IWMF NEWSLETTER

TORCH

Anniversary Issue 1998-2008

FALL 2008

INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION

ANNIVERSARY COVERAGE

INSIDE THIS ISSUE

IWMF President Judith May

PRESIDENT'S CORNER

BY JUDITH MAY

It's time to celebrate!

July 21 marked an important date for the IWMF: our tenth anniversary as a private non-profit corporation. We are proud to designate this issue of the *Torch* the IWMF anniversary edition. In the President's Corner and other articles we return to our roots to share with you the early development of the foundation and how we have grown.

We cannot adequately praise the founder of our organization, Arnold Smokler, a retired pharmacist who was diagnosed with WM in l994. Finding little information available about the disease and no organized support group, he wrote to the National Organization of Rare Diseases (NORD) and requested the names of patients listed with Waldenstrom's macroglobulinemia. Upon receiving a list of 21 patients, Arnie mailed a questionnaire to each of them to elicit interest in forming a WM support group. It was a hit.

As the next step Arnie started a newsletter that consisted of letters written by patients about personal experiences with the disease and with treatment therapies. From colleagues and contacts within the health professions, Arnie had access to professional journals, publications and studies. Soon he expanded the scope of the newsletter by locating and publishing creditable information on WM, albeit in a very limited way. Arnie was careful to always reference his sources, and the newsletter earned respect among health professionals and the readership alike.

One thing everyone who knew Arnie will remember is that he promptly returned every call he received from every patient and provided personal encouragement, references, and advice on accessing research findings and cancer institutes. He established in each of us the mind-set that we are in this together and that there is so little information out there that we are on our own to develop knowledge of the disease.

By September of 1995 a monthly newsletter was being mailed to 125 patients, and in November of the same year Arnie established the Waldenstrom's macroglobulinemia web site. Arnie named this early organization the Waldenstrom's Macroglobulinemia Support Group (WMSG).

In April of 1996, 75 people attended the first WMSG conference in Arlington, Virginia. As membership grew, Arnie recruited a small board of trustees and a group of seven medical advisors. In September of 1996 the IRS recognized the WMSG as a not-for-profit organization under the IRS code in section 501(c)(3).

The second WMSG conference took place in April of 1997, again in Virginia, with 200 attending. The membership had grown significantly, boasting 10 support groups in the U.S. and one in the U.K. This marked the evolution of the WMSG into an international organization. By early 1998 the organization became known as the International Waldenstrom's Macroglobulinemia Foundation.

The first election of IWMF Board of Trustees was held at the June 1998 forum (by now an annual event) in Atlanta, Georgia. The nominees presented themselves to the assembled members and spoke about their qualifications and motivation. Twelve individuals were then chosen by vote of the members present to sit on the first elected IWMF Board of Trustees. I was one of those 12 charter members of the Board.

President's Corner, cont. on page 2

President's Corner, cont. from page 1

The new Board of Trustees met the following September and set about to develop an efficient and effective infrastructure. The Board approved a committee structure and board policies. Workload management was discussed. An application for incorporation was submitted in the state of Florida. (Florida was selected because Arnie had previously established the IWMF office there and the IWMF by-laws were developed in Florida)

Periodically the governance issues have been reviewed and changes made when necessary for a more efficient Board. However, the Purpose and Objectives in application today have remained the same as they were in the early years of the WMSG:

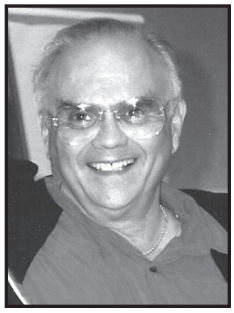
To provide encouragement and support to WM patients and their families

To provide a means of communication for patients and their families

To provide information and educational programs that address issues important to WM patients

To increase awareness of the issues related to WM

To encourage and support research leading to more effective treatment and, ultimately, a cure for WM.



IWMF Founder Arnie Smokler

In the second year following incorporation, Arnie Smokler decided to entrust the foundation to other strong hands and step down. He left an energized Board of Trustees, strong educational and medical research programs, and growing contributions. We are eternally grateful for Arnie's leadership and dedication to the foundation, and, above all, for his devotion to WM patients. When Arnie stepped down, Vice-President Ben Rude became the IWMF's second president.

Second President of IWMF Ben Rude

I cannot overstate Ben Rude's contribution to maintaining and strengthening the foundation during his tenure as president. Ben had great energy and intelligence and was an inspiration to us all. A major goal for Ben was to achieve wider awareness and understanding of WM and the IWMF among the physicians, government agencies, and other cancer organizations which comprise the global arena of cancer research. Ben was very successful at this, particularly at strategizing and building relationships. I know first-hand as I was often with him at meetings and conferences as the Vice President for Research.

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Special thanks to Ken Edmondson for designing the Torch anniversary masthead.

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

IWMF is a 501(c)(3) tax exempt non-profit organization Fed ID #54-1784426. Waldenstrom's Macroglobulinemia is coded 273.3 in the International Classification of Diseases (ICD) of the World Health Organization.

President's Corner, cont. from page 2

We were extremely saddened to lose Ben Rude in January of 2005. His legacy as president will always be remembered. I was subsequently elected to become the third IWMF president, and my objective has been to continue our outreach to cancer researchers, physicians, and other organizations, as well as expanding services to IWMF members.

The early services of the IWMF included a newsletter, an annual patient conference, a website, and a talk list. Since 2000 membership has grown continuously and membership services have expanded significantly. We now publish a series of informational booklets that we continually update and expand, some in as many as five languages. The IWMF has 22 different telephone Lifelines manned by WM veterans who will answer questions from patients and their families. We provide support group leader training workshops and a written guide to forming a support group. We have initiated a membership outreach program named the Awareness Project and an International Committee to strengthen services for international members (including a first-time patient seminar scheduled for Stockholm, Sweden, this October). Our expanded, and still growing, fundraising program is directed by experienced leadership. Our extensive research program is limited only by the funds available for its support. And, finally, a comprehensive patient database and a revised IWMF website are under way.

