire group was 71%.

Swiss Researchers Improve Rituximab Activity – Researchers from the Swiss Federal Institute of Technology and University Hospital Schleswig-Holstein in Germany explored the use of a human monoclonal antibody L19 combined with interleukin-2 (IL2) in the treatment of B-cell non-Hodgkin's lymphoma patients. L19 selectively localizes to lymphoma-associated blood vessels. The combined L19-IL2 treatment, when co-administered with rituximab, activated the body's own natural killer cells, induced complete responses of localized lymphoma, and provided long-lasting protection from disseminated lymphoma. L19 is manufactured by Bayer Schering.

Rituximab Maintenance Therapy Results in Higher Risk of Infection – The Department of Medical Oncology at Hacettepe University Institute of Oncology in Turkey studied the infectious complications of rituximab maintenance therapy in lymphoma patients. Because B-cells are depleted throughout the maintenance period and even longer, this may render patients at higher risk for infections. This study, which reviewed five previous trials of such maintenance therapy, concluded that patients receiving rituximab maintenance treatment do have a higher risk of neutropenia and infection and that those patients who had also received fludarabine regimens are even more susceptible to infectious complications and require extended follow up and vigilance.

Genentech Evaluating Antibody-Drug Conjugates for NHL Treatment – Genentech Inc. has reported on the use of antibody-drug conjugates, which are potent cytotoxic (toxic to the cell) drugs linked to monoclonal antibodies via chemical bonds, as a means to increase the effectiveness of therapy in non-Hodgkin's lymphoma. The company identified seven antigens (CD19, CD20, CD21, CD22, CD72, CD79B, and CD180) which could potentially work well with these conjugates and has tested them in animal models.

Concurrent Plasma Exchange May Interfere with Rituximab Effectiveness – The Department of Haematology at University College London, UK, studied the effects of plasma exchange on rituximab levels and response to rituximab in patients with acute idiopathic thrombotic thrombocytopenic purpura. This disease is thought to be autoimmune in nature and attacks the platelets, causing bleeding disorders. Because these patients are sometimes given rituximab during the period that they are undergoing plasma exchange, the researchers wanted to know whether rituximab is removed and whether this affects response to treatment. Rituximab levels in 16 patients were measured before and after plasma exchange, after each rituximab dose, and then when each patient was in remission. In addition, patients who received rituximab only were also tested as a control. The researchers concluded that rituximab was removed by plasma exchange (it was detected in the removed plasma) and that the peak doses achieved were higher in those

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who did not receive plasma exchange. Higher rituximab levels were associated with fewer exchanges. Longer term follow up is needed to determine whether the peak rituximab concentration achieved correlates with duration of remission. This study also has implications for cancer patients who undergo plasma exchange while receiving rituximab therapy.

Vidaza Used for Treatment of Myelodysplastic Syndrome – Results of a Phase 3 study of azacitidine (Vidaza) for the treatment of myelodysplastic syndrome were reported in the British medical journal *Lancet.* Between February 2004 and August 2006, 358 patients were randomly assigned to receive azacitidine versus conventional care (supportive care, low-dose cytarabine, or intensive chemotherapy). After a median follow up of 21 months, median overall survival for the azacitidine group was 24.5 months compared to 15.0 months for the conventional care group.

Vidaza Also Studied in WM Cells – Meanwhile, Dana-Farber Cancer Institute evaluated the effects of azacitidine in WM cell lines, as it has been reported in preclinical studies on a number of other myeloid and lymphoid disorders. Azacitidine induced significant apoptosis (programmed cell death) by inhibition of mTORC1 activity while no significant toxic effects were observed in healthy peripheral blood cells.

Alcohol Consumption May Reduce NHL Risk – Alcohol consumption is associated with decreased risk of most types of non-Hodgkin's lymphoma, according to the University of Maryland School of Medicine. The observed lower risk does not seem to vary with beverage type. It appears that low dose chronic exposure to ethanol inhibits the mTORC1 pathway, resulting in decreased lymphoma growth, thus underlining the importance of mTOR signaling in lymphoma.

Relatives of CLL Patients May Have Increased Risk of Developing CLL, WM, and Hairy Cell Leukemia – The National Cancer Institute evaluated the risk of chronic lymphocytic leukemia (CLL) and other indolent non-Hodgkin's lymphomas (NHL) among relatives of patients with CLL. Population-based registry data from Sweden were used to evaluate outcomes in 26,947 first-degree relatives of 9,717 CLL patients, compared to matched controls. Compared to the controls, relatives of CLL patients have an increased risk for CLL and certain other NHLs, particularly lymphoplasmacytic lymphoma/WM and hairy cell leukemia. These conclusions may provide novel clues to research designed to uncover the early mechanisms that lead to the development of these diseases.

Deletion of Chromosome 6q in WM Does Not Appear to Impact Overall Survival – The deletion of the long arm of chromosome 6 (6q deletion) is the most common genetic abnormality associated with WM, but its prognostic significance is unclear. The University of Toronto in Canada investigated 77 patients with WM and correlated their disease status with the patients' clinical features and survival. 6q deletions were detected in 41.6% of patients but there did not appear to be any significant difference in time to initial treatment between deleted and non-deleted groups or in overall survival.

High Ki-67 Expression in Follicular Lymphoma May Predict Treatment Effectiveness – Showa University in Tokyo analyzed the relationship between the effect of rituximab plus chemotherapy and the expression of Ki-67, a cancer antigen found in growing, dividing cells but not in resting cells. While the marker has been used to predict prognosis for several solid tumors, this study investigated the marker in cases of follicular lymphoma and diffuse large B-cell lymphoma. Forty four patients were included in this study. Significant correlation was found between an inferior response to treatment and high Ki-67 expression in follicular lymphoma. The cell cycle appears to be an important factor in the effectiveness of treatment; therefore, Ki-67 expression may be an important treatment predictor.

