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STOCKHOLM WORKSHOP REVEALS SURGE IN WM RESEARCH

BY GUY SHERWOOD, M.D.

I attended the 5th International Workshop on Waldenstrom's Macroglobulinemia (IWWM5) in Stockholm in the fall of 2008. The Stockholm Workshop was the latest in a long list of WM cancer conferences I have attended since my diagnosis of WM in March 2001. What struck me as very special, perhaps even staggering, about the IWWM5 conference was the quantity of new information presented, given the span of one short year since the previous IWWM4 conference held in Greece in 2007. For the first time since attending these conferences I felt that a concerted effort was finally in place to address the peculiarities of this mysterious disease exclusively, rather than just as an add-on topic to conferences devoted to multiple myeloma or non-Hodgkin lymphoma.

In the past the rarity of WM led to a relative lack of original research in WM proper when compared to research in plasma cell disorders such as MM (multiple myeloma) and MGUS (monoclonal gammopathy of undetermined significance) or in very common B-cell disorders such as CLL (chronic lymphocytic lymphoma). Now, however, many dedicated researchers and oncologists around the world are focusing their efforts on WM. Dr. Steven Treon and his team at Dana-Farber's Bing Center are leaders in this new direction and have without a doubt put WM "on the map." In my estimation, IWWM5 was a crowning achievement. And even more exciting is the realization that many more of these "crowning achievements" are sure to cap IWWM5 in the next few years.

As a WM patient diagnosed in 2001 at the age of 40, I have followed the new scientific developments in WM research with great anticipation and often with frustrating disappointments. As I left the IWWM5 conference in Sweden last year, I was very encouraged and excited. I felt very secure in the thought that WM would be manageable for years to come and that a cure was no longer as elusive as I had once believed.

We are now able to unlock many of the mysteries of the genetic code. New research, predominantly in population based studies, has confirmed that WM follows certain genetic predispositions in selected families. We are increasingly aware that there are inherited genes, as well as acquired genetic mutations, that may render many at increased risk of developing WM. Coupled with new large-scale epidemiological studies, it is becoming increasingly clear that WM is a disorder of genetic mutations and that environmental factors may indeed trigger the emergence of WM in genetically susceptible individuals. Further studies will not only permit us to identify individuals who may be at risk for WM but will also enable those individuals to minimize their exposure to certain identifiable environmental triggers and prevent the development of the disease.

The explosion of knowledge in basic biological science over the past half-century continues at an exponential pace. We are now aware of the crucial role that the microenvironment--the bone marrow "neighborhood"--plays in WM. Many normal cells in the bone marrow are co-opted by the WM cells to assist in survival of the tumor clones. Survival of the tumor clones may involve the production of specialized molecular messenger molecules, the development of blood vessels that help feed the WM tumor cells, or other mechanisms. Now, however, the normal cells can be



Dr. Guy Sherwood

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identified and targeted by safe drugs to cease their unknowing, perhaps even unwilling, support of the WM tumor cells.

Basic research, be it decoding the mysteries of genetics or understanding the microenvironment, is leading to more efficacious and safer drugs for the treatment of WM. The increased participation of WM patients in clinical trials is now enabling clinicians to gather data, previously elusive, in numbers sufficient for formulating accurate prognostic markers. Researchers and clinicians can now share their experiences with various treatment protocols for WM with their colleagues throughout the world and accurately compare these various treatments on a uniform basis.

Basic biological research has answered many questions but has also resulted in new challenges. We are now beginning to place increased emphasis on the heterogeneous collection of tumor cells that make up a WM tumor. And now the implications of this heterogeneous mixture of cells become clearer. In a WM tumor there are abnormal B-cells, plasma cells, "in-between cells", and perhaps the mysterious WM stem cells. Are some of the current treatments, Rituxan for example, only targeting the abnormal WM B-cells, while ignoring the other abnormal cells? Are certain treatments, based primarily on multiple myeloma protocols (Velcade for example), targeting only the abnormal WM plasma cells and ignoring the other types? It is no accident that combination therapies, Rituxan combined with Velcade for example, appear more efficacious. Will we ever see a cure for WM unless we address the possibility of a WM progenitor stem cell and develop specific targeted therapies?

Many mysteries and unanswered questions remain. Nonetheless, tremendous progress has been made and new discoveries are continuously being reported. Quite simply, the WM research community seems to be on a bit of a roll, and only through continued support of these dedicated researchers, whether by financial means or by a commitment to participate in clinical trials whenever possible, will we achieve the ultimate goal of a cure for WM.

Donate and participate.

Dr. Sherwood's summary (in layman's terms) of the research papers presented at IWWM5 in Stockholm is available on the IWMF website, iwmf.com, under Publications: Therapeutic Options-- Updates from the International Workshops on Waldenstrom's Macroglobulinemia



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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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ED FORUM COMING UP JOIN US IN MEMPHIS!

BY CINDY FURST, IWMF TRUSTEE

The 2009 Educational Forum, set for April 24-26 in Memphis, Tennessee, will again provide hundreds of patients and caregivers the opportunity to hear about the latest scientific advancements in treating and understanding WM. On Friday and Saturday the presentations by top clinicians and researchers are aimed at first-time attendees as well as those who have been at previous forums. The breakout sessions on special topics encourage discussion with the experts, and on Sunday morning the lively and informative ‘Ask the Doctor’ session offers the opportunity to ask your own questions of our WM specialists.

The Ed Forum Committee has been working hard to create the 2009 program and now can announce a lineup of excellent speakers including:

- Dr. Rafat Abonour, Indiana University Bone Marrow and Stem Cell Transplantation Program, “Complications of WM” and “Transplants”
- Dr. Stephen Ansell, Mayo Clinic, “Conventional Treatments for WM”
- Dr. Morie Gertz, Mayo Clinic, “How Chemo Works”
- Dr. Irene Ghobrial, Dana-Farber Cancer Institute, “What’s New in WM Research and Treatments”
- Dr. Robert Kyle, Mayo Clinic, “Introduction to WM”
- Dr. Todd Levine, University of Arizona, “Peripheral Neuropathy”
- Dr. Mary Lou McMaster, National Cancer Institute, “Familial Studies of WM”
- Dr. Thomas Ratliff, Saint Francis Hospital, Memphis, “Rituxan and WM”
- Dr. Marvin Stone, Baylor Sammons Cancer Center, “Hyperviscosity Syndrome”

The many breakout sessions allow you to choose topics according to your interests and needs. Among those offered are the caregiver’s role, disability benefits, nutrition for cancer patients, estate planning, fundraising in your area, a special session for support group leaders, and—new this year—coping with Medicare.

While the Forum officially opens at 2 PM on Friday, for early arrivals we have scheduled two “early bird” speakers on Friday morning at 10 AM. Plan your trip accordingly and attend either “Self Advocacy: Understand your Medical Tests” or “Genetics of WM.”

The air of friendly informality at the IWMF Ed Forums facilitates the sharing of information between doctors and WMers, as well as between patients and caregivers. Many of our speakers will be on hand for all three days of the Forum and available for informal discussion at the scheduled social events and during breaks in the program.

Memphis offers so many attractions to visitors. The ‘Soul of the South’ boasts beautiful scenery, an interesting history, and reasonable prices. Pay a visit to Graceland or the blues and jazz clubs of Beale Street before leaving town! Cruise the Mississippi by riverboat on Saturday for an enjoyable evening with other participants from the Ed Forum. Our riverboat cruise on the Memphis Queen III is sure to be a highlight of the weekend. See and experience local flavor and sights with the doctors and Trustees who will be on board.

Our 2009 Ed Forum will be fun, informative, and another terrific opportunity for you. Please join us in April!

Complete details of the Forum agenda are posted at www.iwmf.com under Events Calendar on the home page. To register, click on the Ed Forum button at the right side of the home page.

You must make your own reservation for the riverboat dinner cruise. The cost of cruise and dinner is \$45. Information at www.memphisriverboats.net



DOCTOR ON CALL: MARVIN J. STONE, M.D.

PLASMAPHERESIS IN WALDENSTRÖM'S MACROGLOBULINEMIA



Marvin J. Stone, M.D.

Plasma is the fluid portion of the blood. Plasmapheresis or plasma exchange is a procedure involving the separation of plasma from the circulating blood cells in order to remove a disease substance. The red cells, white cells, and platelets are then returned to the patient along with prescribed replacement fluid. Plasma exchange is performed with a machine that uses centrifugation to divide plasma from the cellular blood components. Blood is drawn from a patient's arm vein and anticoagulant is added to keep the blood from clotting. The blood enters the blood cell separator where the plasma is removed from the cells and pumped into a collection bag. The cells and the replacement fluid ordered by a physician are returned to the patient through a needle in the opposite arm. Usually, the plasmapheresis procedure is completed in about two hours. The sterile tubing and needles are used only once. Sometimes a catheter is inserted in order to gain venous access. Side effects from the procedure are few, but sometimes patients feel lightheaded or develop numbness or tingling. These symptoms can be managed by increasing the fluid flow that is returned to the patient and giving calcium. Approximately 300,000 plasma exchange procedures are performed worldwide each year.

Plasmapheresis is performed to treat hyperviscosity syndrome (HVS), a common manifestation of Waldenström's macroglobulinemia (WM). Patients with HVS have skin and mucosal bleeding, retinopathy with visual disturbances, and a variety of neurological disorders. HVS can be diagnosed from physical examination by identifying the characteristic retinal venous engorgement ("sausaging") in the eye on fundusoscopic inspection. HVS can be accurately monitored with an Ostwald tube and usually corrected by plasmapheresis.

HVS was described by Jan Waldenström in his original 1944 report of two patients with macroglobulinemia. Viscosity refers to resistance to flow or stickiness. IgM exists as a pentamer with a molecular size of 925 kilodaltons (IgG is 150 kd and albumin 65 kd). It is thus not surprising that this giant molecule can exert profound effects on blood cells and blood flow, especially when present in the high concentrations of IgM often found in WM patients. In addition to bleeding, visual disturbances and other neurologic problems frequently occur in HVS. Heart failure and other cardiovascular manifestations are less common. Approximately 80% of patients with HVS have WM. Normal viscosity measured with an Ostwald tube is 1.4 to 1.8 relative to water. HVS is unlikely unless the serum viscosity is greater than 4. When IgM level rises above 3g per deciliter, the risk of HVS increases. Viscosity levels in HVS vary significantly between patients but correlate closely with signs and symptoms in the same patient ("symptomatic threshold"). Prompt diagnosis of HVS from the eye exam enables appropriate therapy, i.e., plasmapheresis, to be instituted. In addition to affecting plasma viscosity, macroglobulin coats red cells leading to the characteristic stacking appearance (rouleaux) on peripheral blood smear in Waldenström patients. Protein coating also causes a platelet functional defect which contributes to the bleeding tendency in patients. The presence of cryoglobulinemia, whether single or multiple component, strikingly elevates serum viscosity in WM patients.

The rise in viscosity with increasing serum concentration of IgG is roughly linear. However, above a concentration of 3g per deciliter, IgM relative viscosity rises steeply. The Ostwald tube used by Waldenström in his initial study remains a simple, reliable method for measuring relative serum viscosity in patients. During the last 5 years at Baylor-Dallas, 499 serum viscosity determinations were ordered, 297 of which (59.5%) were elevated. The majority (60.5%) of these patients had monoclonal IgM. Results are usually available within one hour from the time the blood specimen is received in the laboratory.

Plasmapheresis, first carried out for macroglobulinemia in the late 1950s, was demonstrated to reverse retinopathy and other clinical manifestations in most patients. This procedure remains an effective short-term treatment for HVS because of the demonstrated relationship between serum viscosity and IgM levels and also because IgM is 80% intravascular. Chemotherapy is often begun concomitantly with plasma exchange. Some WM patients can be managed predominately with plasmapheresis.

It is usually not necessary to plasmapheresis patients down to normal viscosity to relieve symptoms. A potential exception is illustrated by a patient with documented macroglobulinemia for 37 years who developed peripheral neuropathy associated with an anti-MAG antibody (myelin-associated glycoprotein; the IgM that causes peripheral neuropathy is labeled the anti-MAG antigen). Because her neurological symptoms reproducibly recurred above a serum viscosity of 2.5-3, we sought to keep her viscosity close to normal with frequent plasmaphereses. Over a 23 year period, this patient underwent approximately 400 plasmapheresis procedures with little chemotherapy other than corticosteroids. She died abruptly in 2003 six weeks after knee surgery. Her prolonged course raises the possibility that patients with monoclonal macroglobulin antibodies that

Plasmapheresis in WM, cont. on page 5



produce neuropathy or other organ dysfunction may benefit from a more aggressive effort to maintain serum viscosity near normal. Prospective clinical trials will be necessary to confirm this possibility.

Transient increases in IgM levels after rituximab therapy (“flares”) occur in 30%-70% of WM patients and have been well described. It has been recommended that plasmapheresis be carried out in advance of rituximab therapy if serum viscosity is above 3.5 or IgM level is greater than 50 grams/liter. Because of the relationship of serum viscosity to IgM concentration, it may be wise to consider plasmapheresis in advance if serum viscosity is above 3 or the IgM level is above 30 grams/liter. The mechanism of the flare phenomenon is unclear. The rise in IgM levels may occur disproportionately to the increase in serum viscosity. The flare phenomenon has become less of a problem with use of combination regimens that utilize chemotherapy prior to giving rituximab.