What has made possible this expansion of the IWMF's work, with more committees and projects in place than ever before? Making it all possible is the number of wonderful volunteers who come forward and make the commitment to undertake special projects and to serve on IWMF committees.

Those who have stepped forward to become support group leaders provide a truly great volunteer service to the IWMF. Currently there are 74 support groups serving 38 states and 9 countries. Six states without support groups are served by regional contact persons. We are actively seeking leaders to organize support groups for these and other regions, and we are always open to expanding to every country where there are Waldenstrom patients.

There are many areas where help is needed within our existing member services, special projects, and committees. If you would like to help, we welcome and encourage you to make your skills and the time you can commit known to the Board. To respond to this request, please contact Sara McKinnie at the IWMF office by e-mail (info@iwmf.com) or by telephone (941-927-4963).

To conclude on a personal note, it has given me great pleasure to be part of such a meaningful organization as the IWMF. With your help, I hold great hope that we will fulfill the mission before us.

Stay Well,

Judith

Special thanks to Jim Berg, Jim Bunton, and Bernie Smokler.

DOCTOR ON CALL: MORIE A. GERTZ

Dr. Morie A. Gertz

On June 16, Dr. Morie A. Gertz became Chairman of the Department of Internal Medicine at Mayo Clinic in Rochester, MN, capping a distinguished career of twenty-five years. The Torch takes this opportunity to offer congratulations to Dr. Gertz on behalf of the entire IWMF membership.

Dr. Gertz serves on the IWMF Scientific Advisory Committee and is a frequent and popular speaker at the IWMF educational forums where he shares his wide experience as a WM specialist at Mayo Clinic. In the following article Dr. Gertz continues the series Doctor on Call with a discussion of factors involved in accurate diagnosis of Waldenström's macroglobulinemia.

How is Waldenström's Macroglobulinemia Diagnosed?

by Morie A. Gertz, M.D.

The official designation of Waldenström's macroglobulinemia requires two components. The first is the presence in the serum of a monoclonal IgM protein, the so-called "macroglobulin protein." The second is the presence of an abnormal cell population. The abnormal cells, the so-called "lymphoplasmacytic cells," are in the bone marrow and are responsible for the production of the IgM protein. Waldenström's macroglobulinemia is a "lymphoplasmacytic" or low-grade lymphoma, and the percentage of abnormal cells in the bone marrow by visual estimate must exceed 10% in order for Waldenström's macroglobulinemia to be established.

The presence of a diagnosis, however, is not necessarily an indication for therapy. Variability in the degree of infiltration and sampling variation are also to be considered. It is possible to have the bone marrow show 5% lymphoplasmacytic cells in one area and 10% in another. Therefore, the driver for consideration of therapy is not merely the presence of bone marrow involvement and an IgM protein but rather the clinical manifestations resulting from the protein and marrow abnormalities.

Doctor on Call, cont. on page 4

In the absence of anemia, glandular enlargement, or symptoms of malignant lymphoma, observation (so-called 'watch and wait') may be appropriate, even with established Waldenström's macroglobulinemia. It bears emphasis that the symptoms of Waldenström's macroglobulinemia merit intervention and not simply its presence. Many patients question why, when an early diagnosis of cancer is so heavily emphasized in the media, early intervention is not indicated. The reason is because the disease in its current form is not curable, and the goals of effective therapy are improvement in symptoms. In the absence of symptoms, active intervention may not be warranted. At Mayo Clinic, the size of the IgM protein is not used as a determinant of the need for therapy. There are supporters of the concept that if the IgM is >5000 this, in and of itself, is an indication for therapy. In my own personal experience, I have followed patients with IgM levels as high as 9000 who did not require therapy for up to a year. Realistically, however, the higher the IgM monoclonal protein is, the more likely it is that therapy will be required. Nonetheless, there are substantial numbers of patients who have extreme elevation of the IgM but no symptoms to warrant therapy.

The converse is also true. There are unique situations when the IgM protein level is very small, the infiltration in the bone marrow is minimal, yet therapy is required. There are four specific syndromes that mandate therapy despite the fact that the Waldenström's macroglobulinemia itself has a minimal impact. These four syndromes are amyloidosis, cryoglobulinemia, cold agglutinin disease, and progressive peripheral neuropathy secondary to IgM monoclonal gammopathy. Amyloidosis results from deposits of the IgM protein or fragments into the tissues of the kidney, heart, liver, or nerve, causing these to malfunction. Cryoglobulinemia represents the depositing of the IgM protein in the lining of blood vessels, causing them to become inflamed. This typically can cause a rash on the legs and changes to the kidney and to the liver. Even when the IgM level is as low as 200, treatment may be required. Cold agglutinin disease represents an IgM protein leading to the destruction of red blood cells that can cause anemia severe enough to warrant blood transfusions even when the IgM levels are small. Finally, the presence of progressive peripheral neuropathy may require therapy no matter what the level of the IgM protein is if the neuropathy itself is reaching a point where it is impacting on an individual's quality of life.

There is one syndrome closely resembling Waldenström's macroglobulinemia that has tricked me in the past, and this is splenic marginal zone lymphoma. Whenever I see the spleen disproportionately enlarged in a patient with Waldenström's macroglobulinemia, I always raise this question to ensure that I am making an accurate diagnosis. Therefore, although the diagnostic criteria for Waldenström's macroglobulinemia are relatively simple, the disease can easily be confused with other syndromes, and it takes experience to exclude syndromes associated with IgM monoclonal protein that require therapy. It also requires experience to know when not to treat Waldenström's macroglobulinemia even when a diagnosis is established and the disease is felt to be smoldering.