Important MicroRNAs Determined for WM – The University of Bari Medical School in Italy has evaluated the role of microRNAs in regulating the biology and prognosis of WM. MicroRNAs are short, noncoding RNAs with critical functions in cell growth, survival, and differentiation. They can regulate expression of multiple genes and are often tissue specific and dysregulated in malignancies. Of the seven microRNAs identified in this study as being over- or under-expressed in WM, the most significant appears to be microRNA-155, which inhibits MAPK/ERK, P13/AKT, and NF-kB pathways, all of which are known to be activated in WM and other B-cell malignancies. MicroRNA-155 had similar expression in both treated and untreated patients and may be regarded as a potential therapeutic target for WM.

Arno Therapeutics Plans Phase I Trial for New Oral Drug for Lymphoma – Arno Therapeutics announced that the U.S. Food and Drug Administration accepted its investigational new drug application for the use of AR-12, an orally available drug that blocks the P13/AKT pathway and induces the endoplasmic reticulum stress pathway that helps to regulate protein secretions such as immunoglobulins. Acceptance of the application allows Arno to initiate a Phase 1 clinical trial in adults with advanced or recurrent solid tumors or lymphoma for which no standard therapy is available. The Phase 1 trial is expected to begin during the second half of 2009.

Ginger May Reduce Nausea from Cancer Chemotherapy – According to scientists at the James Wilmot Cancer Center at the University of Rochester, people with nausea from chemotherapy can reduce post-chemotherapy nausea by 40% by using ginger supplements, along with standard anti-vomiting drugs, before undergoing treatment. This Phase 2/3 study included 644 cancer patients, some of

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whom took ginger supplements for three days prior to chemotherapy and for three days following treatment. Researchers cautioned that ginger ale or other ginger-flavored products may not provide the same benefit; this study used a specially formulated gel cap containing concentrated, purified ginger root extract made by Aphios Corporation.

The author gratefully acknowledges the efforts of Arlene Carsten, Peter DeNardis, Mike Dewhirst, Gareth Evans, Daniel Hachigian, John Paasch, Colin Perrott, Howard Prestwich, and Bert Visheau in disseminating news of interest to the IWMF-Talk community.

THE THIRD INTERNATIONAL PATIENT & PHYSICIAN SUMMIT ON WALDENSTROM'S MACROGLOBULINEMIA

BY GUY SHERWOOD, M.D.

The Harvard Club in Boston, Massachusetts, was the setting for the international conference for patients and physicians interested in the latest scientific developments in WM, which took place on the weekend of May 1-3. Sponsored by the Bing Center for Waldenström's Macroglobulinemia at the Dana-Farber Cancer Institute of Harvard University, the summit was attended by 40 WM researchers and experts from all over the world and by over 600 WM patients and caregivers.

The agenda for the meeting closely paralleled the Fifth International Workshop on Waldenström's Macroglobulinemia (IWWM5) held in Stockholm in October 2008. Concise presentations were delivered in seven sessions focusing on the clinicopathological basis, genetic predisposition, pathogenesis, prognosis, treatment options, novel therapies, transplant options in WM. Each session consisted of five or six lectures, and ample time was available for questions from the audience at the end of each session. The final session, comprised of six interesting case presentations in WM and a discussion of possible avenues of treatment, was the culmination of a very informative three days for the patients and caregivers.

As we have come to expect, Dr. Steven Treon and Christopher Patterson (principal organizers of this summit and of the Stockholm Workshop) had planned social events for the evenings that were nothing short of spectacular. The fiftieth floor of the Prudential Tower Skywalk was the site for the welcome reception and dinner on Friday night. Attendees were able to mingle amongst themselves, all the while enjoying a breathtaking panoramic view of Boston's skyline. The historic Harvard Club was the site of the gala dinner on Saturday night. Dr. Anders Waldenström, son of the late Dr. Jan Waldenström, and Dr. Giampaolo Merlini, student and long-time friend of Dr. Waldenström, both shared reminiscences, many amusing, about the great scientist who lent his name to this peculiar disease. Dr. Peter Bing, physician, benefactor, and WM patient himself, delivered a heartwarming and passionate speech about survivorship with WM.

Although much of the conference was organized in formal sessions, many of the WM patients and caregivers present were able to discuss their own personal WM journeys and experiences with others over lunch and during coffee breaks. The overwhelming majority of the WM patients attending were patients, either current or past, of Dr. Treon and Dr. Irene Ghobrial – or patients who had sought out second opinions from these highly qualified physicians at the Dana-Farber Cancer Institute's WM clinic. Many, if not most, of the patients and caregivers were from the New England region, although a few souls did venture from Europe and even Asia. Our European brethren marvel at the accessibility of the WM experts at these conferences – noting that this sort of event where physicians interact with patients in a casual and relaxed manner is rare indeed.

I attended all of the sessions and took quick notes in the excellent syllabus provided. The syllabus contains biographies of the speakers present, abstracts of all the lectures, and photocopies of their PowerPoint slides. Rather than go through and summarize each lecture in every session, I will highlight some of the salient points from several of the lectures (please recall that a summary in "layperson's language" of all of the proceedings from the IWWM5 workshop in Stockholm, October 2008, is available on the IWMF website at www.iwmf.com/Publications.htm).