Plasmapheresis remains a valuable adjunct to the treatment of some patients with WM.

Baylor Sammons Cancer Center

Dallas, Texas

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Marvin J. Stone, a native of Columbus, Ohio, attended Ohio State University. He received his M.D. degree with Honors from the University of Chicago. A residency in internal medicine followed at Barnes Hospital in St. Louis and at Parkland Memorial Hospital in Dallas. He subsequently served as a clinical associate at the National Institutes of Health in Bethesda. In 1976 Dr. Stone was appointed as Chief of Oncology at Baylor University Medical Center in Dallas and Director of the Baylor Charles A. Sammons Cancer Center. Stepping down from these appointments in 2008, he now heads the Internal Medicine Clerkship for third-year medical students and the Medical Oncology Fellowship Program. Dr. Stone is also Clinical Professor of Internal Medicine at the University of Texas Southwestern Medical School. In 1980, he started the first bioethics course for medical students at Southwestern.

Dr. Stone has received Outstanding Teacher Awards from the house staff at Baylor and from medical students at UT Southwestern. The author of over 200 articles and book chapters on various aspects of hematology, oncology, and immunology, Dr. Stone was honored in 1999 when the Baylor University Medical Center created the Marvin J. Stone Library at the Baylor Institute for Immunology Research. Dr. Stone is a Master of the American College of Physicians and received the Distinguished Service Award from the University of Chicago in 2002. He is a past president of the American Osler Society and was the first chair of the American Society of Clinical Oncology’s Career Development Committee. In 2004 Dr. Stone received the Lifetime Achievement Award in Waldenström’s Macroglobulinemia from the International Society for the Study of Waldenström’s Macroglobulinemia. He contributed an essay on monoclonal antibodies to The Lancet’s special issue on Medicine and Creativity in 2006.



PRESIDENT'S CORNER: BULA, BULA FROM FAR AWAY FIJI

BY JUDITH MAY

The Fijians may be the friendliest people on the planet. They are legendary worldwide for smiles, colorful clothing, and generosity. A Fijian never looks at you without smiling. *Bula* is a multi-purpose word meaning “hello, welcome, nice to see you, greetings” and I hear it everywhere and all of the time. It always comes with a big smile.

As I write this column from the deck of a dive boat in Fiji, I am reminded of the wonderful sense of relief and relaxation from getting away and the importance of vacations in managing the stress of living with cancer. My husband and I are avid scuba divers, and we are on a diving trip with our international dive club—a once a year gathering of like-minded souls who love the sea. Three of us on this boat have Waldenstrom’s, but the others do not know, and the talk is focused on diving and catching up with old friends. This pushes WM into the far background, and we all need a break like this every now and then.

However it doesn’t necessarily take a long distance trip to relax. Any opportunity to get away and have a change of scenery, whether visiting friends and family in another state or a long weekend away in another town, the change from daily routine works its magic.

A Change on the Board of Trustees

A new Trustee has joined the IWMF Board. We are delighted to welcome Marty Glassman, co-chair of the Orange County, CA, support group. Marty has joined the Website Committee, initially. Those who come to the Ed Forum next month will meet him there.

Telephone Workshop

CancerCare has announced the Seventh Annual Survivorship Series: Living With, Through and Beyond Cancer. This free, one-hour telephone education workshop will be held on three dates -- April 14, May 19, and June 23 from 1:30-2:30 Eastern Time. To register, call 1-800-813-4673, or register online at www.cancercare.org/tew.

New Information from the National Cancer Institute:

“Researchers Identify New Regulatory Circuit Controlling Immune Cell Production in Mice” [Jan. 11, 2009]

Using a mouse model, researchers have shown that elevated levels of a small protein known as interleukin 7 (IL-7) plays a central role in regulating the production of a type of white blood cell that is recognized for effective immune responses. That finding helps explain the delayed and incomplete recovery of immune system function after treatments in which immune cells are destroyed, such as chemotherapy and bone marrow transplantation, and provides insight into the mechanism by which certain types of immune cells are depleted during HIV infection.



IWMF President Judith May receives Mayo Clinic Benefactors Award from Dr. Robert Kyle

This is important news for us, and we will continue to follow this research. Those who have computers may want to do a search on this subject for more information.

IWMF Receives Award from Mayo Clinic

I am happy to announce an award that the IWMF received from the Mayo Clinic. We graciously accept this award and at the same time acknowledge our gratitude for the many ways Mayo Clinic has benefited the IWMF and its members—including all the research, responses to questions, and assistance with our IWMF booklets.

The text on the plaque reads: “Mayo Clinic gratefully recognizes you among a unique group of friends known as Major Benefactors who form a dynamic partnership with Mayo physicians, educators and researchers in advancing the science and the practice of medicine. Your philanthropy serves as an example to others and an inspiration to all involved in achieving excellence at Mayo, now and in the future.”

Patient Education Forum

I hope to see all of you at the IWMF Patient Education Forum in Memphis, April 24-26. As always, we will have excellent speakers to present new information on WM, a selection of breakout sessions, including one led by a Medicare expert (and WM patient as well) who will take your Medicare questions. And you will be in the good company of many other WM patients.

Stay well,

Judith



DR. KYLE RECEIVES ASH AWARD

At the Annual Meeting of the American Society of Hematology, Dr. Robert A. Kyle of the Mayo Clinic was presented with the Wallace H. Coulter Award for Lifetime Achievement in Hematology. Established in 2007, this award honors individuals who have made a lifelong commitment to the specialty and whose contributions have had a major impact on education, research, and practice. Dr. Kyle was recognized for contributions to the study of multiple myeloma, monoclonal gammopathies, amyloidosis, and related plasma-cell disorders.

The citation at the award ceremony read as follows: "Throughout his 50-year career as a physician-researcher, educator, and consultant, he has focused on defining these diseases, understanding their pathogenesis, presentation, and prognosis, and designing and evaluating therapeutic approaches. In addition, he has authored more than a thousand publications and has trained more than 200 practicing hematologists."

We are very proud to have Dr. Robert A. Kyle on the IWMF Board of Trustees as our Board Advisor and Director of the Scientific Advisory Committee.

REMEMBERING EDDY ANDERSEN

BY JUDITH MAY



Eddy Andersen

It is with great sadness that I inform you of the passing of Eddy Andersen on January 9, 2009. Affectionately known as the "Talk List Mom", Eddy was the manager of our talk list, IWMF-TALK, from 2000-2007, when complications from WM led her to retire from this very demanding position.

Eddy leaves behind her husband of 53 years, Robert Andersen, Sr., sons Robert Jr. and James, two granddaughters, and a great many friends.

Eddy epitomized what makes the IWMF a great organization--good people giving selflessly of their time, heart, and energy to serve fellow patients in need. We now take IWMF-TALK for granted, and few of us know how much dedication it took to create and foster the lively and caring exchange of opinions that gives the IWMF-TALK life. Eddy was not just the Talk List Mom, she was representative of the heart and soul of the IWMF, a friend to all, and a living example of what makes IWMF great. She is forever a part of the history of the IWMF and will not be forgotten.

In accordance with her wishes, Eddy's ashes were spread on the ocean so that she may swim forever with the dolphins.

WM: THE JOURNEY SO FAR AN INTERNATIONAL PERSPECTIVE

BY SANJEEV KHARWADKAR



Sanjeev Kharwadkar

Following graduation from the National Defence Academy of India, Sanjeev Kharwadkar joined the Indian Air Force as a commissioned officer, and for eighteen years he was in the cockpit of fighter aircraft. Upon retirement, then Wing Commander Kharwadkar began a second career, that of commercial pilot, flying out of Mumbai with private airlines in India. In his own words Sanjeev tells how diagnosis of an unsuspected disease interrupted his life at age 44 and how he has been able to surmount the obstacles of WM and treatment to once again fly in a professional capacity.

It is just over three years since I first heard the letters WM put together to mean something so life-changing. As I go through IWMF-TALK and read the *Torch* regularly, I find that our worlds are so different, so far apart, and yet so similar. Bound as our worlds are by this peculiar bloodline, here is how my WM journey has been so far.

WM: The Journey so Far, cont. on page 8



From late September 2005 I was experiencing bleeding from the gums and getting tired. I thought it was lack of exercise and the kind of life style I was leading. Being a commercial pilot meant lots of hotel stays, irregular meals, irregular sleep and, of course, unhealthy diet (read airline food). Blood tests revealed a low Hb (= Hg), and a friend suggested that I see a haematologist. Frankly, I had to look up the dictionary for the word 'haematologist' and soon for 'oncologist.' At age 44 and with regular medical checkups every six months, I thought there is very little that can be seriously wrong with me. By the end of January 2006 I finally saw a haematologist, and within an hour of meeting him I was undergoing a bone marrow biopsy (BMB). Hb was 8.5, IgM 4900, and BM infiltration 10%.

As my BMB reports came in and my doctor mentioned WM, I started to research on the Internet. The fact that WM was treatable but not curable was extremely depressing. In retrospect I feel very lucky to have been in the hands of Dr. Sunil Parekh, a renowned haematologist from Mumbai. Dr. Parekh, a second generation haematologist, has also worked in the US and now serves on ASH committees. He had not only heard of the disease but also had experience in treating it. Doctor Parekh laid down the plan of action and costs involved. In India medical insurance works differently, and I was not covered for such enormous costs. In addition, I would surely lose my job as meeting certain medical criteria is a must.

The plan as laid down by Dr. Parekh was to get initial treatment of Rituxan, stem cell harvest, 6 cycles of FCR (fludarabine, cyclophosphamide, and rituximab) and a bone marrow transplant. I took it as a process that I would have to go through, hoping like hell that at the end of this process I would be able to get back to my earlier existence. The first air pocket I hit was when there was IgM flare after the first two doses of Rituxan and I almost lost vision in my right eye. The damaged retina due to central retinal vein occlusion (CRVO) certainly put paid to any thoughts of getting back my job. While the eye specialists were not very hopeful, one specialist did tell me to tackle the WM first and worry about the eye later. This meant having to undergo plasmapheresis immediately to get the IgM down before treatment could re-commence. Thereafter my treatment followed pretty much what the doctor had planned. The FCR regimen commenced mid-June 2006, but even after three cycles of FCR till late August there was not much improvement.

I started scouring the Net more often for a possible second line of treatment and my doctor mentioned about IWmf. In fact he gave me a copy of the *Torch* and suggested I become a member. All this while I had not come across a single WM patient, and though my doctor mentioned a few of his patients on wait and watch I never interacted them. Going through the IWmf site I realised that I was not such a loner after all, that there were a number of people affected like me, and there was some kind of help or guidance to tackle this problem at the individual level (even though I was sitting half way across the world). My doctor used to hand me a lot of printed material and papers to read on WM, and I found one name common in most, Dr. Steven Treon. After consulting with Dr. Parekh, I took a chance and sent Dr. Treon an e-mail asking about any pilots in the US who had WM but were able to get back to flying. His prompt and positive response significantly changed my view about my own future. I was convinced that I needed to get the numbers right and life would be back on track. By a strange coincidence, the numbers started to improve. By the end of September 2006, with 5 FCR cycles gone, my IgM had come below 1000. That is when, on advice of Dr. Parekh, I decided to visit the USA to meet Dr. Treon on completion of the 6th FCR cycle. The clot in my right eye had also significantly reduced, and vision in my right eye was almost as good as before my treatment.

When I met Dr. Treon at the Dana-Farber Cancer Institute at the end of October 2006, my health had improved considerably: Hb 13, IgM 500, and eyesight almost normal, except for a spot on the retina. In fact, Dr. Treon opined that I was fine, treatment was over, and I ought to go back to work. He suggested a maintenance therapy of 8 infusions of Rituxan over two years. Mentally the visit to DFCI and Dr. Treon's consultation were extremely important. It changed my thinking from "I have a serious illness and am going to sit at home forever" to "I **had** a serious illness which can now be managed and I need to get back to work."

After returning to India, however, I found that it was not going to be so simple to get back to work. I had to convince the doctors at home that it was ok for me to fly professionally. None were convinced. While I was undergoing treatment I kept myself busy by teaching young aspiring pilots aviation subjects, but I could not envisage myself doing that forever. In December 2006 Dr. Parekh took me to attend a lecture by Professor H. Miles from Melbourne on maintenance therapy. The lecture was organised by Roche. In my conversation with him, Professor Miles also opined that I could get back to the cockpit. This led me to visit Australia in February 2007 and consult Professor Miles at the Peter MacCallum Cancer Insititute.

With no hope of flying in India, I approached the FAA and Transport Canada for a medical category and both these agencies approved of my flying commercial aeroplanes, subject to more stringent medical tests. In the interim I also attended the Atlanta Ed Forum. It was terrific to meet so many WMers, to see their approach to WM and life and also the collective will to arrive at tangible solutions. It meant giving faces to names I had mailed to or read about, making plenty of new friends whom I could approach any hour of the day about problems or experiences that very few here understand.



Meeting the support group leaders in Atlanta and listening to them inspired me to attempt to start something similar, in Mumbai at least. I did contact several doctors, but, unfortunately, I found rallying the very few patients difficult. However, some doctors did tell their patients about me, and some of these patients or their relatives do contact me. The whole concept of patient support moves on a personal basis and I do my best to visit them or stay in touch. Someday I hope to develop a support group as in the US, and for that I think there is a need to bring more doctors into the fold for dissemination of information.