Why is Waldenström's macroglobulinemia misdiagnosed? Oftentimes, when physicians see a patient with a monoclonal protein they do not do the immunofixation necessary to separate an IgG and IgA from an IgM protein, and the patient may be mislabeled as having multiple myeloma. It is not until the protein is correctly labeled as IgM that the possibility of Waldenström's macroglobulinemia is entertained. Moreover, 1% of patients with multiple myeloma actually have IgM multiple myeloma, which can easily be confused with Waldenström's macroglobulinemia by an inexperienced physician. Although there is an IgM protein in the blood, the bone marrow clearly does not show lymphoplasmacytic lymphoma but shows the classic plasma cells associated with multiple myeloma. Fortunately, this is a rare syndrome.

What type of testing is required? For the majority of patients, the key studies include the blood counts, a 24-hour urine protein, quantitative immunoglobulins, measurements of liver and kidney function, and a CT scan of the abdomen to assess for nodes that cannot be palpated on routine physical examination, as well as to estimate spleen size. In our experience, the most common symptom of patients with Waldenström's macroglobulinemia is slowly progressive fatigue, difficulty climbing stairs, and shortness of breath with exertion. From a clinical standpoint, multiple myeloma does not resemble Waldenström's macroglobulinemia. The only similarity is the presence of an abnormal protein in the blood. Otherwise, multiple myeloma is different, and the experienced hematopathologist can make the distinction by looking at the cells in the bone marrow responsible for the production of the protein. There are specific cell markers that differentiate the Waldenström's cell from other cells in the bone marrow. Waldenström's cells are lymphocytes and express both CD19 and CD20 as well as surface IgM, which are markers of lymphocytes. Waldenström's cells are typically negative for the markers of CD5, CD10, and CD23. Multiple myeloma, on the other hand, is typically CD20 negative and expresses CD138 and 138 with cytoplasmic immunoglobulin. Technically-adept immunopathology laboratories will routinely do these types of marker studies to help distinguish Waldenström's from other forms of bone marrow cancer.

Dr. Gertz is Professor of Medicine, Chair of the Department of Internal Medicine, and Chair Emeritus of the Division of Hematology at Mayo Clinic in Rochester, MN. Dr. Gertz received his medical degree cum laude from Loyola Medical School in Maywood, Illinois. During a 3-year medical residency at Rush Presbyterian St. Luke's Hospital in Chicago, he was twice voted Resident of the Year. Subsequently completing his training in hematology and oncology at Mayo Clinic, he then continued in a research position at the

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Doctor on Call, cont. from page 4

Thorndike Laboratory at Boston City Hospital. In 1983 Dr. Gertz joined the Mayo Clinic staff.

Author of more than 300 publications, Dr. Gertz has participated in numerous clinical trials in the course of his research directed to multiple myeloma, amyloidosis, and Waldenström's macroglobulinemia. In recognition of his contribution to the understanding of these diseases, Dr. Gertz advanced to professor at the Mayo College of Medicine and to the chairmanship of the Division of Hematology at Mayo Clinic. In 2002 he was awarded the Mayo Distinguished Clinician Award for his contributions to patient care.

Other leadership positions filled by Dr. Gertz at the Mayo Clinic include President of the Mayo Rochester Staff and service on the Mayo Clinic Rochester Executive Board.

Dr. Gertz is a fellow of the American College of Physicians, a member of the Myeloma Subcommittee of the Eastern Cooperative Oncology Group, and a member of several professional organizations. He is currently the treasurer of the International Society of Amyloidosis and serves on three journal editorial boards.

In 2007 at the Fourth International Workshop on Waldenström's Macroglobulinemia, Dr. Gertz received the Robert A. Kyle Award in recognition of his role in advancing the understanding of this rare cancer.

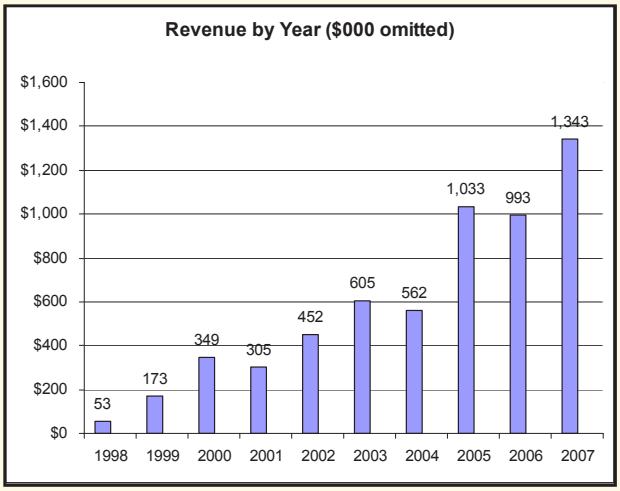
FINANCIAL HISTORY OF IWMF

BY JIM BUNTON

I have been the Treasurer of IWMF for much of the time since it was incorporated on July 21, 1998, and as a result have had a close-up view of the growth of this wonderful organization. Of course, the history of an organization is much more than its past financial results, but they can be an indication of the policies, decisions, and effort that went into producing those results.

The following is a graph showing the total revenue of IWMF in each of the years since inception.

This amazing increase over the years has two components. Our membership has grown each year and all members have been faithful in making an annual contribution when renewing their membership. In addition, we have several members who have been extraordinarily generous in making donations of $100,000 annually.



While the growth in revenue is a good indicator of the growth of the organization, the real objectives of IWMF are revealed in how well that money has been spent. Over the last 10 years we have expended funds in the following areas.

Research grants awarded	$3,036,000
Member services	1,438,000
Operating costs	714,000
Total	$5,188,000

The research grants supported by IWMF are discussed elsewhere in this issue. As well as advancing knowledge and understanding of WM, the money spent on research has raised the awareness of WM throughout the whole medical community. Our booklets, the *Torch*, support groups, IWMF-Talk, the web site, and all our other member services have brought information, comfort, and hope to a large number of WM patients and caregivers. This has been done with efficiency and cost effectiveness. The amount spent on operating costs of $714,000 over the ten years is 12% of the total revenue during that period. This compares favourably with other similar non-profit organizations where operating costs are usually closer to 20%.