As has become the custom at WM conferences, Dr. Robert Kyle led off the meeting with his presentation on MGUS, WM and smoldering WM (SWM). Dr. Kyle stated that IgM MGUS is a precursor to WM; but it is important to note that only 1.5% of IgM MGUS patients per year will progress to WM and that the progression rate from SWM to frank WM is approximately 11% per year with 55% of SWM patients progressing to WM in 5 years and 65% in 10 years.

Dr. Roger Owen from England discussed the pathological findings in WM and reaffirmed the widely-accepted belief that bone marrow biopsy is critically important in the determination of disease state, whether at diagnosis or at a later phase in

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the course of the disease, and is the only currently reliable method of determining the immunophenotype (cell surface marker protein, e.g. CD-20) of WM cells.

A very interesting lecture on Bing-Neel Syndrome questioned whether this peculiar syndrome is caused by cellular invasion of WM cells in the brain ("Type A"?), or simply caused by IgM infiltration ("Type B"?).

Dr. Mary McMaster reiterated that routine screening for WM is not recommended for family members of WM patients.

Dr. Treon mentioned the new FDA-approved test for the FcγIIIA polymorphism that will enable physicians to determine if a WM patient may respond favorably to Rituxan. MicroRNAs are now being studied extensively in WM, and these gene regulatory molecules may hold promise as specific targets in future WM treatments. Gene expression profiling is also an exciting new technology that will predict the clinical response of drugs and drug combinations in individual patients.

Dr. Ghobrial thrilled the audience with her long list of potential therapies to be targeted in the future, and I must admit that I was overwhelmed at the large number of WM patients who have participated in her clinical trials, past and current.

Dr. Kyle reminded us of the "golden rule" of WM treatment: treat only when symptomatic or when significant anemia develops. A number of lectures were presented on current and novel therapeutic approaches in WM, and Dr. Owen also raised the controversial question regarding the use of IgM concentration as a reliable indicator of tumor bulk in WM. Bone marrow biopsies were once again heralded as the gold standard among all diagnostic tests for WM.

The debate regarding bone marrow transplants in WM was alive and well between Dr. Bart Barlogie (an advocate of autologous transplants) and Dr. David Maloney (a promoter of mini-allogenic transplants). Dr. Barlogie bemoaned the fact that over 90% of pediatric cancer patients are on clinical trials (and as a result pediatric cancers have seen more and more cures) while only 10-15% of adult cancer patients participate in clinical trials (and consequently lower cure rates are noted). Dr. Barlogie is a strong proponent of autologous transplants in selected WM patients and delighted the audience with his presentation of his "favorite" long-term patient: diagnosed in 1989 at age 55, she underwent numerous treatments, including an auto-transplant in 1992, and is now in near-complete response at the age of 74 after her second transplant 12 years later in 2004 at age 70!

The formal lectures concluded with an excellent amyloidosis presentation by the world-leader in this field, former student and protégé of Dr. Jan Waldenström, Dr. Giampaolo Merlini.

On the final day of the meeting, the expert physicians presented six WM clinical cases, and their respective approaches to the care of these cases were debated. The varying opinions regarding potential treatment plans impressed the audience – the ever-increasing array of options now available to the WM patient, not to mention the newer targeted therapies currently being evaluated or soon to be put in clinical trials, solidified the positive feelings of scientific progress and hope for a cure that permeated this conference.

DVDs of all the sessions, as well as copies of the conference syllabus including abstracts and slide presentations from the Third International Patient & Physician Summit on Waldenström's Macroglobulinemia will be available soon on the website www.wmsummit.org

The next meeting in this series of conferences, the Fourth International Patient and Physician Summit on WM, is scheduled for March 10-13, 2011, in Disney Village, Orlando, Florida. This will follow closely on the heels of the sixth International Workshop on Waldenström's Macroglobulinemia (IWWM6) which will be held on October 6-10, 2010, in Venice, Italy. One can only wait with great anticipation to hear of the incredible new research advances in the science and treatment of WM that are sure to be presented in these upcoming conferences!

FROM IWMF-TALK

BY MITCH ORFUSS

As always, exchanges on IWMF-TALK kept up a lively pace this spring. Select topics are highlighted below.

Sinus Infection:

Bob Reeber wrote that a mucus culture can help find out which antibiotic will actually work. Bob had a sinus siege and finally got his doctor to take a mucus sample and check it. It turned out that one very old antibiotic was the only one that worked effectively for him, which he took for 3 to 4 weeks, and everything cleared up. Bob's mucus samples generally come from the lungs, coughed up after deep breathing exercises as prescribed by the pulmonary physical therapist. The one time he had a nasal sample taken from the sinuses, the ENT (otolaryngologist) used an optical fiber with a sampler. He was able to see where he was going so as to take a "fresh" sample in the sinuses. To quote Bob, "That was the one time I had not done well on about three broad spectrum antibiotics. When they cultured the sample they were able to directly test against a variety of antibiotics to find an older one that was effective." **Dr. Guy Sherwood** writes that CT scans are notoriously inaccurate for determining whether a sinus infection is present or resolved. "Better to roll the dice," Guy says. "It is difficult to get an accurate bacterial culture from a person's sinuses even if they haven't been on any antibiotics at all. The only good way to get a good representative culture is to stick a needle through your face into one of the sinus cavities, aspirate some pus, and then culture. I would only do it if a nasty fungal infection was suspected, and even then there are other ways to do this, still quite unpleasant." IVIG is what Guy ultimately requires when he starts getting too many sinus infections (most of which are viral in nature). Guy uses a saline nasal solution twice a day, four times a day or more if he has sinus flare-ups. **Rinat Atar** writes that because she too suffers from many sinus infections her hematologist recommends IVIG. **Dr. Jacob Weintraub** added that sinus infections may also be due to anaerobic organisms, which are extremely difficult to culture, even when they are obtained in a good specimen. "Sputum cultures aren't necessarily accurate in determining infecting organism, either. The reality is that in most patients the infecting bacteria is usually one of only a few types that will respond readily to any one of several antibiotics and will require only a single course of treatment." However, in a patient with WM who is having a prolonged infection, Jacob asserts that it is wise to make the attempt to perform whatever procedure is necessary to obtain a valid specimen for culture and sensitivity.