To return to my saga: in the end I was unable to get medical clearance to fly in India, so I chose to move on and seek opportunities abroad. In January 2008 I got employment with a Japanese airline and moved to Tokyo for work. My job allows me to work here in Tokyo for 21 days and go to Mumbai for 9 days. I am required to see a haemato-oncologist every three months in Tokyo. On querying my Japanese doctor about WM in Japan, I was told that he had seen only 3 or 4 high IgM cases in Japan in the last 40 years.

My WM journey has been amazing so far. What seemed insurmountable at first has been tackled, almost as my doctor had planned. My support team which, apart from Dr. Sunil Parekh, consists of my wife, my family, and my close friends, has been amazing. I have also received a lot of financial help from colleagues, certain charities and even Roche India. Thanks to WM I have had the opportunity to travel to far-off lands, meet new people, and make new friends. WM has forced me to seek new horizons for employment and enabled me to fly to places I would never have dreamt of (literally).

Despite living in a country of a billion people, I realise that I belong to a very small community spread across the globe whose futures are inexplicably linked to each other. Each looks to the other to know if the feeling is the same and all look in different directions to find a common solution. And until then, we wait and watch.

On a personal note, Sanjeev acknowledges the tremendous support of his wife, Sucheta, a physics teacher “who is the epitome of positivity and I credit all my recovery to her.” And he adds that their son, Sujeev, is also a pilot and now flies 737s as a first officer for an Indian airline.

TORCH TOPICS

BY ALICE RIGINOS, TORCH EDITOR

With the anniversary issue of the *Torch* (fall 2008) several changes were made in the appearance of the newsletter. The new look sports a masthead created by graphic designer Ken Edmondson and is printed in black ink on white glossy paper.

In response to recent comments regarding the makeover, we would like to provide the following information:

- The switch to glossy paper, as well as to the black and white scheme, was done to improve the sharpness of both the printed word and photograph.
- At the Sir Speedy press in Sarasota, where most IWMMF products are printed, the cost for a 5,000-copy run of the *Torch* is exactly the same, whether printed on matte or glossy.
- The *Torch* is mailed at a non-profit bulk rate based on weight. Glossy paper weighs less than matte and thus costs less to mail.
- Glossy paper is recyclable. Major magazines printed on such paper are acceptable for curbside collection. See www.Earth911.com for information.
- A “green” Web-based option is available to all who receive the *Torch*. The electronic version is posted on the IWMMF web site and is available earlier than the mailed copies. Please see page 36 for instructions on canceling your mailed subscription to the *Torch*.
- There is an easy solution for those who find glossy paper more difficult to read. The *Torch* as posted on the web site can be printed onto paper of your choice. If needed, you may also adjust the size of the print.



TORCH IN THE SPOTLIGHT

BY ALICE RIGINOS, TORCH EDITOR

With this April 2009 issue, your editor completes a full year's set of four IWMF newsletters published since May of 2008 when she was appointed editor of the Torch. In this article Alice "illuminates the Torch" from the editor's perspective and introduces the editorial staff whose talents and dedication throughout the year make the Torch so valuable to all members of the IWMF.

Five thousand copies of each issue of the IWMF *Torch* roll off the press in Sarasota, Florida. Four times a year. These five thousand copies are distributed in several ways.

- IWMF members, with the exception of those who opt for electronic delivery, receive their *Torch* directly by mail.
- The most recent *Torch* is an important component of the new patient information packet which goes to new members and to anyone who inquires, patient or not.
- When the IWMF is represented with a booth staffed by volunteers at hematological conferences, including conferences sponsored by the Lymphoma Research Foundation (LRF), the American Society of Hematology (ASH), and the recent 5th International Workshop on Waldenstrom's Macroglobulinemia, the *Torch* is on display (and available for the taking) for members of the hematological community. Clinicians, researchers, pharmaceutical representatives, representatives of other patient organizations--even patients--may avail themselves of a complimentary copy.

An eye-catching, informative, and well-written newsletter is extremely important in effectively promoting the activities, the goals, and the successes of the entire Foundation.

Consider the many types of medical information provided in this issue of the *Torch*.

- Medical information about WM, invaluable for patients and caregivers alike, is found in the recently launched column 'Doctor on Call', in which a leading authority on WM authors an article, written expressly for the *Torch*, that addresses a specific aspect of WM.
- In 'Medical News Roundup' the very latest research conducted worldwide and with potential impact on the treatment and cure of our common disease is presented in a clear and concise summary.
- A special report from the recent Stockholm workshop, a report written for IWMF members by our own reporter, a physician with the unique perspective of also having been diagnosed and treated for Waldenstrom's macroglobulinemia, sketches for us the steady progress in understanding this still-incurable cancer.
- In 'Research Update' the *Torch* regularly reports on the status of important research supported by the IWMF Research Fund under the oversight of the Vice President for Research.
- Finally, the Medical News Editor regularly contributes an article discussing in detail a specific aspect of treatment or laboratory procedures concerning Waldenstrom's.

The above columns make an issue of the *Torch* a reference worth saving and storing, whether on the literal shelf or in an electronic file.

In addition, every issue of the *Torch* publicizes important information about the IWMF and its many activities. Here the Treasurer's Report gives an assessment of the health of the Foundation's finances, while the Vice President for Fundraising presents suggestions for fulfilling current goals and calls for volunteers. The aim of the International Committee (to focus on the "I" side of the IWMF) is reflected in a report on the IWMF in Australasia, an inspiring account of one patient's WM journey from Mumbai to Tokyo via Boston, and information about the talk lists in French and Spanish (a new addition!). And from her corner, our President keeps us informed of Foundation news and links between the IWMF and the wider cancer community.

Then there are the other regular features that create a feeling of community among IWMFers across the continents. Our column 'From IWMF-TALK' distills information from the past months' talk list and brings to our readership a selection of the concerns, the useful tips, the stories of human interest. Members who do not subscribe to IWMF-TALK (and their reasons for this vary) find 'From IWMF-TALK' a valuable service. In each issue 'Support Group News' reveals a vital organization at the local level as we read of those many activities sponsored by support groups, including informative lectures, good times, and good food.

Torch in the Spotlight, cont. on page 11



Good food! How often do we speak of the importance of the ‘quality of life’? We may each have a private list of the factors and priorities comprising our own quality of life. But we cannot deny the importance of diet, and most of us would opt to combine healthy nourishment with the pleasures of the table. The recipes to be found in Cooks’ Happy Hour aim to do just that. Written just for the *Torch*, these recipes reflect the happy hours spent in the editors’ kitchens creating foods that are fresh, nutritious, delicious, and at the same time easy to prepare, food that nurtures a sense of well being. Quality of life? You bet.

Finally, there is that section of the *Torch* which includes listings for the Lifeline, the contact information for all the support groups, the subscription instructions for the WM talk lists in several languages, acknowledgements of donations. All of this information is updated for each issue by the energetic office staff under the direction of an Office Manager who has been devoted to this Foundation for 11 years.

Those of us who work on the *Torch* hope that the information we provide every three months will be valuable to patients to patients and caregivers, providing hope and perhaps even inspiration to live your lives as fully and richly as possible while we all wait for a cure for WM.

SPOTLIGHT ON THE *TORCH* TEAM

The volunteers responsible for the *Torch* are a team with special talents and specialized interests. Most of the staff members were originally tapped by Don Lindemann, now Editor Emeritus. All have literally carried the *Torch* forward this past year and now step forth and introduce themselves in their own words.



Alice Riginos and Sara McKinnie

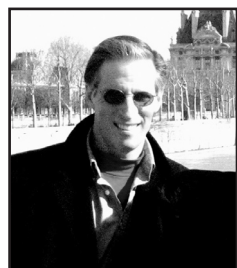
Alice Swift Riginos, *Torch* Editor, grew up on the south side of Chicago but has lived for a long while in Washington, DC, where she taught in the Department of Classics at Howard University for 26 years before retiring in 2002. Alice holds a master’s degree in Classical Archaeology from the University of Chicago and a doctorate in Greek and Latin from Columbia University. As a graduate student she worked at excavations, both on land and under water, in Turkey and Greece. It was in the course of these travels that she met her husband of 41 years, Vasilis Riginos, a communications satellite specialist, now also retired. Diagnosed with Waldenström’s macroglobulinemia in 2003, Alice has been treated three times, most recently during the summer of 2008. Alice and Vasilis are often in transit—an orbit that includes family in Greece and their two married daughters (plus one grandchild) now living in Brisbane, Australia, and in Laikipia, Kenya. Although

trained to read texts preserved on stone and papyrus, your roving Editor will be preparing your *Torch* electronically--on any one of four continents.



Sue Herms

Suzanne (Sue) Herms, Medical News Editor, has degrees in Zoology and in Medical Technology from Ohio University and from the Medical University of South Carolina, respectively. Sue now lives in the sunny South near Charleston, South Carolina, with her husband, Bob Ollerhead, and her cat, Mitzi. She extends an open invitation to any WMer who wants to visit Charleston to let her know because she loves to show off her adopted home (she’s from Ohio originally and is fortunate that her brother, John, his wife, and her parents--who recently celebrated their 60th wedding anniversary--also live in this area). A medical technologist at Roper Hospital in Charleston, Sue’s specialty is clinical microbiology, although she admits that her involvement with the *Torch*, IWMTALK, and the Patient Database “is almost a second job.” In addition to her curiosity about all things medical, Sue enjoys walking, swimming, and reading just about “anything I can get my hands on.”



Mitch Orfuss

Mitchell (Mitch) Orfuss, IWMTALK Correspondent, is a lifetime New Yorker. Mitch grew up in Stuyvesant Town (a lower-middle class housing project), graduated from Stuyvesant High School, then attended Columbia University for seven years where he earned a B.A. in philosophy (“What was I thinking?”), co-captained the Track Team (running slow 440’s), then completed his coursework in the English Department’s doctoral program. After a few years of itinerant adjunct lecturing at the college level, Mitch decided to search for a career with a future, and (through sheer luck) wangled a job as a copywriter at an advertising agency specializing in direct marketing, a marketing discipline that was just then taking off. Mitch spent the next 25 years in the ad agency business. For 8 of those years

Spotlight on the Torch Team, cont. on page 12

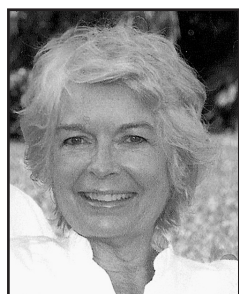


he was president of J. Walter Thompson's direct-marketing unit. Mitch also taught marketing at New York University as a moonlighter for 16 years. He and his wife of 22 years are parents of two nearly grown children.



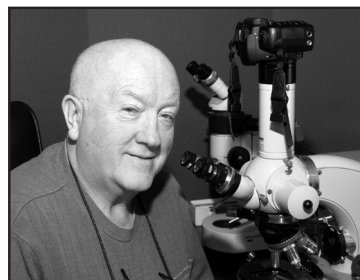
Penni Wisner

Penelope (Penni) Wisner, Support Group News Editor and Culinary Editor, is a San Francisco-based, free-lance writer specializing in food and wine, who learned the business from the ground up. From editing House & Garden magazine's Wine & Food section to working grape harvests around the world, she developed a range of knowledge on the pleasures of the table. She has written for newspapers, magazines, and Web sites. Her book credits include *Summer Cocktails*; *Flavored Vinegars*, *Flavored Oils*, and *The Tra Vigne Cookbook* with Michael Chiarello; *The Basque Kitchen* with Gerald and Cameron Hirigoyen; *Modern Asian Flavors* for Richard Wong; and *Burger Bar*, *The Ultimate Burger Experience* with Hubert Keller (Wiley 2009). Penni began her Waldenstrom's journey in the summer of 1998 and joined the IWMF shortly thereafter. She underwent chemotherapy from September 1999 to March 2000.



Nancy Lambert

Nancy Lambert, Culinary Editor, was born and raised in Fond du Lac, Wisconsin, and attended both the University of Wisconsin and the University of Minnesota, from which she graduated with a Bachelor of Science degree. Her master's degree in Liberal Arts is from Mc Daniel College in Maryland. Nancy and husband Larry raised 3 sons while moving 15 times throughout the upper Midwest states. Finally landing in rural Pennsylvania, not far from Gettysburg, Nancy taught art, gardened, read, and traveled. When diagnosed with Waldenström's macroglobulinemia in 2002, Nancy was treated with 6x Fludara. Subsequently diagnosed with diffuse large B-cell lymphoma (DLBCL) in 2008, she was treated with 6x CHOP + R. Thanks to Dr. Treon, she is, hopefully, cured of the DLBCL. Nancy describes her concern with healthy snacking as follows: "Our Happy Hours started when we began taking our 8 grandchildren to our extensive grocery store salad bar, where they would load their plastic trays with an assortment of healthy food so that it never mattered if they liked G'ma's casserole or not. We have continued the tradition in Pennsylvania and in North Port, Florida, where we spend our winters."



Ron Draftz

Ronald (Ron) Draftz, Science Advisor, is a WM patient (Dx 2000) who joined the IWMF in 2003 after his wife, Germaine, dragged him to Reston, Virginia, to attend the Ed Forum. He holds her accountable for what resulted from her persistence to attend a Forum and that includes working on: the *Torch*, Research Committee, Patient Database, Talk list (back-up), Ed Forum (still photographer and DVD editor) and a brief stint as trustee. He is also part of the program committee for the Chicago Area Support Group. He no longer protests -- about anything. When he's not doing IWMF he operates his consulting research lab as principal scientist specializing in the microscopical characterization of particles & powders with an emphasis on environmental studies. Best of all is time spent with his six grandkids that he reluctantly shares with other family members. As Science Advisor Ron is responsible

for "Doctor on Call" and edits "Research Update" and all articles of a technical nature. Ron Draftz is the official *Torch* photographer.