During this period the number of members also grew. Unfortunately, the records for the first few years are not consistent with those kept subsequently. However, the number of members at July 2001 was 1,448 compared to 2,875 today, which represents an increase of 100% over that period.

We also maintain a list of doctors who have expressed an interest in WM and who receive the *Torch* and other publications. The number of doctors on our mailing list at July 2001 was 332 and is now 1,160. The increase of 350% is an indication of how IWMF has increased awareness of our disease in the medical community.

I would like to end on a personal note. I was diagnosed in 1994, the same year as Arnie Smokler. As a result, I spoke to him a number of times before I came on the Board in 2000. I was amazed at his determination and the energy he put into getting IWMF started. Looking at the last 10 years of the organization he founded, I am sure he would be very proud of it.

RESEARCH PROGRAM HISTORY

BY JUDITH MAY & TOM MYERS, FORMER AND CURRENT VICE PRESIDENT FOR RESEARCH

By 1999 the IWMF had received research contributions sufficient to begin a research program. But where to start? Waldenstrom's macroglobulinemia, rarest among the rare of blood cancers, had until then received little research attention. The IWMF Board of Trustees was determined to support basic research and also to increase awareness of our disease among researchers, government agencies, cancer clinics, other cancer organizations, as well as physicians. In order to clarify the current state of knowledge about this disease, we approached the National Institutes of Health to jointly sponsor a meeting of scientists identified by the NIH as currently engaged in WM research projects. Fortunately we received approval from the NIH's Office for Rare Diseases and the National Cancer Institute's Department of Cancer Therapy and Evaluation Program, Clinical Investigations Branch. We also received NCI matching funds for an NCI-IWMF jointly sponsored conference to take place on September 8, 2000, in Bethesda, Maryland. Among the small group of 21 researchers invited to attend were the eventual first four recipients of IWMF funds for research studies: Dr. Steven Treon, Dana-Farber Cancer Institute; Dr. Rafael Fonseca, Mayo Clinic; Dr. Vincent Rajkumar, Mayo Clinic; and Dr. Ayad Al-Katib, Wayne State University.

The IWMF has continued to provide support for the follow-up workshops, later designated the International Workshops on Waldenstrom's Macroglobulinemia. Dr. Treon, a physician-researcher of international repute, ably organized and directed these subsequent workshops. In 2002 the second workshop took place in Athens, Greece; in 2004 the third workshop was held in Paris, France; and in 2007 the IWMF helped sponsor the Fourth International Workshop on Waldenstrom's Macroglobulinemia in Kos, Greece. The number of scientists attending and presenting papers has increased at each workshop, exceeding 70 in 2007.

At the conclusion of each international workshop consensus panels are held to address the following areas:

1. Defining WM
2. Clinicopathological definition of WM
3. Prognostic markers and criteria to initiate therapy
4. Treatment recommendations
5. Uniform response criteria

The IWMF has published the important information issued by the consensus panels in booklet form for distribution to IWMF members.

Once the IWMF had sufficient funds to sponsor research, the trustees turned to the scientific community to enlist prominent doctors and researchers to form a Scientific Advisory Committee (SAC) to review research projects submitted to the foundation and to make recommendations regarding their funding. The IWMF is honored to have had Dr. Robert Kyle of Mayo Clinic as the coordinator of the SAC since its establishment. Currently this committee is composed of 14 doctors from 4 countries. Early on the SAC recommended that the IWMF support research by funding research fellows. The committee also recommended that the IWMF offer support to younger investigators to attend the international workshops.

To share the workload of monitoring the principal investigators of IWMF funded grants, volunteers with a scientific a background serve on the IWMF Research Committee. Each research project funded by IWMF is assigned a member of this committee as the Project Liaison Manager (PLM). The PLM meets with the principal investigator at least once a year and provides guidance concerning project financing. The PLM is also responsible for transmitting progress reports from the researcher to the committee. Eight IWMF members currently serve on the Research Committee.

The IWMF Research Committee has established the following categories for funded projects:

Origin of Waldenstrom's:

Comprehensive studies into the genetic basis and pathogenesis of WM

Familial studies

Characterization of WM Environment:

Genetic characteristics of WM

Waldenstrom's macroglobulinemia genomics

Factors regulating immunoglobulin producing B-cells in patients with WM

Molecular and functional sequelae of the P13K pathway in WM

BlyS inhibition in immunoglobulin producing B-cells

Study of the neuropathy associated with WM using a mouse model

Blood vessel development and cell division and growth in WM

Establishment of a WM animal model

Development of therapy targets:

In vitro and in vivo molecular profiling of WM as a framework in the design of novel combination therapies for the disease

High dose chemotherapy followed by autologous or allogeneic hematopoietic stem cell transplantation in patients with WM

Treatment of WM by anti-body mediated immunotherapy and induction of tumor selective antigens

Because so little was known about this disease in the late 1990's and early 2000's, the research funded by the IWMF has focused on understanding the causes of Waldenstrom's and how the disease survives and grows in the body. Since

Research Program History, cont. on page 7

Research Program History, cont. from page 6

2000 we have awarded over $2.5 million distributed in 15 research grants, some for one year, others for multiple years. The studies funded are basic research studies, reflecting the categories set forth above, and their subjects include genetic characteristics and abnormalities, molecular profiling, B-cell proteins and pathways, and WM mouse models. These studies have shown that the formation and propagation of Waldenstrom's cells is very complex, with a number of genes and proteins contributing to the process.

Over the eight years since the IWMF began funding research, a number of significant findings have been reported. In 2000 Dr. Treon explored how monoclonal antibodies such as Rituxan work to control WM. He also identified other antigen targets that may be useful in treating the disease.

Dr. Rajkumar showed that WM tumors did not demonstrate the same degree of blood vessel development as seen in multiple myeloma. This finding predicts that agents such as thalidomide will not be as effective in treating WM as they are in myeloma. Indeed, subsequent studies have shown only modest activity with thalidomide in WM.