Acyclovir Dosage:

Jaye Bauser asked about the dosage of acyclovir for those taking it long term. **Dr. Tom Hoffmann** suggested that we not self-prescribe based on what other patients do. **Guy Sherwood** offered that having had shingles 5 times post-Fludara, he started acyclovir full-time at 400 mg twice a day for a year, then went down to 400 mg once a day, and the result was no more shingles since then (more than 4 years now). **Lou Birenbaum** said that he's taken one 200 mg capsule daily since participating in the clinical trial that resulted in the approval of acyclovir. In the very rare instance of a recurrence of herpes outbreak, Lou increases the dosage to 5 200 mg capsules daily. His internist and oncologist are aware of Lou's acyclovir regimen and have expressed no reservations.

Howard Prestwich abstracted a range of TALK submissions on this subject. One patient said he was on 400-1000 mg per day originally and now takes 200 mg per day. Another said he takes 400 mg of acyclovir twice a day as a precaution against shingles. With fludarabine, he started on acyclovir automatically, but, though he believed he would be on it only for a year post-treatment, his counts did not rebound. And so he said he'd remain on it until that changed. Another TALK participant said they took a 500 mg dose of Valtrex once a day; he decided to cut the dose in half, so he ended up taking only 250 mg a day and suffered neither problems nor further outbreaks. Another writer offered that he had not had shingles, but for prevention his doctor had him on two 200 mg caplets of acyclovir daily. He had had four rounds of cladrabine (2CdA) with Rituxan over the past 4 prior months and, following that, so far, so good – no side effects and his numbers were improving. Another writer said he had been taking oral acyclovir, 200 mg daily, for more than 20 years. His purpose had been to decrease both the intensity and the frequency of herpes outbreaks. The acyclovir definitely accomplished both of these purposes. At the time he wrote, it had been more than a year since his last herpes outbreak, which itself had been mild compared to outbreaks more than 20 years earlier. Another said it seems that 400 mg per day does the trick – 200 mg early in the day and again late in the day. One last example: a writer said he'd had shingles post-Fludara more often than he cared to remember and now takes acyclovir at a dosage of 800 mg twice a day; though he says that a dose reduction was a possibility, he tolerated the seemingly high dose well and vowed not to stop unless assured that he would never get shingles again.

Rituxan and Bone Marrow Infiltration:

Mike Berndt wondered if there is even a rough relationship between bone marrow infiltration and response to Rituxan. The conversation then expanded to include discussion of whether a diagnosis can definitively be made without a bone marrow biopsy (BMB), which many patients dread (though many others report having relatively easy experiences). **Daniel Hachig** wrote that the BMB is the gold standard when it comes to diagnosis and that his wife's first BMB was

From IWMF-Talk, cont. on page 28

"simply awful." Daniel adds that at Mayo Clinic Arizona (and, he also assumed, at Rochester) they pretty much exclusively perform BMB's with conscious sedation. Others have vouched for conscious sedation in terms of reducing or eliminating discomfort. **Guy Sherwood** added that nobody enjoys a bone marrow biopsy, but he also said it is essential in that there is no other test that is as reliable and gives as much information, irrespective of bone marrow infiltration percentage. Guy went on to say that IgM levels, as a sole marker of disease burden, can mislead us and that while IgM levels can be used to monitor progress most times, in the end a bone marrow biopsy is still the gold standard, and, as was repeated recently in Boston by the "experts," biopsies are not administered nearly often enough. Note that Guy has undergone 6 bone marrow biopsies and, despite some discomfort, remains keenly interested in knowing all the information possible before making treatment decisions. The last 4 biopsies have been under sedation – basically painless, an "easy trade-off" compared to the valuable information provided. Besides, he suggests, they are mandatory if you want to be sure your disease is WM.

RAD001 Trial:

Larry Adam Siker advised that after 10 one-month cycles, the latest result shows him maintaining his lowest IgM and M-spike since diagnosis in March 2003. Larry is on a minimum dose of 5 mg per day with no side effects. Mayo Clinic Rochester will be opening a new trial soon. What pleases Larry is that RAD001 is not a chemotherapy but a bacterial compound. In Larry's view there is no controversy here about maintenance. He feels he may indeed be on this regimen for 5 years. Larry is hoping the study will yield us a new silver bullet. **Ray Morgan** is also in the RAD001 Trial at Mayo Clinic Rochester – in the second 4-week cycle. After the first cycle he says his IgM is down 37%, with his M-spike down 39%. His doctor was excited about this result in such a short time, indicating this was among the best results in the trial to that moment. It was Ray's understanding that the trial closed when it reached its goal of 230 participants.