HOW THE *TORCH* IS LIT

BY SARA MCKINNIE, IWMF OFFICE MANAGER

My ever-so-glamorous role in the *Torch* production process begins with finalizing the list of memory/honor donations received during the previous quarter and extracting the various mailing lists from our membership database. Whenever a *Torch* calling for inserts is assembled, the mailing lists are populated accordingly and passed along to the printer who physically assembles the newsletter and gets it in the post. Our office then logs the mailing list cut off date to insure that a newsletter is sent to anyone who contacts IWMF afterwards.

Next, I watch my inbox fill up with e-mails from *Torch* Editor, Alice Riginos, with edited articles and photographs attached. Madam Editor also furnishes instructions as to content and order of placement in the newsletter. I then round up standing articles and the listings which appear in the *Torch* regularly and tweak them for correctness. When all articles are organized and laid out (some cut-and-paste is involved here) we are on the home stretch.

Now the job is carried to the trusty local printer, Sir Speedy, who is quite familiar with our beloved *Torch*, to review the mailing lists and identify who gets which inserts and the total number of newsletters to print. The turnaround for a proof is

How the Torch is Lit, cont. on page 13



generally 2 days, and then I do some clean-up and any necessary reorganizing. Upon review and approval it's ready for the editor's eyes. After proofreading, Alice sends me her comments and changes. At this juncture, she and I often discuss copy flow and space utilization. Alice's changes are then incorporated into the final proof.

Once I know the estimated mail out date, I notify IWMF Trustee Peter DeNardis so that he can post the issue at the Publications page of our website on a specific date. The *Torch* is generally available at www.iwmf.com two weeks in advance of an issue arriving in your mailbox.

That's how the "*Torch is lit.*" Voilà!

TREASURER'S REPORT FOR THE YEAR 2008

BY BILL PAUL, TREASURER

The finances of IWMF are operated through two separate funds: the Research Fund and the Member Services Fund. The assets of these funds are kept separately as are the accounting records. For the sake of simplicity they are summarized as follows, with a comparison to last year. Amounts are rounded to the nearest thousand.

Research Fund	<u>2008</u>	<u>2007</u>
Contributions Received	\$ 518,000	\$ 901,000
Interest Income	46,000	51,000
	<hr/>	<hr/>
	564,000	952,000
Research Grants Awarded	<u>60,000</u>	<u>38,000</u>
Increase for Year	<u>504,000</u>	<u>914,000</u>

Contributions during 2008 were significantly lower than during 2007. The year 2007 included many large donations, and this, combined with the economy during 2008, accounted for the difference. However, since only one research grant was awarded during 2008, this kept the amount in the checking account and CDs at \$1,797,000. With research grants payable at \$784,000 on December 31, 2008, the Research Fund is still in a healthy financial position. We expect more Research Fund requests during 2009, and we anticipate those requests with enthusiasm as we search for a cure for WM. It is also expected that the various campaigns started during 2008, such as the Five-In-Five Campaign, will help to increase our contributions for 2009.

Member Services Fund	<u>2008</u>	<u>2007</u>
Contributions Received	\$ 390,000	\$ 390,000
Member Services and Operating Costs	<u>411,000</u>	<u>449,000</u>
Increase or (Decrease) for Year	<u>\$(21,000)</u>	<u>\$(59,000)</u>

Income for 2008 was coincidentally identical to 2007. Although the Member Services Fund still showed a deficit at year end, it was an improvement of \$38,000 over 2007. With your help this can be turned around in 2009 and we can report a profit. Overall, the Fund is in a relatively healthy position, with assets in the checking account and CDs of \$283,000, compared with \$304,000 at the end of 2007.

IWMF, the Economy and Your Money

It seems appropriate to mention the safety of your money when donating to IWMF. I would like to reassure you that the Board of Trustees is very concerned with the safety of your money. During these troubling times with a plummeting stock market, not a penny has been lost due to poor investment decisions by the IWMF Board. We have had no funds invested in the stock market, and the financial situation of IWMF is very healthy.

The world economy is truly financially concerning, and the IWMF is financially challenged as are all donation-dependent organizations. Please know that by donating to IWMF you are contributing to an organization that has very low administrative costs and helps patients, families, and friends directly. The monies donated have an immediate impact on the Education Forums, the *Torch*, the web site, IWMF-TALK, e-mail alerts, and our many other member services. This is not a time to stop giving, whether you designate your contribution to the Research Fund or leave it to the discretion of the Board. Either way, your donations are helping to save lives and to improve the quality of lives.

If you have any questions on IWMF financial matters please do not hesitate to contact me directly at 901-767-6630 or billpaul1@juno.com.



MAKE IT SIMPLE

BY DICK WEILAND, VICE PRESIDENT FOR FUNDRAISING

If you want to simplify your estate planning you may want to consider a bequest.

Bequests are simply gifts made through a will to provide special support for your favorite non-profit organization. Given our health conditions, IWFM must certainly be at the top of your list. Right?

If so, there are several simple options available to us, including:

1. **A Specific Bequest** This is when you give a specific dollar amount or asset from your estate to IWFM.
2. **A Residuary Bequest** This is when you direct to IWFM all or a percentage of what is left in your estate after other terms of your will have been met.
3. **A Contingent Bequest** This is when IWFM would receive all or some of your estate dependent upon certain conditions you make, such as financing your grandchildren's college education.
4. **A Restricted Bequest** This is when you restrict your bequest to support a specific project associated with IWFM, such as the soon to be announced Dr. Robert A. and Charlene M. Kyle Endowment Fund for Research.

Here is an example of language to share with your legal counsel for a **Specific or Residuary Bequest**:

"I, [name] of [city, state, ZIP] give, devise and bequeath to the International Waldenström's Macroglobulinemia Foundation, 3932D Swift Road, Sarasota, Florida, 34231-6541, [written amount or percentage of the estate or description of property] for its unrestricted use and purpose."

See the Ben Rude Heritage Society Inquiry Form, complete and send in the enclosed envelope. Dave Benson or I will be pleased to follow up with a response to any questions you may have.

Simple. Right?



THE BEN RUDE HERITAGE SOCIETY INQUIRY FORM

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

- | | | |
|---|---|---|
| <input type="checkbox"/> A Bequest in my Will or making a Codicil | <input type="checkbox"/> A Charitable Remainder Trust | <input type="checkbox"/> A Gift Annuity |
| <input type="checkbox"/> A Life Estate or Real Estate Gift | <input type="checkbox"/> A Charitable Lead Trust | <input type="checkbox"/> Life Insurance |
| <input type="checkbox"/> Other _____ | | |

Signature

Name (please print)

Address/City/State/Zip

Telephone Number

E-mail Address



IWMF FUNDRAISING VOLUNTEERS: A-Z

BY DICK WEILAND, VOLUNTEER VICE PRESIDENT FOR FUNDRAISING

IWMF is in need of talent across our panoply of IWMF services ranging from A to Z, from apheresis to Zevalin.

When I was engaged in fundraising administration for a living I liked to estimate how much budget relief was experienced each year through volunteerism. Now, at IWMF as a volunteer Vice President for Fundraising, I find myself still engaged in fundraising administration, but this time for the living, for longer life, including me. I estimate we are saving at least between \$200,000 to \$250,000 in fundraising costs when we factor in the contributed salaries of a Vice President for Development, contract writers for foundation proposals, Membership Fund leaders, event coordinators for the “a-thons,” the tulip sales, the silent auctions, planned giving programs, marketing folks ...and on and on.

There are different levels of help needed in fundraising—from “A” to “Z.” You can try a task and if it doesn’t work out try another more to your liking in the IWMF alphabetical range. When my hemoglobin was at 7 and my IgM at 10,000 I struggled

IWMF Fundraising, cont. on page 16

Volunteer Fundraising Talent Search

Please consider helping us help others by selecting an IWMF volunteer fundraising task for which you have skills or talents with areas you might be interested in, or you would like us to hear about. Match the talents or skills in the left column with the headers to the right with a check mark, provide your contact information, tear out the sheet and send to: IWMF Office, 3932D Swift Road, Sarasota, Florida 34231-6541 or bring to the Education Forum.

Contact Don Brown (Ldonbrown@msn.com), Membership Services Volunteer

IWMF Volunteer Need (Your Talent or Skill)	Membership Services Fund	Research Fund	Estate Planning	Foundations/ Corporate Grants	Fundraising Events
Finding Potential Donors					
Contacting Donors by phone					
Contacting Donors in Person					
Writing Letters					
Writing Proposals					
Internet/Email Marketing					
Marketing Fundraising Activities					
Making Fundraising Presentations					
Analyzing Fundraising Trends and Data					
Leading, Organizing and/or Administering Fundraising Activities					
General Support of Fundraising Planning					

Your Name: _____

Address: _____

City, State and Zip Code: _____

Phone Number: _____ Email Address: _____

Membership Services Fund

To be used to operate IWMF office, produce educational materials, support administrative costs for the Research Fund, help Support Groups, and other annual operating expenses.

Research Fund

All contributions go directly to research efforts for WM. Projects are determined by IWMF SAC

Estate Planning

Professionally guided information on methods and benefits of assigning a part of one’s estate to the IWMF for IWMF priorities in keeping with interests of the donor.

Foundations/ Corporate Grants

Non-profit Foundations are required to grant a percentage of the foundation’s value each year. Corporations want to give back to the community that are their “customers.”

Fundraising Events

There are a myriad of ways that funds can be raised.

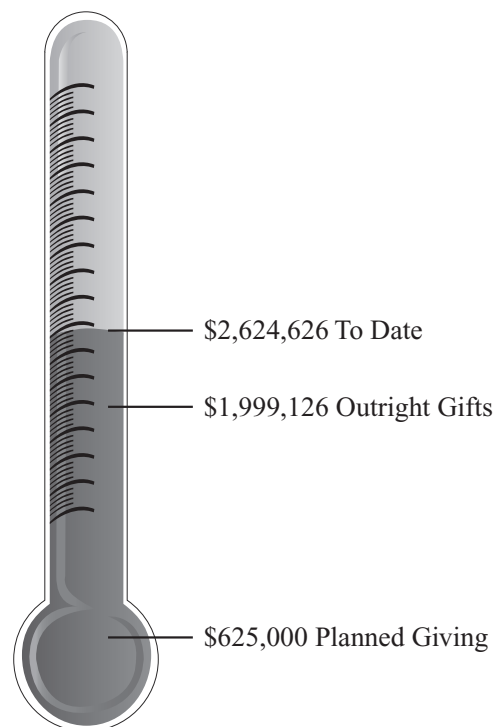


to lick envelopes for the local American Cancer block letter writing campaign. But if you can get out of bed in the morning, we may have something for you, something between “A” to “Z”

In general, we have a need for leaders and followers. There is a need to match your gifts, talents and skills with IMWF priorities so we can save another \$250,000 or so as we seek another \$1million for 2009.

On page 15 you will find a form, designed by Don Brown, Membership Services volunteer and Chicago area support group leader, to match your interests or talents (or IWMF needs) with five major areas of fundraising: Membership Services Fund, Research Fund, estate planning, foundations/corporate grants and fundraising events. Run your pen from left to right to see where you have a match and check the box you would like to try, tear off the page and send it to the IWMF office in the enclosed envelope. Or bring it to the Education Forum in Memphis where we can chat with you in person.

Remember: Volunteers R U.



SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Please note: contact information for all support groups is printed on pages 19-20.

IWMF CHAPTERS—USA

ARIZONA

On March 14, IWMF partnered with the Lymphoma Research Foundation (LRF) for an educational session on WM at the Scottsdale Resort & Conference Center in Scottsdale Arizona. Dr. Morton Coleman of New York Presbyterian Hospital presented to approximately 70 patients and caregivers. Following lunch, Ed Nadel, IWMF Phoenix area support group leader, coordinated a patient panel discussion with Dr. Coleman.

CALIFORNIA

Los Angeles

Dr. James R. Berenson, Medical and Scientific Director, Institute for Myeloma & Bone Cancer Research, met with the Los Angeles WM support group in January. He answered questions with patience and discussed nutrition, supplements, vaccinations and WM, and drug interactions. In a particularly interesting tidbit for sufferers of peripheral neuropathy, he mentioned that a supplement, alpha lipoic acid, can be very helpful when taken in 600 to 1200 mg doses.

Sacramento and Bay Area

Finding a new doctor presents a challenge all patients face. This challenge formed the basis of the group discussion at

the winter meeting. As WMers live longer, the necessity of replacing doctors occurs again and again. First and foremost, when a trusted doctor retires or moves, the patient must come to terms with the surprising and often uncomfortable feelings of betrayal and abandonment. Then comes the hunt for, and interviewing of, a new doctor. Members traded tips, techniques, and advice. The next meeting will take place in May or June.

COLORADO & WYOMING

The Denver group recently watched the forty-minute video of Dr. Steve Treon of Dana-Farber Cancer Institute speaking at the Stockholm international workshop on WM. He covered the new conclusions about familial connections in WM, the current research and clinical trials being conducted and what has been learned from these trials, as well as new trends that attempt to tailor treatments to each patient. Much progress has been made over the last year. It was a positive message as usual from Dr. Treon. After the video, the group discussed current WM issues and questions. Through the group's partnership with the Leukemia and Lymphoma Society, which announces WM support group meetings in its own flyer, two new patients attended. A Society representative provided snacks and outlined programs available to WMers through the LLS. The next meeting will be in early June when activities and key messages of the Memphis IWMF patient forum will provide the discussion topics.