Dr. Constantine Mitsiades' seminal work found that WM cells have different sub-types. His work was confirmed by that of Dr. John Shaughnessy who demonstrated through micro-array analysis that there are several forms of WM. Perhaps these studies indicate why different WM patients react differently to the same treatment. Dr. Mitsiades also performed preliminary studies on a number of agents (bortezomib, heat shock protein-90 inhibitor) that have proven promising enough to be the object of trials and to warrant further study in WM.

Extensive work on the proteins and chemicals that control the life, death, and proliferation of WM cells has been funded by IWMF. Dr. Stephen Ansell is studying a protein called BlyS and the agents that control the behavior of BlyS in regulating the generation of IgM. Dr. Irene Ghobrial's research uncovered perifosine, a chemical that appears to cause WM cells to leave the "shelter" of the bone marrow and enter the blood stream where they can be killed. Dr. Treon is looking at molecular mechanisms that cause lymphoplasmacytic cells to multiply in the bone marrow of WM patients.

Drs. Linda Pilarski, Esteban Braggio, and Fonseca study genetic patterns in WM patients, with potential results in new genetic engineering approaches for controlling WM. Dr. Pilarski demonstrated that mutations in the HAS1 gene are predictive of the type and severity of WM. Dr. Fonseca discovered that over 50% of WM patients show a deletion of the 6q arm of chromosome 6. Such a deletion is not observed in MGUS patients. Dr. Braggio is studying mutations in tumor suppressor genes. As these genes regulate cell growth and death, the mutations may result in excessive WM cell growth. These results suggest that a treatment by proteosome inhibitor might control the negative effect of the mutated genes.

Finally, the IWMF has supported the development of mice which have WM and therefore can be used to study the effects of various treatments. Dr. Al-Katib used WM mice to evaluate the effects of a substance isolated from a marine organism and of 2CdA. Dr. Anastasia Tsingotjidou has developed WM mice that exhibit peripheral neuropathy (PN). She has not, however, studied treatments for these mice with PN.

At the Fifth International Workshop on Waldenstrom's Macroglobulinemia, to be held October 15-18 in Stockholm, Sweden, approximately 55 papers will present research in this disease conducted, literally, all over the world. The IWMF, with a view to fostering the next generation of WM researchers, has awarded travel stipends to allow 10 younger investigators to attend the workshop. At the workshop's conclusion the doctors and scientists will review the material presented and make recommendations on the five areas of consensus mentioned above. A follow-up meeting, scheduled for late October in the U.S., will attempt to match the research findings with the particular characteristics of certain drugs in order to develop new treatment methods.

THE CORPORATE MEMORY

BY SARA MCKINNIE

Sara McKinnie

IWMF Office Manager Sara McKinnie shares her memories of the past ten years, recalling the early days of IWMF and the chance events which led her to become the first salaried employee hired by founder Arnie Smokler. Sara's story sketches the expansion of member services over the past decade and the personalities who made this growth a reality.

During tax season of 1998 I called my accountant to see if she might have some overflow work to supplement my income as a professional bartender. My accountant wasn't in the market for clerical support but said one of her clients was looking for part time help. I called IWMF founder Arnie Smokler to set up an interview and was hired to answer phones, process the mail, and prepare bank deposits a few hours each week for an organization whose name I could hardly pronounce.

Arnie was usually on the tennis courts or working on the computer system for his homeowners' association when I came into work in the afternoon. But communication was very important to him and he liked to stay informed about what was going on at the office. My interaction with trustees and members at that time was strictly by telephone because e-mail was not yet an option. I remember talking with such charter members as Davell Hays, Neil Massoth, Thad Raushi, John Sullivan, the Povalls, Mary Ughetta and Peter Sissman, to name a few.

The Corporate Memory, cont. on page 8

In 1999 IWMF was scheduled to exhibit at the American Society of Hematology Annual Meeting in New Orleans. Arnie became ill and was not able to attend, so I flew to New Orleans and had a wonderful time working at the IWMF exhibit booth alongside the Rudes and the Renshaws. Ben Rude was Vice President and John Renshaw was Treasurer at the time. Attending this convention committed me to IWMF and represented the beginning of an unexpected career move for me. Born and raised in southern California, my background had been primarily in banking, entertainment, and hospitality.

Arnie's declining health left many administrative matters to me by default, and this was a time of transition for the foundation. Inheriting office management, including the ever-growing membership database, kept me very busy. Having listened to Arnie on the phone taking calls from patients and others concerned about WM, I found myself enthusiastic about keeping the IWMF spirit alive and well. Arnie's approach to educating yourself about treatment, your medical records, and your rights as a patient was eye-opening and something I had not thought much about. Jim Bunton joined the Board (soon to become Treasurer) and worked zealously to expand and improve member services. Ben Rude successfully formed alliances with other cancer-related non profit organizations to develop awareness about WM. Ben and Jim and I were a team on a mission to build up the support group network and establish policies commensurate with IWMF's growth.

In 1996 Arnie started the Waldenstrom's Macroglobulinemia Support Group (WMSG) in the Washington DC area prior to retiring to Sarasota, Florida. In 1998 WMSG was officially incorporated as IWMF. Today, reading WMSG board meeting minutes taken in 1996 by Sue Lynch (Mrs. Row-Bob-Row) is quite entertaining. Thanks to an incredibly supportive and generous membership and dedicated volunteer trustees, IWMF continues to flourish. The many valuable services and publications IWMF has to offer, especially the *Torch* newsletter, are awesome, and I think Arnie would be proud.