Prednisone and Dexamethasone:

Lou Birenbaum wrote that prednisone is strong stuff. His first treatments way back in 1992 included Cytoxan and prednisone. The first month, Lou had daily Cytoxan with 50 mg of prednisone. The prednisone was for 5 days, then stopped abruptly, causing flu-like aches on days 6 through 8. Lou told this to his doctor, the dosage was adjusted so that this eliminated the withdrawal symptoms completely. **Jerry Fleming** agreed that prednisone, although a useful drug, causes unpleasant side effects. Prior to diagnosis with WM, Jerry was misdiagnosed as having polymyalgia rheumatica and was prescribed large doses of prednisone. He reported becoming very sentimental, breaking out in tears for little reason. When finally diagnosed with WM, he was glad to be weaned off of the prednisone, which took 3 weeks. Now that Jerry is facing an allo transplant for bone marrow failure caused by fludarabine, it will be necessary for Jerry again to be on prednisone, this time to reduce the symptoms of graft versus host disease (GvHD), which can follow transplantation. **Bob Reeber** said he was prescribed prednisone about 7 years ago to help control extreme coughing from inflamed bronchial tubes. After taking the maximum dose he reduced it for at least four days in increments. It was an interesting experience in that Bob became hyper-charged, could not sleep, and ended up writing a Fortran program night and day to analyze stocks.

Audio-taping Physician Visits:

Dr. Jacob Weintraub wrote that he had never had anyone ask to tape an office visit with him. He said he understood where it could make for an uncomfortable setting, although he could also see where it would actually work to a doctor's advantage since a patient could not claim to have forgotten what the doc said. **Bill Paul** responded, saying that he had asked his own internal medicine doctor about taping visits some time ago, and the doctor said he would not be opposed to it but felt he learns a lot more about his patients in casual conversation than in a more formal Q&A type session, which he feared a taped visit would become. **Ann Gray** wrote that her transplant doctor comes into the room and actually turns on her tape recorder, talks for 5 to 10 minutes about treatments, and makes recommendations. When he is finished and Ann looks at her two pages of questions, she invariably finds that her doctor has already answered the majority of her questions. In addition, Ann says she very seldom "gets it" the first time through but, with a tape, she can go back and listen again. Ann believes this saves the doctor time and helps herself to understand more thoroughly. **Ron Draftz** weighed in with the thought that the doctor's corporate attorney might be gulping Maalox if he knew his client was being taped by a patient. **Dr. Tom Hoffman** feels that the problem lies with disgruntled patients who might use their tapes against their doctor. Some physicians will pay dearly for this practice. There is no way that a doctor can give anybody 100% of the right answers, including all possibilities, outcomes, and potential side-effects in this or any type of setting. Plaintiff lawyers can and will seize on these things. **"Jsbarber"** says taping certainly helps her (the patient) and seems to help her doctor also. She always asks first if taping is permitted and has only had one doctor say "no." Jsbarber is so rushed, trying to concentrate on what to ask and, simultaneously, on what the doctor says, that she can miss important information. She does not tape when at a local doctor but, after traveling great distances to see her specialist and with only a small amount of time, it certainly helps to listen at home and see what was missed or forgotten. Plus it saves time by reducing the need for further phone calls.

Chlorambucil:

One reader asked about chlorambucil/Leukeran. **Stuart Alper** said he took chlorambucil for 3 years in the early

From IWMF-Talk, cont. on page 29

90's and found it a very easy medication to take with no short-term side effects. His IgM went from over 9000 down to 1900 in those three years. **Ann Tygart** wrote that she had three months of Lukeran, which put her viscosity back in the normal range. Side effects were mouth sores, heartburn, tinnitus. **Frederick van Hartesveldt** votes thumbs-down on chlorambucil/Leukeran unless there's no better option. When he was diagnosed he was given a 90 day, 3 times a day protocol but felt so run down that he stopped after 60 days. After the first 30 days, his IgM dropped from 5700 to 4700; after the second 30 days and ever since his IgM has bounced between 3,500 to 5,500, with or without treatment. His chlorambucil experience led him to swear off alkylating agents altogether as "old school," with as many problems as they solve. **Mike Hilt** had chlorambucil for a total of 5 years from the beginning of 1998 after diagnosis to the end of 2002. Mike took it for 5 days with prednisone once every 6 weeks. Over the 5 years the total chlorambucil he took added up to some 1.7 gms. It kept Mike's IgM remarkably constant in the 2100 to 2200 range all that time. However, he noted that with the years it began to have less and less effect until after 5 years it could not longer control his WM, and every single blood statistic crashed, while his IgM shot up to 6000. It seemed to Mike that there is a limit to the cumulative amount of chlorambucil an individual can receive before it begins to have little effect. It gave him 5 good years, but when it failed he was glad he had responded well to Rituxan in 2003.

Ofatumumab Trial (A Personal Note):

Your IWMF-TALK correspondent saw his hemoglobin fall from a steady 10-ish reading down to 6.7 starting a year after finishing a course of solo-Rituxan that seemed to have no effect either way. My oncologist said it was time to treat and suggested I participate in a Phase 2 trial of ofatumumab, a next-generation antibody targeting CD-20. I took one shot of Aranesp and had 4 weekly ofatumumab infusions. While I initially experienced allergic reactions in the form of hives and itching during infusion, the immediate results were encouraging and gratifying. My hemoglobin rose over the month of treatment to 12.7, my IgM dropped 1000 points to about 2400, and I regained feeling in the toes on my left foot for the first time in years (though my doctor is not sure this was caused by the ofatumumab). I was also able to start exercising again. The care I received was excellent, and I'm glad that I decided to participate in this trial.

Other Discussions:

Many other topics were aired and can be accessed in the IWMF-TALK archives, including CRP variations, sed rate, bone marrow biopsies, FCR-Lite, family/hereditary issues, maintenance-Rituxan, R-CHOP, and hairy black tongue.