Support Group News, cont. on page 17



FLORIDA

Ft. Lauderdale Area

Dr. Steve Treon, Dr. Daren Grosman of Memorial Hospital West in Pembroke Pines, and our own Bob (row-Bob-row) Lynch made presentations at the group's spring meeting in March. The local chapter of the LLS provided a complimentary lunch for attendees. Following the presentations we had our always popular "Ask the Doctors" session which was well received by the attendees.

Southwest Florida

On Feb. 28 IWMF collaborated with the Suncoast Chapter of the Leukemia & Lymphoma Society (LLS) in a meeting held at the Wellness Community in Sarasota, Florida. Approximately 65 attendees were treated to an excellent presentation by Dr. Rachid Baz of the Moffitt Cancer Center in Tampa FL. IWMF Support Group Leader, Linda Rothenberg, plans to arrange another meeting in the Tampa area this fall.

GEORGIA

Mal and Judy Roseman gathered their group for a meeting in February.

HAWAII

Group leader **Sandy Skillicorn** divides her time between the islands and the mainland. The Hawaii group is small and has not yet had a meeting. However, Sandy meets with members individually, when possible, and keeps up to date with them by telephone and email.

IDAHO

The Southeastern Idaho support group met at the home of **John Stanger** in January for a "caring and sharing" afternoon. Several members are in treatment or maintenance and they spoke of their experiences. The discussion included the need for second opinions and several of the new options/trials currently available. Support group leader **Barbara Britschgi** will attend the Memphis Forum and the group will meet again in May to discuss any new ideas presented.

ILLINOIS

The Chicago Area support group has started planning for its 2009 meetings. The first meeting will be May 9 at Lutheran General Hospital in Park Ridge, Illinois. The meeting will hopefully feature its first Internet conference call with Dr. Irene Ghobrial who is very active in WM research at the Dana-Farber. If the technical details and funding issues can be worked out, the group may be able to communicate with DFCI more regularly without necessitating the cost and time-consuming travel by the great doctors at DFCI. If the Internet link is not ready, the group will view and discuss a recent video presentation. Also in the planning stages: a summer picnic.

NEVADA

The Las Vegas group is off and running. Its inaugural meeting was hosted by the local chapter of the LLS. The members enjoyed getting to know one another, sharing stories and information. The patient services manager of the LLS offered her support for the group and shared valuable information on the services of LLS. The group met again in January and plans to meet again after the IWMF patient education forum. Meanwhile, members keep in touch, mostly through e-mail, even when they cannot attend meetings.

NEW ENGLAND

Boston

A good-sized crowd of 50 patients and caregivers come out on a brisk New England winter's day to hear Dr. Irene Ghobrial of DFCI speak. She reviewed the on-going DFCI research and clinical trial efforts and discussed some of the new trials that would be opening up in the near future. Some of these will employ new, novel, targeted drugs that have not before been evaluated in a clinical setting for use in Waldenstrom's. Dr. Ghobrial described the clinical trial process step-by-step. She noted that, although there usually are Phase 1, Phase 2, and Phase 3 parts to the process, there has never been a Phase 1 trial specifically for Waldenstrom's. A Phase 1 trial is conducted to determine the toxicity and response rates of a new drug for the first time in humans.

Dr. Ghobrial reminded the group that treating Waldenstrom's is driven by a patient's symptoms, and that patients may each have different degrees of symptoms for different levels of IgM. Therefore, comparing IgM levels is usually pointless. After Dr. Ghobrial's presentation, she answered questions ranging from cryoglobulinemia and neuropathy in Waldenstrom's through PET scans, new ways to characterize the disease burden, and the need to be sure that one really has Waldenstrom's before any form of treatment is initiated. Finally, Dr. Ghobrial emphasized that there is a shift in thinking about treating Waldenstrom's in the light of the new, targeted drugs that are becoming available. While finding a cure is the focus of the work she and other researchers are doing, these therapies will hopefully soon lead to turning Waldenstrom's into a chronic condition that can be controlled much like hypertension.

NEW YORK

Northeast NY/Western New England

Gilda's Club in Latham, NY, easy to get to and with convenient parking, has become the group's regular meeting spot. It is a great community resource and some members now volunteer there. At the meeting, the group warmly greeted new members, discussed the IWMF April Patient Education Forum and the May Dana-Farber Conference. Plus they viewed the "Treatment for WM" by Dr. Morie Gertz of



Mayo Clinic portion of the 2008 Forum DVDs. The group was delighted to learn that its founding member, **Thad Raushi**, was back home from the hospital. As this issue goes to print, the group gathers for its annual restaurant gathering, an event devoted to food and socializing at the Dragon Buffet in Colonie, just outside of Albany.

OREGON/SOUTHWEST WASHINGTON

The group meets quarterly on the fourth Saturday of January, April, July, and October from noon to 2:00 pm at the Fairfield Inn & Suites, Fireside Room, 6100 SW Meadows, Lake Oswego, Oregon. Meetings for 2009 are tentatively scheduled for May 9 (not the 4th Saturday of April due to the IWMF Educational Forum in Memphis, TN), July 25, and October 24. At the winter meeting, the group viewed the segment on gene profiling from the 2008 Ed Forum DVDs. After the DVD, the group of 24 broke into two smaller groups with WM patients in one group and caregivers in the other. The patient group shared date of diagnosis, treatments received, recent lab test results, and symptoms. Discussion followed about stem cell transplants (one new member had SCT as part of a clinical trial in 2000 and now has normal labs) and other clinical trials, specifically RAD001, which one person is taking with good results, including gradually decreasing IgM levels, improved energy and mental clarity. The caregiver group discussed similar topics but from the viewpoint of the caregiver. Although the meeting officially ended at 2:00, both groups continued in discussion.

SOUTH CAROLINA

On Valentine's Day, the small group had a fun and informative session over lunch. One of the main topics was interpreting blood test results. Also, throughout the past several months, group members helped newly diagnosed patients locate oncologists with WM experience. The next meeting is planned for the afternoon of June 13 at the Hope Lodge (part of MUSC campus) in Charleston, SC.

TEXAS

Dallas & Northern Texas

The January meeting featured a presentation by Kim Brown from the LLS. She described their services and discussed the society's co-pay assistance program which had been suspended for WM patients because of lack of funds. It is now available again and pending claims will be processed first. **Jerry Fleming**, the group's leader, described the Life-After-Cancer-themed spring meeting that included several presentations: "My Treatment is Over, Now What? Living Life after Cancer", presented by Page Tolbert, LCSW, Post Treatment Resource Program, Memorial Sloan-Kettering Cancer Center; "Employment/Legal Issues" presented by two attorneys; and "Long Term Side Effects of Cancer" presented by a physician. Also included, a roundtable discussion for young adult survivors led by survivors and caregivers.

TEXAS

Houston

The Houston support group announces their next meeting on April 26th, at 21 Briar Hollow Lane, Houston, TX 77027. The guest speaker will be Dr. Maria Scouros on "Understanding Your Blood Values." Dr. Scouros, Board Certified in Medical Oncology and Internal Medicine, is the Director of the Houston Cancer Institute. She specializes in hematology. The meeting will be coordinated with the LLSociety of Greater Houston. **Ann Gray**, the Houston IWMF representative to the Los Angeles LRF Conference, will update us on what she learned there.

VIRGINIA

The Spring gathering in Richmond is tentatively scheduled for late April after the IWMF Ed Forum. The group normally meets twice a year.

WASHINGTON D.C./METROPOLITAN AREA

The enthusiasm instilled by Dr. Treon's visit with the group in December carried them through their early spring meeting in March when they welcomed new members and exchanged news.

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. Please e-mail Support Group Coordinator Arlene Hinchcliffe at wmfc@noco.ca if you would like to participate.



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If you can't get to a local support meeting, use our IWMF Telephone Lifeline to call a WM veteran.

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

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MEDICAL NEWS ROUNDUP

BY SUE HERMS

Long-Term Outcome Reported for Fludarabine and Rituximab in WM – The Bing Center has reported the long-term outcome of a multicenter study of fludarabine and rituximab for treatment of WM. Of 43 patients enrolled, the overall response rate was 95.3% and the major response rate was 86.0%. Toxicities included neutropenia, thrombocytopenia, and pneumonia. With a median follow-up of 40.3 months, three cases of transformation to aggressive lymphoma and three cases of myelodysplasia/acute myeloid leukemia were observed. While this treatment regimen is highly active in WM, short and long term toxicities need to be carefully weighed.

Cladribine Treatment May Also Include Significant Risk of Transformation – A different study, conducted by M.D. Anderson Cancer Center and the University of Athens School of Medicine in Greece, reported on the incidence of transformation to other malignancies in WM patients treated with cladribine alone or in combination therapy. An analysis of 111 patients revealed that 23 (21%) had either transformation to aggressive lymphoma or development

of a second malignancy within a median time period of 55 months.

Combination Therapy with Pentostatin Is Effective with Less Toxicity than Other Nucleoside Analogs – The M.D. Anderson Cancer Center reported that the combination treatment regimen of pentostatin, cyclophosphamide, and rituximab provided the same remission rate as other combinations but with minimal long-term bone marrow suppression in patients with indolent B-cell lymphoma. In this 80-patient study, no patients developed myelodysplastic syndrome. Pentostatin is a nucleoside analog, in the same family as fludarabine, and appears to be less toxic than other members of this drug class.

Studies Released on Maintenance Rituximab Therapy in Follicular Lymphoma – A Phase 3 study, conducted by the European Organisation for Research and Treatment of Cancer study group and presented to the American Society of Hematology (ASH) conference, reported 6-year follow-up results on the use of rituximab maintenance therapy in patients

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with recurrent follicular lymphoma. Patients given rituximab maintenance therapy after their initial chemotherapy treatment had a median response of 3.7 years compared to 1.3 years for those who did not receive maintenance therapy. Another study from the Rabin Medical Center in Israel compared survival data for 985 follicular lymphoma patients, contrasting maintenance versus no maintenance therapy. Maintenance therapy was associated with a 40% improvement in overall survival compared to retreatment with rituximab at relapse. However, this study noted nearly twice the rate of infection-related adverse events in patients with maintenance therapy.

Study Determines Maximum Tolerated Infusion Rate of Rituximab – A group of researchers from the Departments of Medical Oncology and Cardiology, Ospedale San Giovanni in Bellinzona, Switzerland, completed a Phase 1/2 study to determine the maximum tolerated infusion rate of rituximab with steroid premedication in patients who had received at least one previous rituximab infusion in the preceding three months. The study paid particular attention to determining if any cardiac toxicities developed from an increased infusion rate. Thirty-two patients were included in the study, and all were able to safely tolerate an infusion rate of 700 mg/hour without major side effects.

Mayo Clinic Presents Report on Statin Use with Rituximab Treatment – A new Mayo Clinic study found that statins do not interfere with rituximab treatment for lymphomas, in contrast to an earlier report which suggested that statins may inhibit rituximab binding to CD20 cells. The Mayo study focused on the impact of statin use on patients with diffuse large B-cell lymphoma and follicular lymphoma. The most commonly used statins include Lipitor, Zocor, Parvachol, Lescol, Mevacor, and Crestor. The Mayo study said that not only did statin use not adversely affect rituximab treatment but that follicular lymphoma patients actually benefited from statin use, with 80% having no disease progression or re-treatment at two years versus 69% for those not taking statins.

Study Evaluates R-CHOP Versus CHOP in WM – A study from the University of Munich in Germany evaluated the addition of rituximab to CHOP chemotherapy (R-CHOP) versus CHOP (cyclophosphamide, doxorubicin, vincristine, and prednisone) alone in 48 WM patients. R-CHOP resulted in a significantly higher overall response rate (91%) than CHOP alone (60%). The time to treatment failure was also significantly longer, with a median of 63 months for R-CHOP and 22 months for CHOP. There was no major difference in treatment-associated toxicity between the two groups.

International Prognostic Scoring System for WM Developed – A multi-center group from Europe and the United States recently released an International Prognostic Scoring System for Waldenstrom's Macroglobulinemia (ISSWM), developed by studying a group of 587 patients. The goal was to optimize treatment according to the prognostic

indicators and to facilitate the comparison of clinical trials for various treatments. Five adverse factors at initiation of treatment were identified: age > 65 years, hemoglobin ≤ 11.5 g/dL, platelet count ≤ 100 x 10⁹/L, beta2-microglobulin > 3 mg/L and serum monoclonal protein > 7.0 g/dL. Three risk categories, low, intermediate, and high, were based on the number of these adverse factors present. The risk categories impacted 5-year survival rates, with low risk patients having a 5-year survival rate of 87%, intermediate risk 68%, and high risk 36%. Meanwhile, the Southwest Oncology Group from the United States identified increased serum lactate dehydrogenase (LDH) as an additional variable that impacted survival rates and was useful in assessing prognosis.

The Bing Center Investigates Tunicamycin in WM Cell Cultures – The Bing Center at Dana-Farber Cancer Institute is investigating an agent called tunicamycin for its antitumor effects on WM cells. This agent acts on the UPR (unfolded protein response) gene, which enables cells to produce and secrete high amounts of proteins such as immunoglobulins. Tunicamycin triggered this gene to cause cytotoxicity (cell damage), apoptosis (programmed cell death), and cell cycle arrest in WM cell cultures and appears to synergize with other agents used in the treatment of WM.