Working autonomously in the IWMF office has unexpectedly led to my role as point of contact for the entire foundation. Ben's nickname for me was the 'Iron Maiden.' Judith refers to me as the 'Glue.' But I prefer to think of myself as a traffic director taking care of business so that things get done, people are happy, and we keep moving forward. Helping people use this foundation's resources to benefit from the vision of one persistent man's ambition is immensely satisfying. Plus I have the pleasure of meeting many incredible people along the way. In my role with IWMF, banking, entertainment, and hospitality experience, surprisingly, comes in handy all the time.

EDDY ANDERSEN: THE IWMF-TALK MOM

BY JUDITH MAY

Eddy Andersen

We wish to honor Eddy Andersen in this anniversary edition of the *Torch* for all her hard work in the role of IWMF-Talk manager (fondly known as "Talk-List Mom") over a seven-year period, from 2000-2007.

Eddy developed the ground rules for IWMF-Talk and held everyone to those rules. When you strayed, you heard from her. She viewed it as managing a family, and she did it well. Eddy also was a teacher, gave comfort and advice when needed, and endeared herself to all.

We appreciate Eddy for the person she is and all she has done to help WM patients.

Thank you, Eddy.

THE IWMF SCIENTIFIC ADVISORY COMMITTEE

BY ROBERT A. KYLE, M.D.

The IWMF Scientific Advisory Committee (SAC) consists of fourteen physicians/scientists who have experience with Waldenstrom's macroglobulinemia. The majority continue to see patients with this disease. Three of the fourteen members are from outside the United States.

Research proposals are forwarded to Robert A. Kyle, Chairman, who then sends the proposal to three or four reviewers who have a special expertise in the area. The Chairman frequently sends these research proposals to scientists who are not members of the Scientific Advisory Committee for review because some proposals are quite complex and require review by a scientist who works in that area. The reviews are performed anonymously, which is the same practice as the National Institutes of Health (NIH) reviews. A list of specific questions is given to the reviewer, and he/she is asked to comment on all of them. The reviews are then sent to all members of the IWMF Research Committee (Chairman, Tom Myers) for their review. The Research Committee consists of nine persons, seven of whom are physicians or scientists.

The final decision for funding is made by the Board of Trustees of the IWMF upon the recommendation of the Research Committee. Oftentimes the investigator is asked by the reviewer or the Research Committee to supply additional data or information concerning specific aspects of the project. If the additional information is substantial, the original SAC reviewer is queried as to whether the investigator has satisfactorily responded to the concerns of the reviewer. Researchers may submit proposals ranging from basic science to clinical aspects of WM.

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RITUXIMAB – HOW IT WORKS AND WHY RESISTANCE OCCURS

BY SUE HERMS

We have all heard of rituximab and many of us have been treated with it. But how does it work? Why does it work well for some of us but poorly or not at all for others? And what "new and improved" versions of rituximab are on the horizon?

Rituximab was developed by Idec Pharmaceuticals and initially approved by the Food and Drug Administration in 1997 for B-cell lymphomas that did not respond to other chemotherapy treatments. But now it has become standard therapy, alone or in combination with other drugs, for initial treatment of B-cell lymphomas as well as for certain auto-immune diseases such as rheumatoid arthritis, multiple sclerosis, and systemic lupus.

Rituximab is sold under the trade names of Rituxan in the U.S. and MabThera overseas and is currently marketed by Biogen Idec and Genentech in the U.S. and by Roche in the European Union. It is an engineered mouse/human monoclonal antibody directed against the CD20 antigen located on the surface of most B-cells. The CD20 antigen does not circulate freely in the blood nor is it normally shed from the surface of the B-cell. It should be noted that, because rituximab acts against all B-cells with the CD20 antigen, it targets normal B-cells as well as lymphoma B-cells.

The CD20 antigen appears early in maturing pre-B cells and remains as they mature but is lost or minimally present when B-cells develop into plasma cells. For this reason, it is a good "marker" for B-cell development and for B-cell lymphomas such as WM. Although the function of CD20 is still relatively unknown, it is currently thought to play a role in the movement of calcium across the B-cell membrane, maintaining the concentration of calcium in the cell and allowing the activation of B-cells during the body's normal immune response.

How Does It Work?

How exactly does rituximab cause B-cell destruction? Those of us who have been treated with Rituxan surely wonder what is occurring as we watch the clear fluid dripping into our veins, hour after hour. This simple question is not easily answered.

Rituximab – How it Works, cont. on page 10

There are several mechanisms proposed to describe rituximab's effect on B-cells , but they are still not completely understood. These processes have been studied in tumor cell lines and in animal models, but there are obvious difficulties with determining how they work in the human body. Probably all of them play some role in the destruction of B-cells, but it has not yet been determined which is the dominant mechanism, if indeed there is one.

Some studies suggest that rituximab interferes with the internal function of B-cells. Such studies indicate that rituximab can induce apoptosis (cell death) directly by interfering with CD20 calcium regulation and elevating the amount of calcium in the B-cells to abnormal levels. It may also interfere with various cell factors, causing outright cell death or inhibiting cell growth. Among these cell factors is *Bcl-2*, a member of a small family of closely related genes that can be divided into death-inhibiting genes, such as *Bcl-2* and *Bcl-xL*, and death-promoting genes, such as *Bax* and *Bad*. The balance between death-promoting and death-inhibiting gene expression is critically important in both B- and T-cells, because these populations are regulated so that a person will, in the absence of infection, maintain a constant level of B- and T-cells despite the production and death of many of these cells each day. Typically, *Bcl-2* and *Bcl-xL* are over-expressed in lymphomas, and rituximab appears to be able to interfere with their signaling pathways and reduce their expression. The over-expression of *Bcl-xL* may also play a role in making B-cell lymphomas more resistant to other types of chemotherapy; therefore adding rituximab to the therapeutic regimen appears to increase the effectiveness of the therapy.