HOW TO JOIN IWMF-TALK

Here are two ways to join:

1. Send a blank e-mail to: *iwmf-talk-subscribe-request@lists.psu.edu*

   Make sure to enter the word subscribe as your subject, and do not sign or put anything in the message area (make sure you do not have any signature information in there). Also, do not put a "period" after "edu" or it will reject. Once approved you can post by sending e-mail to *iwmf-talk@lists.psu.edu*
2. Contact Peter DeNardis at *pdenardis@comcast.net* and provide your full name

INTERNATIONAL TALK LISTS

TALK LIST FOR AUSTRALIA
To subscribe send e-mail to:
WMozzies-owner@yahoogroups.com

TALK LIST FOR FRENCH LANGUAGE
For information:
http://sympa.medicalistes.org/wws/info/waldenstrom
Contact: Nicole Bastin *nicbastin@yahoo.fr*

TALK LIST FOR GERMAN LANGUAGE
For information:
http://www.leukaemie-hilfe.de/foren.html?&tx_mmforum_pi1[action]=list_topic&tx_mmforum_pi1[fid]=14
The talk list in the German language for Waldenstrom patients and support givers is maintained and operated by the DLH (Deutsche Leukämia & Lymphoma-Hilfe), the German Leukemia & Lymphoma Patients' Association.

TALK LIST FOR NORDIC COUNTRIES: IWMF-TALK-NORDIC
To subscribe send e-mail to:
iwmf-talk-nordic-subscribe-request@lists.psu.edu

TALK LIST FOR SPANISH LANGUAGE: IWMF-TALK-ESPANOL
To subscribe send e-mail to:
iwmf-talk-espanol-subscribe-request@lists.psu.edu

TALK LIST FOR THE UNITED KINGDOM
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SUPPORT GROUP NEWS
EDITED BY PENNI WISNER

Arlene Hinchcliffe is stepping down from the IWMF Board and as Support Group Coordinator while Cindy Furst is stepping up as our new SGC. Here's Arlene:

> "I would like to take this opportunity to say how much I have enjoyed being the IWMF SGC this past year. I have met many of you over the years at the Ed Forum and found your enthusiasm and commitment to the members in your communities an indication of your willingness to face this disease head on.
>
> I now plan to concentrate on developing awareness of Waldenstrom's and support groups across Canada. I have had the pleasure of working with Cindy on the Board and I know she will do an outstanding job as SGC. We are very fortunate to have her leading the support groups and I will assist her in any way I can. I will continue to be the contact for the Canadian groups as well.
>
> As an outgoing Board member I know all members join me in saying thank you to all our support group leaders around the world. No support group in your community? Why not step up, stand up, reach out, and join the many people who have done just that. Discover how being a support group leader can change your life and the lives of others with this orphan disease."

Note: contact information for all support groups is listed in this issue.

IWMF CHAPTERS—USA

CALIFORNIA

Los Angeles

The Los Angeles and Orange Country groups invite each other to meetings. So six members of the Los Angeles WM support group attended the Orange County meeting in May. The next meeting – also with Orange County – is planned for October 3 and Dr. Steven Treon will be the guest speaker.

Orange County

Members of our group (and also some from Los Angeles) expressed an interest in knowing more about how nutrition can impact health, especially in light of diagnosis and treatment. Hoag Hospital, where the group meets, is fortunate to have two dietitians attached to the Cancer Center there. Denise Juve Lohman MPH, RD, our speaker, has been a registered dietitian since 2000 and received her B.S. degrees in Dietetics from the University of Maryland and in Sports Medicine from Pepperdine University. She then obtained her Masters in Public Health Nutrition from Loma Linda University. Denise is currently a member of the American Dietetic Association, Oncology Nutrition and Nutrition in Complementary Care. She led a very active session during which she wove together her formal (PowerPoint) presentation with participants' many questions.

After the presentation, members watched a DVD of Dr. Steven Treon's "Novel Therapeutics in WM," a selection from the IWMF Patient Forum in Stockholm, Sweden, in October 2008. The next meeting will be held on October 3 at Hoag

Support Group News, cont. on page 31

Hospital when a record-breaking attendance is expected to greet Dr. Treon in person, when he will make a new presentation, "Update on the Genetic Basis, Pre-Dispositions, and New Treatment options in WM."

Sacramento and Bay Area

Good fortune rains in northern CA (unfortunately, not actual rain from the sky). **Judith May**, IWMF Board President, was at home in Napa in June and able to attend the summer meeting and bring us up to date on all the activities of the Board. It is always exciting to hear how fundraising efforts lead directly to research activities and to patient outreach and support. In October, thanks to the Lymphoma Research Foundation, Dr. Morie Gertz of the Mayo Clinic will be speaking in San Francisco. And Dr. Treon will be speaking to the group in Vallejo on November 14.

FLORIDA

Southwest Florida

During the summer doldrums when so many are away the group takes a hiatus. But stay tuned as Dr. Treon will be back in Sarasota for a presentation in 2010, most likely in February or March.

EASTERN IDAHO

This small group comprises two patients and two spouses. One member attended the Ed Forum in Memphis and not only brought back reports on the scientific aspects of WM but also of the awareness project for finding other local Waldenstrom's patients. The group received materials from the IWMF office and plans to distribute them to the few oncology offices and cancer centers in the area. Members also plan to attend the Snake River Cancer Alliance's Cancer Survivor Celebration Day on June 6, 2009, and to participate in the SRCA cancer run and walk event.