Phase 1 Clinical Trial Evaluates Small Molecule Oral Drug for Non-Hodgkin's Lymphoma – SuperGen will initiate a Phase 1 clinical trial to evaluate SGI-1776, an oral small molecule anticancer compound, on patients with refractory prostate cancer and refractory non-Hodgkin's lymphoma (NHL). The drug targets the Pim kinase family of proteins, which are key regulators in many signaling pathways implicated in cancer.

Drug Targets Bcl-2 Proteins in B-Cell Lymphomas – Scientists at Roswell Park Cancer Institute reported on a drug called obatoclax, developed by Gemin X. This therapy targets the Bcl-2 protein family and has demonstrated the capability to induce cell death and/or cell degradation in cell lines from patients with B-cell lymphomas. This drug also appears to enhance the activity of rituximab and sensitizes lymphoma cells to the effects of a wide spectrum of chemotherapy agents.

Data Available from Phase 2 Study of RAD001 (Everolimus) in WM – Previous studies have demonstrated the clinical activity of the mTor inhibitor RAD001 (Everolimus) in lymphomas. The Dana-Farber Cancer Institute and the Mayo Clinic College of Medicine conducted a Phase 2 study of this drug, developed by Novartis, in patients with relapsed or refractory WM. All patients received daily oral RAD001 for 28 days and repeated the cycle as tolerated. Eighteen of 19 patients from the Dana-Farber study arm were evaluated at the end of the study. The overall response rate was 72%. Toxicities included thrombocytopenia, pneumonia, hyperglycemia, nail cracking, mucositis, diarrhea, and fatigue. Future studies of RAD001 with rituximab and bortezomib are being planned.



Increased Rantes Expression Associated with B-Cell Cancers – The Department of Hematology at Mayo Clinic has found a significant elevation of the cytokine Rantes/CCL5 in WM patients as well as a correlation with disease activity. Rantes expression is associated with a wide range of immune-mediated diseases, including B-cell proliferative disorders. Rantes is thought to mediate IL-6 secretion in the bone marrow stromal cells, thus promoting IgM production by the malignant B-cells.

Dana-Farber Evaluates WM Cells with New Drug Produced by Novartis – The Dana-Farber Cancer Institute evaluated the antitumor activity of NVP-BEZ235, produced by Novartis. This drug acts on WM cells by means of the P13K/Akt and mTor pathways and induced cytotoxicity and apoptosis in cell lines, suggesting its potential for inclusion in future clinical trials.

Large-Scale Study Confirms the Risks of Using ESAs for Anemia in Cancer Patients – A large-scale study presented at the 2008 American Society of Hematology conference examined how survival rates are affected by the use of erythropoiesis-stimulating agents (ESAs) for the treatment of anemia in cancer patients. ESAs include Procrit, Aranesp, and Epogen. A total of 13,933 cancer patients participated, of which 10,441 patients were receiving chemotherapy for their cancer. Survival rates were compared in patients who received both red blood cell transfusions and ESAs versus patients receiving red blood cell transfusions alone. The study found that for all cancer patients, ESAs increased mortality by 17% and worsened overall survival by 6%. For patients undergoing chemotherapy, ESAs increased mortality by 10% and worsened overall survival by 4%.

Mayo Clinic Evaluates Pomalidomide with Dexamethasone – Mayo Clinic researchers evaluated a new immunomodulatory agent, called pomalidomide, in combination with dexamethasone for treatment of relapsed multiple myeloma patients. To date, 58% of patients have responded to this therapy with at least a 50% drop in their detectable tumor burden. Side effects included anemia, decline in blood counts, and deep vein thrombosis, although most effects were mild. Both drugs are taken orally. Another key finding was that pom/dex treatment was helpful for 29% of patients who previously did not respond to lenalidomide (Revlimid), which is in the same drug class. Meanwhile, researchers from a multi-center study in Great Britain evaluated pomalidomide on an alternate day dosing schedule and found that the safety profile of the drug improved while maintaining excellent activity. Dr. Treon's group at Dana-Farber Cancer Institute is planning to propose a clinical trial of this drug on WM patients.

Surgical Outcomes Evaluated in Patients with Hematological Malignancies – Surgical intervention in patients with malignant hematological disorders is a major undertaking due to the expected risks of bleeding, infection,

and poor wound healing. A retrospective study from the Riyadh Armed Forces Hospital in Saudi Arabia identified leukemia and lymphoma patients who underwent surgical procedures compared with those of a control group with the same spectrum of diseases but who did not require surgery. Follow-up of both groups of patients revealed a shorter long-term survival and higher rates of disease relapse and severe infections in the surgical group.

Final Results Available for Perifosine in Phase 2 Trial with WM Patients – Final results from a Phase 2 trial of the oral Akt inhibitor drug perifosine in relapsed or refractory WM patients were released. Patients receiving single agent perifosine achieved a 36% overall response rate, and 58% had stable disease, with a median time to progression of 10.7 months.

Mozobil Use in Bone Marrow Transplantation Approved in U.S. – The U.S. Food and Drug Administration approved Mozobil, a Genzyme product, for use in bone marrow transplantation in patients with multiple myeloma or non-Hodgkin's lymphoma. Mozobil, in combination with granulocyte-colony stimulating factor, helps to increase the number of stem cells collected for transplantation. Genzyme has submitted an application in Europe for approval of Mozobil and has recently filed applications in Australia and Brazil.

Phase 2 Study Evaluates Treanda and Rituximab Combination Therapy – Also presented at the ASH conference was a Phase 3 study of bendamustine (Treanda) and rituximab combination therapy in patients with relapsed or refractory follicular, indolent, or mantle cell lymphomas. The study compared this regimen to R-CHOP (rituximab plus cyclophosphamide, doxorubicin, vincristine, and prednisone). The overall response rate and the complete response rate were similar in both groups, but there was a lower incidence of relapsed disease in the bendamustine group. The researchers concluded that bendamustine combination therapy also has a better toxicity profile as well as fewer infectious complications.

New Oral Nucleoside Analog Drug in Clinical Trials – An oral drug called clofarabine, developed by Genzyme, is currently being tested in a Phase 1/2 study in patients with relapsed/refractory non-Hodgkin's lymphoma. It is a purine nucleoside analog, similar in action to fludarabine and cladribine.

Researchers Report on FCR-Lite Treatment Regimen – In an effort to reduce the toxicity of combination therapy fludarabine, cyclophosphamide, and rituximab (FCR), researchers at the University of Pittsburgh evaluated a reduced-dose regimen in patients with chronic lymphocytic leukemia. In this so-called FCR-Lite regimen, the monthly doses of fludarabine and cyclophosphamide were decreased and the dose of rituximab was increased. FCR-Lite resulted



in substantially lower rates of neutropenia while maintaining high response and survival rates.

Artificial Bone Marrow Developed – A team from the University of Michigan has been attempting to grow human bone marrow artificially. The team tried to replicate the interior of bone by using a material called hydromel, which is similar in composition to a soft contact lens. They seeded the hydromel with tiny polystyrene spheres. When the hydromel solidified, the spheres were dissolved, leaving a porous matrix. When the researchers introduced marrow cells from donors, the transplanted cells behaved as if they were in real marrow tissue. To test the artificial marrow, influenza viruses were introduced, and the marrow cells released antibodies as they normally would in natural marrow. The researchers hope to use their artificial marrow to test anticancer and antiviral drugs.

Dana-Farber Studies New Drug in Multiple Myeloma Cells – The interaction of multiple myeloma cells with their environment in the bone marrow provides a protective environment and resistance to therapeutic agents. Dana-Farber Cancer Institute reports that AMD3100 induces disruption of this interaction by interfering with adhesion of the tumor cells to bone marrow stromal cells and enhances sensitivity to bortezomib treatment.

Researchers Evaluate New Agent with Anti-CD 19 Antibody – Seattle Genetics and Roswell Park Cancer Center have evaluated the antitumor effects of an agent called monomethyl auristatin E (MMAE) conjugated to a humanized anti-CD19 monoclonal antibody. The CD19 antigen is found on almost all B-cells. Mouse models have indicated that this treatment may present a promising option for lymphoma patients who are resistant to rituximab.

Phase 1/2 Study of Acadesine in CLL – Investigators are conducting a Phase 1/2 study on the use of acadesine, a protein kinase activator, in patients with chronic lymphocytic leukemia. Preclinical studies suggest that acadesine causes apoptosis of B-cells in various types of lymphoma without injuring T-cells, thus minimizing the serious immunosuppressive side effects caused by many other treatments.

Ofatumumab Application Submitted to FDA – GlaxoSmithKline and Genmab have announced the submission of a Biologics License Application to the U.S. Food and Drug Administration for Arzerra, also known as ofatumumab or HuMax CD-20, to treat patients whose chronic lymphocytic leukemia is resistant to previous therapies. Arzerra targets a different portion (epitope) of the CD20 molecule found on B-cells than does rituximab. A Phase 2 trial has begun of this drug in patients with WM.

Green Tea May Interfere with Velcade Effectiveness – Researchers at the University of Southern California have found that a component of green tea extract called EGCG destroys the anticancer activity of the drug Velcade

(bortezomib) in mouse models with multiple myeloma and mantle cell lymphoma. It appears that the EGCG molecule and the Velcade molecule are able to form chemical bonds, inhibiting the binding of the Velcade molecule to its intended target inside the tumor cells.

Rituximab Combined with Epratuzumab – Weill Cornell Medical College and New York Presbyterian Hospital collaborated in a trial evaluating rituximab plus epratuzumab (anti-CD22) in patients with relapsed/refractory indolent non-Hodgkin's lymphoma. Fifty-four percent of follicular lymphoma patients had a response, including 24% with a complete response. The median response duration was 13.4 months.

Milatuzumab Evaluated in Lymphoma and Multiple Myeloma – Weill Cornell Medical College and New York Presbyterian Hospital also evaluated preclinical data for milatuzumab, a humanized monoclonal antibody targeting CD74, which is expressed in non-Hodgkin's lymphoma and multiple myeloma. The antibody was toxic to cell lines and mouse models of both types of cancer, and its effectiveness was dramatically increased when attached to a toxin or radioactive agent. Phase 1 trials are now underway.

Additional CD Profiling Recommended for Diagnosis of WM – Analysis of the standard profile of CD antigens used in the diagnosis of WM may show atypical results for some WM patients. In order to more accurately identify a profile for WM distinctive from that of other B-cell malignancies, a group of scientists from the University of Paris, France, studied the antigens CD69, CD83, CD80 and CD86 in 24 WM patients. CD80 was positive in all cases, and CD83, CD69, and CD86 were always negative. CD80 positivity and CD86 negativity appear to be unique to WM, as distinguished from other B-cell lymphomas, and the researchers suggested that CD80 and CD86 be included in diagnostic panels.

Revlimid Receives Preliminary Positive Recommendation in England and Wales for Multiple Myeloma Patients

– Celgene International announced that it has received a preliminary positive recommendation from the National Institute for Health and Clinical Excellence for the use of Revlimid (lenalidomide) in the National Health Service in England and Wales for treatment of relapsed multiple myeloma patients. The preliminary recommendation will now undergo further study, with a final recommendation expected during the second quarter of 2009.

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 IWMMF-TALK community.



FROM IWMF-TALK

BY MITCH ORFUSS

IWMF-TALK was as active as ever this winter, with discussion across a wide range of topics relating to WM. What follows are highlights from many of the strands that produced the most comments.

The prospect of a bone marrow biopsy can make patients anxious, and there is always discussion about how to control the anticipatory and physical pain associated with them. **Bob Bent** asked about Versed. **Jacob Weintraub** referred to a visit to Mayo, where he was told they do BMBs the civilized way—with propofol, which was compared favorably to Versed. **Jerry Fleming** has had experience with Versed in his oncologist's office but was later directed to have his BMBs done at hospital, where the most powerful opioid known—fentanyl—was used. **Guy Sherwood** referred to Versed as “great stuff!”

The merits of R-CHOP, R-CVP, and R-CVD were also discussed. **Bob Bent** again wrote that several years ago, owing to evidence for progressive disease, the original plan was for him to have 6 courses of R-CHOP, which was amended to leave out the H (hydroxydoxorubicin [Adriamycin]) to prevent further suppression of counts. After only one R-CVD round Bob's treatment had to be stopped because of fast suppression of his white, red, and platelets. Then Bob “remarkably” began to improve and almost two years later his numbers are all strong, in normal ranges, except for IgG. Dr. Ghobrial, who joined the list in an expert capacity since our last report, replied that both R-CHOP and R-CVD are fine and suggested a third and possibly stronger option: instead of V (vincristine), try another V—Velcade—but recommended such a switch only after talking with your personal oncologist. (Correspondent's note: we could not be luckier than to have Dr. Irene Ghobrial of Dana-Farber voluntarily reviewing IWMF-TALK daily and adding expert texture to many of the questions that surface. Thank you, Dr. Ghobrial!) **Katharine McCleary's** husband had excellent results (90% drop on IgM and no presence of disease in the marrow) following the Velcade substitution. **Bill Block** found R-CVP very effective treatment. **David Lynch** had 7 treatments of R-CHOP—one every 3 weeks. His IgM is down from 6000 to 400 and he feels better than he has in years. **Daniel Hachig** weighed in with a close look at the abstracts from the Stockholm WM Workshop, and pointed out that R-CP does not have a significantly different objective response rate from R-CVP and R-CHOP.