There are also three main ways in which rituximab acts in concert with the body's own immune system cells once the rituximab antibody has entered the blood stream and attached to a B-cell. The mouse portion on one end of the rituximab antibody is the part that targets the CD20 antigen on the B-cell, while the other end of the antibody is human IgG, kappa type. When the mouse portion "locks" onto the CD20 "docking site" on the B-cell, the human IgG portion on the other end attracts or "recruits" the body's own immune system cells, also called effector cells, to respond. These effector cells include macrophages, neutrophils, and natural killer cells, and they attach to the rituximab antibody at a specific location called the Fc receptor site. This Fc receptor site is important and will be referred to later in the discussion on rituximab resistance. In this context, one can think of rituximab as a "bridge" that brings together the B-cell and the effector cell so that the B-cell can be destroyed.

One way or mechanism by which the B-cell is destroyed is through direct ingestion of the B-cell by the effector cell in a process called antibody-dependent phagocytosis. The effector cells in this scenario are usually macrophages, which are activated monocytes. Several studies have shown that this scenario occurs in laboratory cell lines, but other studies have suggested that this plays a relatively minor role in B-cell destruction in the body.

A second and more important mechanism appears to be antibody-dependent cellular cytotoxicity (ADCC). In this case, the intact B-cell is not ingested or phagocytosed. Instead, certain effector cells (usually natural killer cells and possibly also macrophages) are triggered to release pore-forming proteins that penetrate the B-cell membrane and proteolytic enzymes that break up its structure and degrade its chromosomes. This process ultimately causes cell death through lysis (destruction of a cell by damage to its outer membrane).

A third important mechanism for B-cell destruction is referred to as complement-dependent cytotoxicity (CDC). Complement is a system of small proteins circulating in the blood that, when stimulated, form a series of enzymes which can directly attack the cell membrane or target the cell for destruction by phagocytosis. Its activity is said to "complement" the activity of antibodies, hence its name. Rituximab is capable of binding to complement proteins to initiate this response, in this case against the B-cells that it attaches to. It has been demonstrated that, when rituximab is infused into a patient, complement in the bloodstream is temporarily consumed or used up because of this process.

Another theory suggests a fourth way that Rituxan cooperates with the immune system. The suggestion is that B-cells coated with rituximab are capable of stimulating dendritic cells, which are special cells that are able to recognize antigens, present them to T-cells, and activate T-cells to attack the antigens, in this case the coated B-cells. This may be one reason why rituximab appears to work for several months after actual treatment, even though blood and tissue levels of the drug may no longer be in the therapeutic range.

It bears repeating these words from the first paragraph in this section: the proposed mechanisms are still not completely understood and probably all of them play some role in the destruction of B-cells, although it is not yet determined which is the dominant mechanism.

Why Is There Resistance?

Unfortunately, depending on the type of lymphoma, 30%-50% of patients show no response to rituximab, either initially or upon re-treatment. The problem of resistance to rituximab has been a continuing source of interest and speculation and is the target of much research. Mechanisms for tumor resistance are complex and can be host-related or tumor-related.

Host-related factors can include such things as the efficiency of the complement system and the various effector cells in eradicating B-cells. One fairly recent development in this regard is the discovery that some individuals respond better to rituximab because of the genetic makeup of some of their effector cells (macrophages and natural killer cells). In particular, this involves the Fc receptor site of the effector cell that attaches to the IgG portion of the rituximab molecule mentioned above. Think of this as a locking mechanism—the better the effector cells fits and binds to rituximab, the better it will work. Sequences of amino acids make up the genes that

Rituximab – How it Works, cont. on page 11

Rituximab – How it Works, cont. from page 10

code for this Fc site, and the sequences can vary somewhat from one individual to another. It has been demonstrated that one part of the Fc site, called FcRIIIa, can have either the amino acid valine or the amino acid phenylalanine in position 158 of its gene sequence. Since a person receives one gene from his father and one from his mother, a person who has two valine amino acids at this position has a better response to rituximab (40% of WM patients in one study) than a person who has two phenylalanines (9% of WM patients), and a person with one valine and one phenylalanine has an intermediate response between the two. The valine seems to confer a better binding site or "locking" mechanism for the effector cell. In this connection, a test has been developed that can determine the makeup of a patient's FcRIIIa and thus possibly predict his response to rituximab therapy.

Tumor-related factors that can influence response to rituximab include the location or the environment in which the tumor cells are located. Typically, bulky lymph nodes are difficult to treat with rituximab because it cannot penetrate easily. Generally speaking, a higher tumor burden (and/or a higher IgM level in WM patients) may be more difficult to treat with rituximab than a lower tumor burden. It has been suggested that B-cell lymphomas with greater CD20 expression, such as diffuse large cell lymphoma, respond somewhat better than lymphomas with lower CD20 expression, such as small lymphocytic lymphoma. Follicular lymphoma and WM appear to fall somewhere in the middle. Other cells and cell factors can influence the growth of lymphomas and thus may complicate the treatment issue. In WM, for example, mast cells have been implicated as important for stimulating the growth of WM cells. Some WM patients have demonstrated tumor cells that exhibit resistance to the effects of complement, a phenomenon probably true for other lymphomas as well.

Just as bacteria can mutate and become resistant to antibiotics with prolonged treatment, tumor cells may become resistant to rituximab. Some B-cell lymphomas may diminish in their CD20 expression upon repeated exposure to rituximab, or the actual structure of the CD20 molecule may be altered. If tumor cells do not already show resistance to complement, they may develop it. They may also compensate by developing increased expression of *Bcl-2* or *Bcl-xL* or may develop other protective factors that diminish the ability of the body's immune system to kill them.

Fortunately, researchers are exploring ways to improve the action of rituximab and other similar anti-CD20 antibodies to get around these various resistance mechanisms. These improvements will be the subject of an article to appear in the next issue of the *Torch*.

This discussion is by no means an exhaustive or all-inclusive one. Anyone interested in additional or more technical information regarding these topics is encouraged to contact the author at suenchas@bellsouth.net. The author wishes to acknowledge with thanks an earlier article by Guy Sherwood in the Summer 2006 *Torch* entitled "Monoclonal Antibody Therapy for Waldenstrom's Macroglobulinemia - A Brief Literature Review."