GEORGIA

The next meeting of the Atlanta area support group will be held on October 10, and Dr. Steven Treon will be the guest speaker. For further information, contact **Mal** and **Judy Roseman** at 770-392-1255 or malroseman@comcast.net

ILLINOIS

Perhaps looking toward the future of support group meetings, in May the Chicago Area support group held its first Internet video conference meeting between Dana-Farber Cancer Institute in Boston and Advocate Lutheran General Hospital in Park Ridge, Illinois. The meeting was very well received with Dr. Irene Ghobrial presenting her talk on new treatments for WM and conducting an interactive question and answer period to an audience in the Lutheran General auditorium. The meeting agenda also included a time for personal sharing and summer picnic planning. The next meeting, an inaugural group picnic, will be held on Saturday, August 15, at Ty Warner Park in Westmont, Illinois.

NEW YORK

Eastern NY/Western New England

Dissemination and discussion of the information and research presented at the recent conferences in Memphis and Boston were the focus of the spring gathering. August 1 is the date for the annual picnic. Anyone who happens to be near Albany, NY, on that date and would like to join the fun should contact the group leader, **Mel Horowitz,** for details. Fall meeting plans include showing excerpts from the IWMF annual conference DVDs.

WESTERN OHIO, EASTERN INDIANA, & NORTHERN KENTUCKY

In April, a new member joined the group at the spring meeting. Another long-term member, who has been troubled by joint pain, shared with the group that her pain has been lessened since she starting taking Tai Chi lessons and exercises. The next meeting will be at the Leukemia and Lymphoma Center in Cincinnati on Saturday, July 18th.

OREGON/SOUTHWEST WASHINGTON

Personal reports from the annual IWMF weekend conference in Memphis and the Dana-Farber Summit in Boston filled the May meeting agenda. Several people attended for the first time. Future meetings are tentatively scheduled for July 25 and October 24.

PENNSYLVANIA

Central and Southeast PA and Northern MD

At the May meeting a new member reported finding the IWMF via an Internet search rather than from the cards members post on bulletin boards at hospitals and clinics. Plans were laid to redouble efforts to make sure local oncologists and other medical professionals are aware of the IWMF. Several members reported on current treatments and all were all encouraged by their progress and good humor. Next up is a potluck picnic at **Larry** and **Nancy Lambert's** home. This will be August 9, the second Sunday. Anyone who would like to attend and bring something can contact Nancy at llne3@aol.com. The Lamberts live outside Dillsburg, PA. The last meeting of the year will be back at Messiah Village on November 8 from 2 to 4 pm. The program has yet to be arranged.

Philadelphia

The Philadelphia area support group met in early April in its comfortable Bryn Mawr Hospital meeting place. It is in an old building that used to house the nursing students. Large windows on one side of the room and a big fireplace on the other make it feel very pleasant. Sixteen members shared a large plate of cookies, a bowl of pretzels, and lots of talk. The usual "round table" sharing brought up a wide variety of WM topics. **Ron Yee**, an IWMF Board member and a group member, gave a report on the last Board meeting and in particular the IWMF fund-raising thrust for research dollars.

Support Group News, cont. on page 32

For the June meeting, the twelve members who attended the Ed Forum or the Boston International Summit at the Bing Center of the Dana-Farber Cancer Institute kept attendees' interest with their personal reports. The Pindzolas' little dog, Heidi, has not been attending meetings as usual but planned to be able to make the June meeting!

SOUTH CAROLINA

The South Carolina group held an informal meeting in Charleston in mid June. Group member **Sue Herms**, the *Torch* Medical News Editor, made a presentation on research advances that are leading to improved WM treatments, with an emphasis on rituximab. The next meeting will be in the fall (DTB). Stay tuned.

TEXAS

Dallas & Northern Texas

The north Texas WM support group met for the May meeting at Baylor University Medical Center in Dallas. The facilitator, **Jerry Fleming**, had attended the IWMF Educational Forum in Memphis and reported on the highlights. He was particularly inspired by the speaker from St. Jude's Children's Hospital who reported that the cure rate for childhood cancer has increased from 5% to 80%. If that can be done, WM can be cured, too! Since the group does not meet in the summer, the next meeting will be on September 19.

Houston

The Houston group meets at 1 pm on the last Monday of each month at the Houston Cancer Institute, 1220 Blalock, Suite 200, Houston, TX 77055. Our program includes a presentation by a physician or other professional service provider followed by a reception with WMers and their caregivers for self-support discussions. Refreshments are served. The program is underwritten by the Houston Cancer Institute and hosted by the co-chairs, **Barbara** and **John Manousso.**

WASHINGTON

The Washington group met March 14 in Kirkland and enjoyed getting acquainted with Stacy Martin of the Washington-Alaska chapter of the Leukemia and Lymphoma Society. Stacy provided a helpful introduction to the LLS. We also viewed Dr. Steve Treon's interesting presentation of novel therapies for WM. Our deep thanks to **Deloris Morrical,** who is stepping down from her role as group secretary. Deloris has served the group graciously and effectively for a number of years. **Kristen Jenson** is stepping into this gap to help us keep organized and in touch. The group is looking forward to its next gathering on Saturday, July 11, for a potluck picnic at **Bob** and **Peggy Horton's** new home in Port Orchard.

WASHINGTON D.C./METROPOLITAN AREA

Dr. Ashraf Badros of the Greenebaum Cancer Center at the University of Maryland will be the featured speaker at the November 8 meeting at Holy Cross Hospital.