An issue that comes up frequently is the use of acyclovir and other anti-virals during and after treatment. **Gerri McDonald** writes that because she has suffered a few week-long breakouts of shingles she has been on anti-viral Famvir for nearly 2 years and has no plans to discontinue its use. **Sue Herms** has been on acyclovir for more than 4 years and has plans to continue indefinitely. **Jeff Atlin** took Famvir for a year following a course of treatment with fludarabine and cyclophosphamide,

and 4 months after stopping the Famvir he came down with his first case of shingles. Jeff immediately began high-dose Famvir for 5 days and stayed on for an additional 60 days; he has had no trouble since. **Davis Cunningham** developed severe shingles and was treated with dressings and ointments for 6 weeks until the shingles dried up. Jeff treated the shingles with gabapentin and morphine sulphate and asked about the possibility of better pain relief. **Ann Gray** responded that Lyrica “did the job” with her shingles.

The question of how open (or not) to be about having WM generated some emotional discussion, some of which bears paraphrasing at longer-than-usual length. **Arlene Carsten**, who lives on an isolated inlet, writes that she had told 3 friends of her condition, and some years later, 5 friends commented on how well she looked. In retrospect, she concluded, it would have been easier not to tell anyone. **Ron Draftz** offered that it is one thing to swap stories with other cancer patients, especially this community of WM friends, but entirely another to do so with neighbors and friends. Everyone is different. Some have a stronger sense of privacy than others. **Gerri McDonald** offered that some want to share experiences and fears with many, but she thinks we all have to find our own comfort level with this issue. Initially it's hard to know where our comfort level lies, but, as time goes by, we usually strike our own balance. **Ken Warner** tells no one beyond his doctors and others who “need to know.” Ken says he has better things to do than be caught up with WM—no time to waste on it. The biggest problem **Cindy Luce** sees with other people knowing her condition is that they almost all think she should be in treatment now! Cindy catches them staring, which makes her very self-conscious. If she sneezes they all start praying. **Jeff Atlin** offered this take about his children. None of his children had known of his WM for 4 years. During this time his oldest was in post secondary education but living in town with her mother. His second oldest, however, was heading out of town to university in September. Jeff didn't want him to deal with the news by himself, or become distracted by Jeff's health, at a time that would already be a period of major adjustment for him. So about the middle of August, after dinner when they were all together, Jeff told them what was happening—one of the most difficult and emotional things he had ever done. It was a great help, however, that they soon realized he had been living with WM for 4 years without any apparent problems from the disease.

Edna Talbert queried whether any patients on Rituxan maintenance experience headaches and nausea. **Lou Birenbaum** replied that while nausea was not one of his symptoms, bothersome headaches were. The headaches went away following a second course of daily Cytosan. **Iain Purchase** said he'd had a bad headache for 8 weeks after a

From IWMF-Talk, cont. on page 27



dose of Maintenance-R. A CAT-scan found nothing. The headache declined for 3 months but returned after the next maintenance dose.

There was an extensive exchange about WM and insomnia. **Ken Warner** recommended 3 to 6 mg of melatonin at bedtime, claiming it's harmless, and also chamomile tea. **Herb Stahl** said that he took a higher dose than Ken, alluding to purported anti-cancer properties as well. **Lori Eastman** suffered terribly from lack of sleep for half a year after treatment. Her oncologist prescribed low-dose Lorazepam but she found it addictive even at the low dose. Lori then tried Lunesta for quite awhile, followed by 3x/day Neurontin. **Bob Reeber**

added that older folk decrease production of melatonin. **Ann Tygart** uses the prescription drug Flexeril, a muscle relaxant, which Ann says has the benefit of not being addictive.

There were many short queries and extremely brief conversations in the last 3 months as well that bear quick mention. These included such topics as chemo and constipation, risks and benefits of clinical trials vs. "standard" therapies, the benefits and liabilities of transplants (auto and allo), WM in the lungs, transformation risk after treatment with nucleoside analogs, ear infections, tongue blisters, bug bites, body pain, and the benefits and liabilities of treating vs. doing nothing.

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2. Contact Peter DeNardis at pdenardis@comcast.net and provide your full name

COOKS' HAPPY HOUR

BY PENNI WISNER AND NANCY LAMBERT

Penni and Nancy are spending a happy hour in conversation concerning a favorite topic. Penni leads off while Nancy responds in *Italics*.

For the last few months and, I bet, the next few, my CSA (Community Supported Agriculture) box from Mariquita Farms in Half Moon Bay has been chock-a-block with root vegetables: parsnips, turnips, radishes of all descriptions, parsley root, carrots. The last box contained six-plus pounds of carrots.

And it has been cold, and thankfully, rainy. These circumstances combine to create the perfect conditions for roasting vegetables. This might be the easiest way to cook vegetables, especially if you have a convection oven that preheats quickly.

The method emphasizes sweetness; the roasting caramelizes the sugars in vegetables giving them a richness that makes them irresistible. Especially when warm or at room temperature. Serve them on their own with toothpicks as snacks with drinks, or pop them atop your bruschetta, scatter them in salads, add them to sandwiches, serve them as side dishes.

I'm not sure I can think of a vegetable that cannot be roasted: asparagus, green beans, broccoli and cauliflower (broken into florets), Brussels sprouts (halved unless very small), winter squash (whole, sliced, or cubed), carrots (whole ones with the chicken just last night), turnips, parsnips (especially cut

into fat fries and dusted with a little chili powder), potatoes (on their own or with that chicken). Well, maybe English peas would be an exception.

Nancy, you are as big a fan of roasting vegetables as I am, although our methods might vary slightly. Which is one of the things that makes cooking endlessly fascinating.

I have many recipes for roasted root vegetables, but extra-virgin olive oil and fresh herbs are the basic ingredients for most of them. My earliest memory of fresh beets is a memorable day when I was helping my mother can beets. The pressure cooker suddenly erupted like Vesuvius; the lid flew off and beets spewed all over our white kitchen.

Stories like these don't happen with current, ultra-safe, triple-safety release cookers. Plus they are one of the best ways to save energy.

Later, as an adult, I ate my first roasted beet and was so surprised by the heavenly flavor. To roast beets, wash them and wrap them individually in heavy-duty aluminum foil. Bake them in a 350 degree F oven until tender throughout, an hour or more, depending on the size of the beets. When done, unwrap, and when just cool enough to handle, slip off the skins (which do just slip off).

I toss my beets in a covered pot with a little olive oil, salt and pepper, and bake. Then I don't have to deal with used foil.

Cooks' Happy Hour, cont. on page 28



I ran across this gem from the Bombay Bicycle Club years ago. Peel a large onion and cut out the top core. Add a little butter, wrap in foil, and bake until done.

In markets in Italy, you will find whole roasted beets sold with whole roasted onions. I've served these as a dinner party first course with vinaigrette and some minced fresh herbs. Roast the beets and onions separately.

My daughter-in-law, JoAnne, taught me to roast garlic in foil and spread the soft garlic on bread.

I hope you all are familiar with the addictive flavor of roasted garlic; if not, do try roasting it. Again, my method differs slightly from Nancy's: cut the whole, unpeeled head of garlic in half horizontally. Put the garlic in a baking dish, season the cut sides with salt and pepper, and drizzle with olive oil. Cover and bake at 400 degrees F until the cloves begin to push out of their skins. Uncover and bake until light brown. You can freeze the garlic without further ado and serve a half head on the side of a green salad with blue cheese, for instance, or squeeze the cloves out into a bowl, add the now delightfully-flavored cooking oil, and refrigerate for up to a week or so, or freeze. I love to spread pizza dough with roasted garlic paste, then add whatever comes next. When fresh garlic comes

on the market—usually June/July in California—I buy 30+ heads to roast and freeze.

Tereze, my niece, thanked me for the roasted beet idea by sharing her method for roasting corn. At an Ohio road stand, she was told to roast unhusked ears of corn on a cookie sheet for 30 minutes at 350 degrees F. To ready the corn, you cut through the ear, 1 inch back from the corn kernels on each end of the cob. To neaten each ear, cut off the little flaps on the husks. If the husks look too bad, I may pull off one or two layers, but never more. I have even been known to let my guests dehusk their own corn at table so that the ears stay hot until they are ready to eat.

As we both look forward to the delicious abundance of the coming spring and summer, Nancy has it right: It seems to me that often the best foods for us are also the easiest to prepare. I had my first sliced peaches and pineapple on the grill last week and loved them. I am constantly amazed at the elegance of good, simple food.

Our motto: Eat Well to Stay Well

IWMF IN AUSTRALASIA – THE WMOZZIES

BY GARETH EVANS

Within moments of meeting Dr Treon I had drawn his blood. How's that for role reversal? He'd been trying to clip on a microphone that had two little claws so I helpfully attached it for him. It drew an "Ouch" and a spot of red on his thin white shirt.

That was in 2005 when he and Drs. Kyle and Gertz were in Sydney for a myeloma conference. The IWMF and its Australasian support group, the WMozzies, had arranged a patient seminar addressed by the three experts. Members flew from as far as Perth (4000 km) away and from New Zealand. That was the day, more than ten years after diagnosis, that I first met another WMer, in fact seventy of them! The day was a great success but it remains the only physical meeting we have ever held.

In response to my comment that we have the population of New York State spread over the same area as continental USA, our beloved former president Ben Rude had first suggested in late 2002 that Australian IWMF members link by e-mail. The WMozzies was born in January of 2003, using e-mail addresses supplied by Sara McKinnie at head office. It soon became difficult to manage so within a few months the WMozzies was established as a Yahoo group. In that format we've just notched up our thousandth message. We're so widely dispersed across "the wide brown land" and neighbouring New Zealand that actual meetings are difficult, but through the WMozzies we are able to support each other, discuss our medical systems, drug availability, second opinions, and relay information for those who don't also participate in IWMF-TALK.

There are usually about eighty of us subscribed, but I share the frustrations that Sara and Peter DeNardis must experience all the time. It is in the nature of our organization that members do pass on, and the Foundation does not wish to distress relatives by chasing memberships. But most of the time, it's just that members change e-mail addresses and forget to tell anyone. So I beg all IWMF members to keep at least Sara advised of your current contact details. Advice from your family when the time finally comes would also be much appreciated.

In January of this year WMozzie Michael van Ewijk joined the Community Ride section of the Tour Down Under in which cancer survivor Lance Armstrong made his comeback to cycling. Michael's sponsored 97 km ride raised money for the IWMF Research Fund. Fortunately it was only 73°F/23°C in Adelaide on Michael's big day. Within a week the maximums in the south had risen to 110°F/43°C which lingered for weeks, further priming the parched landscape for the worst bushfires in our history.

IWMF in Australasia, cont. on page 29



As I write the danger is not over and has preoccupied the WMozzies and all Australians. While most of the country is gripped by the longest-ever drought, other regions are isolated by flood. It does all lend a perspective to our health problems, real as they are. But we're a tough lot, and in times like these you'll often hear us saying

I love a sunburnt country,
A land of sweeping plains
Of ragged mountain ranges
Of droughts and flooding rains.
I love her far horizons
I love her jewel-sea,
Her beauty and her terror --
The wide brown land for me!

From 'My Country' by Dorothea McKellar, 1908

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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.

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THE FRENCH LANGUAGE TALK LIST

BY NICOLE BASTIN, CO-MANAGER OF LA TALK LIST WALDENSTRÖM

The French talk list was, until November, 2003, the plan of Freddy Bastin, "the man of the IWMF in France," as President Ben Rude called him. Freddy, however, did not have time enough to complete this project.

Created in September 2006, the talk list at present has 102 French-speaking members who write from France, Belgium, Canada, and Switzerland. We are lucky to have at our disposal *Medicalistes*, a server for non-profit organizations. *Medicalistes* welcomes more than one hundred talk lists, a large number of which are dedicated to rare diseases.

In setting up this talk list, the objective was to provide a means for patients to discover other French-speaking patients and to put them or their families in touch with others nearby. Now they are able to share their experiences about the disease and treatments. Another objective was to allow the French patients to take advantage of the publications of the IWMF to increase their awareness of the issues related to WM and its treatments.

The e-mails are numerous, warm and courteous, sometimes forceful; humor is often present in our electronic family!

The French Language Talk List, cont. on page 30



The IWFMF is our main source of information. Every new member receives a mailing which invites him or her to go on the IWFMF website and to ask for the *infopack* in French. The quarterly review, the *Torch*, is translated from the first issue of 2007 to the present and is available on-line at a public open site. For some weeks these translations have also been available on the French page of the IWFMF website.

Although virtual exchanges are valuable, our members also wish to meet in person. In 2008 about twenty persons met in Avignon in a very social way, but without medical guest speaker. In 2009 we are organizing a meeting in Vienna in the Rhone-Alpes region. We will have as our guest Xavier Leleu, M.D. Ph.D., whom we met in Stockholm. He is a clinical practitioner in the “service des maladies du sang” (blood diseases unit), Hôpital Huriez, CHRU (Regional Teaching Hospital) in Lille, France, and a researcher at the Kirsh Laboratory for Waldenstrom Macroglobulinemia, at the Dana-Farber Cancer Institute and Department of Medical Oncology, Harvard School of Medicine, Boston, MA.

We hope that many members can attend this meeting

We also plan to join the “EWM Network” (*European Waldenström Macroglobulinemia Network*) which is being created at the initiative of Marlies Oom, a member of the CKP (the Dutch organization of Waldenström and Multiple Myeloma patients). The aim of this network is to help the voice of patients suffering from rare diseases to be heard at the European level.

LA LISTE DE CONVERSATION DES PATIENTS FRANCOPHONES

PAR NICOLE BASTIN, CO-GESTIONNAIRE DE LA TALKLIST WALDENSTRÖM

La liste de conversation en français était un projet de Freddy Bastin, qui fut « l’homme d’IWFMF en France », comme le disait le président Ben Rude, jusqu’en novembre 2003. Mais Freddy n’a pas eu assez de temps pour réaliser ce projet.

La liste de conversation en français a été créée en septembre 2006. A ce jour, elle regroupe 102 adhérents francophones qui écrivent depuis la France, la Belgique, le Canada ou la Suisse. Nous avons la chance de pouvoir disposer du serveur informatique d’une association à but non lucratif. *Médicalistes*, c’est son nom, accueille plus de cent listes de conversation dont un grand nombre est dédié à des maladies rares.

En ouvrant cette liste l’objectif était de procurer aux patients le moyen de découvrir les autres patients francophones et de rester en contact, eux ou leur famille, avec des patients proches. Ils peuvent maintenant partager leur expérience de la maladie et des traitements.

Un autre objectif était de permettre aux patients francophones de bénéficier des publications de l’IWFMF pour mieux les sensibiliser aux questions touchant à la maladie et aux traitements.

Tout nouvel adhérent reçoit un courrier l’invitant à se rendre sur le website de l’IWFMF et à demander l’*infopack* en français.

Les échanges sont nombreux, chaleureux et courtois, quelquefois vigoureux mais l’humour est souvent présent dans notre famille électronique!

En ce qui concerne l’information, l’IWFMF est notre principale source. La revue trimestrielle la *Torche* est traduite depuis le premier numéro de 2007 et disponible en ligne sur un site ouvert au public. Depuis quelques semaines, ces traductions sont également disponibles sur la page en français du website de l’IWFMF.

Si les échanges virtuels sont appréciés, nos adhérents souhaitent aussi se retrouver ensemble. En 2008 une vingtaine de personnes s’étaient rencontrées en Avignon de façon très conviviale, mais nous n’avions pas de médecin invité. Pour 2009 nous préparons une réunion à Vienne, en région Rhône-Alpes. Nous aurons un invité médecin: Xavier Leleu, M.D., Ph.D., que nous avons rencontré à Stockholm. Il est à la fois clinicien au CHRU de Lille, France, dans le «service des maladies du sang» de l’Hôpital Huriez, et chercheur au Kirsh Laboratory for Waldenstrom Macroglobulinemia, Dana-Farber Cancer Institute, et au Department of Medical Oncology, Harvard School of Medicine, de Boston, MA, USA.

Nous espérons que beaucoup de membres pourront assister à cette réunion.

Nous avons aussi le projet de nous joindre au réseau européen EWM Network (*European Waldenström Macroglobulinemia Network*) qui est en cours de création à l’initiative de Marlies Oom membre du CKP (*Association néerlandaise des patients Waldenström et Myélome Multiple*) afin d’aider à faire entendre la voix des patients atteints de maladies rares au niveau européen.



SUBSCRIBING TO IWMF-TALK-ESPAÑOL

To start: you must subscribe.

To subscribe to IWMF-TALK-ESPAÑOL send an e-mail to:

iwmf-talk-espanol-subscribe-request@lists.psu.edu

Type the word “subscribe” in the subject area and leave the message area blank.

Then follow the instructions in the confirmation e-mail you will receive from *lists.psu.edu*.

To send e-mails to subscribers:

All messages that you wish to send to fellow list members should be addressed to:

iwmf-talk-espanol@lists.psu.edu

(be sure to use “dashes” and “dots” in the appropriate places)

To view archives and manage your account:

To visit the archives, once you are registered with IWMF-TALK-ESPAÑOL go to:

<http://lists.psu.edu/archives/iwmf-talk-espanol.html>

If you have difficulty, contact Roy Parker roypar@comcast.net or Peter DeNardis pdenardis@comcast.net

This list is a service run by the International Waldenstrom’s Macroglobulinemia Foundation whose members are seeking information, care, and support. It is designed primarily for Spanish-speaking members throughout the world to discuss issues that are pertinent to them. You can find out more by going to www.iwmf.com

INSTRUCCIONES PARA IWMF-ESPAÑOL

Primero, es necesario suscribirse.

Para suscribirse, favor de enviar un e-mail a:

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Fíjese que la ñ de español no lleva tilde en esta dirección. Teclee la palabra “subscribe” en la línea del “subject” (asunto) y deje el resto en blanco.

Siga las indicaciones en el email que recibirá de *lists.psu.edu*.

Para enviar e-mails:

Los emails dirigidos a participantes del “Talk List” deben enviarse a:

iwmf-talk-espanol@lists.psu.edu

(No se olvide poner los puntos y guiones tales como aparecen aquí; fíjese que la ñ de español no lleva tilde en esta dirección.)

Para ver los archivos y manejar su cuenta de e-mail (sin costo):

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(sin tilde en la ñ de español).

En caso de cualquier duda: favor de contactar a Roy Parker roypar@comcast.net o Peter DeNardis pdenardis@comcast.net.

El “Talk List” en español es un grupo de apoyo de la IWMF (Internacional Waldenstrom’s Macroglobulinemia Foundation), cuyos miembros buscan información, consuelo y apoyo. Facilita el diálogo entre los miembros de habla española del mundo entero a fin de explorar los temas que más les preocupan e interesan.

Se puede encontrar más información en www.iwmf.com



ESPAÑOL TALK LIST: A WORD OF WELCOME AND A REQUEST

Dear Spanish language member of the IWFMF,

We hope that you are pleased with your membership in the IWFMF and hope that you enjoy our quarterly newsletter the *Torch* as well as our many publications and the DVD disks of our annual patient forums in the USA and, now, disks from our first European forum that was held last October in Stockholm.

Since last year we have increased our efforts to provide greater patient services to our international members. One such service is our talk list. We have such Internet communication groups for English speaking persons in the UK, Australia, and the USA. We have foreign language groups for the Nordic countries, France, and Germany. And now we have established IWFMF-TALK-ESPAÑOL, a talk list in Spanish for our members throughout the world.

IWFMF-TALK-ESPAÑOL will make it possible for you to be in contact with fellow WM patients to exchange ideas, ask questions, and get information. There is no cost for this service. It is free and part of the service that the IWFMF provides to all its members. Instructions on how to subscribe to the Spanish language talk list are written below. Once you are a subscriber you can post your messages to the e-mail address shown.

If you have any questions about the IWFMF-TALK-ESPAÑOL, please contact me by e-mail (in English as I am not fluent in the Spanish language). If this is not possible we have a few volunteers who are willing to translate brief e-mails.

Finally, we need a Spanish-speaking member to monitor the talk list. This involves observing the e-mails posted on IWFMF-TALK-ESPAÑOL to make certain that only WM matters are on the list and that all correspondence is friendly, positive, and definitely non-commercial. If you are interested in becoming the talk list monitor, please write to me.

We welcome your thoughts, ideas and suggestions.

Yours truly,

Roy Parker, Chair
International Committee
Secretary of the IWFMF
Parker Roy roypar@gmail.com

IWFMF-TALK-ESPAÑOL

Estimado miembro de habla española de la IWFMF:

Espero que se encuentre a gusto con los servicios que recibe de la IWFMF, como el boletín trimestral el *Torch* y las demás publicaciones y los DVDs de los foros anuales en los Estados Unidos y del primer foro europeo, que se realizó en Estocolmo en octubre pasado.

En los últimos meses nos hemos empeñado en brindar mayores servicios a los miembros internacionales. Uno de ellos es el “talk list” IWFMF-TALK, un medio de comunicación de la Internet. Ya contamos con un “talk list” para Francia y para Alemania, además del “talk list” para los miembros de habla inglesa del Reino Unido, Australia y los Estados Unidos. Ahora proponemos IWFMF-TALK-ESPAÑOL, un “talk list” para los miembros de habla española en todo el mundo.

El IWFMF-TALK-ESPAÑOL le hará posible intercambiar opiniones, plantear dudas y recibir información de otras personas que padecen WM. Este servicio no tiene costo alguno dado que es parte de los servicios que le ofrece la IWFMF. Abajo encontrará las indicaciones para suscribirse. Una vez que se haya apuntado, puede enviar sus preguntas y comentarios por email.

Si tiene alguna duda sobre el IWFMF-TALK-ESPAÑOL, favor de contactarme por e-mail, de preferencia en inglés (no domino el español), o de no ser posible, en español, y un traductor voluntario me hará el favor de traducirlo.

Por último, se requiere una persona de habla española para supervisar el IWFMF-TALK-ESPAÑOL es decir, leer los e-mails y hacerse responsable de que se traten exclusivamente asuntos relacionados con WM y que sean cordiales, sin actitudes agresivas de ningún tipo, y sin fines lucrativos ni comerciales. Si a usted le interesa ser el responsable del “talk list” en español, favor de ponerse en contacto conmigo.

Pedimos sus opiniones, ideas y sugerencias.

Atentamente,
Roy Parker, Chair
International Committee
Secretary of the IWFMF
Parker Roy roypar@gmail.com

Translation thanks to Betsy Beazley



WE GET LETTERS

Mike Young from the UK writes:

Just received the anniversary issue of the *Torch* and wanted to say many thanks to all involved for a **fantastic** issue. Read every single word in it and found it extremely interesting and useful – even the tomato sauce recipe!

As a UK resident diagnosed with WM in Jan 2006, and having received fludarabine chemo and an unfortunately failed attempt at a stem cell harvest, I am now on “watch and wait” with a view to re-attempting the autologous stem cell transplant and further chemo early next year. My wife signed up to IWMMF soon after my diagnosis and I have been receiving the *Torch* ever since. I have always found it very informative and helpful, but the anniversary issue is exceptional. The article by Dr Morie Gertz explained my illness and treatment in a more understandable way than I have ever seen it expressed before, even though I have been under the care of our sensationally good National Health Service here in the UK. I found the “From IWMMF-TALK” (thanks Mitch) and the “Medical News Round-Up” (thanks Sue) very informative and supportive. And the historical articles from the day when Arnie Smolker first laid the foundations of IWMMF were fascinating and inspirational.

I am also very conscious of the expense of sending me the *Torch* and would like to sign up for the electronic version, please. An automated e-mail announcing a new edition each time would be very useful, though, for me and no doubt for others.

Keep up the fantastic work.

Best wishes,

Mike Young

From Northville, Michigan, Ronald Irwin contributed the following:

As I read from the “President’s Corner” about IWMMF’s 10th anniversary, it reminded me of my own anniversary. On February 18, 2009, I will have been diagnosed 20 years ago. I don’t know where that fits in for living the longest, but it has to be up near the top of the list. I’m 67 years old but still have a pretty good quality of life.

I want you to know that IWMMF has been great source of encouragement and help for me. In the early days of IWMMF, the newsletter had limited content. It was printed on a mimeograph machine and probably everything that was in it was prepared by Arnold Smolker. I don’t remember how I became aware of Arnie and his work, but I do remember talking to him on the telephone several times in the late 90’s.

It is absolutely short of amazing how this forum has grown. Thanks to you people, the disease has caught the interest of numbers of doctors and research groups, and more progress is being made every day to find a cure. It is great that you are able to provide grants to some of these people. The support groups are another great resource.

As for my own situation, as soon as I was diagnosed, I became a patient at the University of Michigan Cancer Center. When I first started receiving treatment there, they had about 6 dedicated patient rooms and an infusion room that had previously been a janitor’s closet. Now they have a whole building that is bigger than a lot of hospitals I’ve been in.

They started treating me with Cytosan in several forms with no help. Then I had fludarabine and then 2CdA and then CHOP. It wasn’t until Rituxan happened on the scene that I really got better. Rituxan has literally added years to my life. I usually get a tune up of Rituxan every 16 to 24 months, and every 6 weeks I get IVIG to boost my immune system. I also take Exjade to reduce my iron level because I do usually get 3 transfusions a year. I can’t thank the UM Cancer and particularly Dr. Bockenstadt enough for keeping me going for all these years.

If I have any advice for new patients it would be: Don’t get into this “why does it have to be me” thing. The fact is, that it has happened and there is nothing that you can do about. Accept it. Learn to laugh and smile again. Stay with the good attitude and think about all the great things that you have in your life. Learn more about your disease and listen to what your body is telling you. And most importantly is some advice a nurse told me a long time ago: don’t worry about things that you don’t have any control over. It simply doesn’t do anything good for you; in fact it hurts you. When you worry, it raises your stress level and that, in turn, hurts your immune system.

My life is not normal, I need to take naps and don’t have the energy to do some things BUT it is still good and it sure is a lot better than the alternative.

Thanks again,

Ronald Irwin



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We would like to send the *Torch*, and other information geared specifically towards WM physicians, directly to your doctor. Please provide us with your doctor's contact information so that we may add him/her to our physicians' mailing list.

U. S. Oncology Hospital Listing

The Business Office has a listing with contact information for over 2500 institutions in the United States. This document is in Excel format. To request the electronic file or a hard copy, send an email to lisagreenlund@iwmf.com or call 941-927-4963.