WMF CANADA

Toronto

The next meeting is planned for November 7, and Dr. Steven Treon will be the guest speaker. For further information, please contact **Arlene Hinchcliffe** at 905-337-2450 or wmfc@noco.ca

SUPPORT GROUP LEADERS TALK LIST

This list is only for support group leaders to use in communicating with each other about support group issues. It is used by the leaders to share their experiences and ideas for facilitating our IWMF support groups. Contact Cindy Furst at *cindyfurst@msn.com* if you would like to participate.

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THE LIFELINE

If you can't get to a local support group meeting, use our IWMF Telephone and E-mail Lifeline to call a WM veteran. The Lifeline provides telephone numbers and e-mail addresses of IWMF volunteers who will answer questions about their first-hand experience with specific treatments for WM.

The Lifeline is seeking volunteers who speak a language other than English. If you would like to volunteer, please contact the IWMF business office at 941-927-4963 or info@iwmf.com.

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In honor of Florence Dunne:
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Contributions in honor of the 7th Annual Nancy O'Soro/Lisa Lawton Fundraiser:
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THE LAST WORD

COMPILED BY SARA MCKINNIE

What is the Telephone & E-mail Network? The original concept of putting WM patients in touch with each other was developed by IWMF Founder, Arnie Smokler.

When you were newly diagnosed and first made contact with IWMF, you may have received a list of telephone numbers and e-mail addresses of other WM survivors and caregivers in your area. Today, the Telephone & E-mail Network remains a valuable resource, providing comfort and reassurance, especially for those who do not have Internet access. Additionally, this method of networking has proven useful in the formation of support groups.

The membership/contribution envelope enclosed with your newsletter has boxes to check if you wish to participate. The same opportunity to participate is available when you join or renew your membership online at the IWMF website.

Participating means you are willing to share your e-mail address and telephone number with WMers nearby. Members who indicate they do not wish to share their contact information will not appear on the Telephone & E-mail Network list.

The Telephone & E-mail Network list for your area is available upon request from the IWMF Business Office.

Educational Forum DVDs. As in previous years, we are producing recordings of the medical presentations from the 2009 Educational Forum in Memphis, TN. Each set of DVDs will feature outstanding presentations by various speakers including Drs. Rafat Abonour, Megan Andersen, Stephen Ansell, Morie Gertz, Robert Kyle, Todd Levine, Mary Lou McMaster, Marvin Stone and Brian Van Ness. Each support group leader will receive a complimentary set for showing at local support group meetings.

The DVDs will be available in early July. The cost is $35 U.S. including shipping, and an order form is enclosed with this newsletter. If you attended the Ed Forum and already pre-ordered your DVDs, there is no need to order again or fill out the enclosed form. You may also purchase the DVDs online at www.iwmf.com

IWMF Physicians Database. In addition to our membership database, the foundation maintains a mailing list of a growing population of physicians and researchers who specialize in and/or treat WM patients worldwide. While the IWMF does not "recommend" doctors, we are often able to direct patients to a doctor in their area. It is very important to build this database for many reasons, including:

- Providing a list of physicians that have experience treating WM for patients and their physicians to consult
- Allowing the networking of physicians in a given locale to consult with one another to increase their knowledge about WM
- Promoting awareness of IWMF in the medical community
- Enabling patients who live in remote locations to find care by experienced WM professionals
- Recognition by pharmaceutical companies and other organizations that offer financial assistance

We encourage all of our members to send us an e-mail to office@iwmf.com or write the information down and send it along in the envelope provided with this newsletter.

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Elmo and **Dolores Schmid** have a fascinating story as well. They went to school together in Nebraska, before he went off to fight in World War II and she went to nursing college in San Diego. They corresponded during the war, and upon his return Elmo proposed to Dolores. They have now been married for over 50 years. Both retired from their careers – Dolores from 28 years as a nurse and Elmo from being the Post Office Supervisor in West Orange County – and both went into the antique business. Elmo was diagnosed in 2005, and he has participated in many clinical trials. The Schmids had two daughters, one who passed away and a surviving daughter married to a British Consul and living in England. So the international connection continues.

The final honoree, providing our last international connection, is **Arlene Hinchcliffe.** Arlene was born and raised in Toronto and began her working career in the hospitality industry, in sales and catering for the Four Seasons Hotel chain. Looking for further challenges, she became a manager and buyer for a Canadian giftware company. When she and her husband started a family, it proved to be a career choice that was most challenging. Indeed, her role as a domestic engineer (House Mom) allowed her to learn many trades. It also allowed her to become involved in the Canadian community where she has remained the consummate volunteer. In 1999 Arlene took on her most passionate role, namely that of the first support group leader in Toronto for the IWMF, following the passing of her father in 1998 from WM. Since then she has helped to start several other groups in Canada, formed the Waldenstrom's Macroglobulinemia Foundation of Canada, and served on the IWMF Board for three years. She is now retiring from our Board to continue to serve as President of the WMFC. As a going away present to all of us, Arlene bequeathed through her will – for the newly established Kyle Endowment Fund – a gift of $100,000! What a way to kick off this very special initiative!

Dr. Kyle came forward in Memphis to present IWMF's very special recognition piece to Arlene. Laurie Rude concluded the program by asking us to reflect on the roster of Ben Rude Society members and observed that "you don't have to be a Warren Buffet to participate in the Ben Rude Society."

The same holds true for the Kyle Endowment Fund, for that matter. Indeed, if any of you are thinking about your personal estate planning and can find a way to share some of your resources to enable the IWMF to continue serving members and supporting research, please call Dick Weiland (507.645.2633) or Dave Benson (952.837.9980) to help make it happen.