REAFFIRMING THE POSITIVE SUPPORT GROUP LEADERS WORKSHOP IN LA

BY ARLENE HINCHCLIFFE,
WMFC PRESIDENT, IWMF TRUSTEE

Thirty-five dedicated support group leaders from the USA, Canada, and Greece participated in the workshop held on the Thursday afternoon prior to the opening of the Educational Forum in Los Angeles. The attendees, many of whom traveled long distances, had in common their enthusiasm at being able to give back in some way to others who live with the rare disease called Waldenstrom's macroglobulinemia.

The success of the workshop, which was organized by outgoing Support Group Coordinator Karen Pindzola, was due in large part to the outstanding speakers who addressed the assembled leaders on topics relevant to all WM patients and caregivers. The words of Connie Paul offered advice to caregivers, a segment of the support groups that is often overlooked. Dr. Guy Sherwood, a former Trustee familiar to most members of the IWMF as the author of several IWMF publications and a frequent contributor of wise words to IWMF-Talk, spoke on "What questions you should ask your oncologist." His valuable recommendations reflected his dual role as physician and WM patient. A round table discussion followed on why one should join a support group. Lastly, Don Brown, leader of the Chicago support group and Trustee of the IWMF, made valuable suggestions, based on his support group's efforts, about what we can do, both individually and as a group, to raise research funds in our own communities.

On Friday the leaders met for breakfast and pooled strategies for increasing participation and attendance. All left the 2008 workshop energized and eager to share the words of the day with their respective support groups, at home and abroad. And they also offered great suggestions for our next Support Group Leaders Workshop in 2009.

One final note on support groups. In the USA new groups are forming this fall in: Reno, NV; Las Vegas, NV; and North Carolina. New support groups are needed in northeast Florida, Wisconsin, Nebraska, North Dakota, South Dakota, and Santa Barbara, CA. In Canada there is a need for formation of new groups in the following areas: Winnipeg, MB; Calgary, AB; London/Kitchener/Waterloo.

Anyone who is interested in starting a support group but who is uncertain as to what is involved may contact the author. It is very rewarding to be able to bring together people struggling with an orphan disease and to see their relief when they connect with others who understand their anxieties. The first step is to make that phone call and invite others to share what only another WM member can offer–understanding, friendship and support. It is as easy as that.

Arlene Hinchcliffe, newly appointed IWMC/WMFC Support Group Coordinator, can be contacted by e-mail at: ace@noco.ca

FUN IN FUNDRAISING

BY DICK WEILAND

More and more members of the WM family are expressing interest in developing and promoting bigger and better fundraising events to help us find the cause and cure for Waldenstrom's. In the spring edition of the *Torch* we highlighted some great activities put into play, including Row-Bob-Row, the Blue Tulip project, bike-a-thons, cards, book royalties, jazz concerts, Avon Calling, auctions, class projects, raffles, crafts, bake sales . . . and the list goes on. Some folks are now thinking about golf outings, regattas, fundraising balls . . . and the list continues.

In the spring issue of the *Torch* we also asked for volunteers to serve as a resource person for WMers considering some kind of "gig." *Et voilà!* Kathy Miner stepped forward as a volunteer adviser/consultant for those groups or individuals interested in initiating fundraising events.

Kathy has a wealth of experience in staging fundraising events for non profit organizations. She is the founder of A Miner Miracle (AMM), a San Francisco-based non profit organization that provides professional clothing, image counseling, and presentation skills to low-income men, women, and young adults seeking employment. Her development experience comes from over fourteen years of having to raise money for her cause. She started small the first year with a raffle and then moved to a silent auction/reception. Finally she graduated to a silent and live auction and dinner, and now she produces their "signature" annual event, a gala and five-day designer clothing event extravaganza. Recently she opened a social enterprise retail store (SHOP), a vehicle that raises money through the sale of famous maker clothing.

Clearly, Kathy knows her way around the money-making block. So check her out at her website: www.aminermiracle.org or feel free to contact Dick Weiland at rjweiland@msn.com to make connections with her. You will want to talk with Kathy if you are looking for advice on how – or how not – to put fun in your fundraising!

COOKS' HAPPY HOUR

BY PENNI WISNER & NANCY LAMBERT

My kitchen is awash in tomatoes in the process of becoming sauce. Seven quarts have taken up residence in the freezer. But, should the power go out, I have another six quarts canned and more on the way. Since tomato plants keep producing until frost hits, perhaps tomatoes are on your mind, too.

While discussing healthy tomato ideas, Nancy described her pursuit of low-salt, no-sugar-added tomato products and her discovery of a zillion uses for tomato paste. She reads labels and chooses a paste that is nothing more than pureed tomatoes cooked down to a thick paste. She thins the paste with water to make tomato juice and blends it in the food processor (you could use a blender as well) with gazpacho ingredients (onion, garlic, green pepper, and herbs) to make a gazpacho drink. Her experiments have expanded her tomato-paste-drink repertoire to include Virgin Mary, Italian, and Dill Pickle flavors. All of these make themselves at home during Happy Hour with or without a jigger of gin or vodka.

Nancy makes her tomato sauce from paste. But here, she and I part company, mostly because here in California it is easy to find tomatoes canned without added salt, and they are organic to boot. (Plus I have to use all the sauce I put up) When making sauce from canned tomatoes, I'll often add a tablespoon of tomato paste or the same of chopped, dried tomatoes. But in late summer and fall I make tomato sauce, and I make it as easy on myself as possible. This year I've discovered a new trick I'll pass on to you.

In a large, deep, nonreactive pot sauté a large amount of onion until very soft. (This year, in two out of three batches of sauce, I left out the onions; didn't get to the store) Add whatever herbs you like—bay leaves, thyme, basil, oregano, some mint. Though I don't measure or weigh, I might use a ratio of 1 1/2 pounds yellow onion to 10 pounds of tomatoes.

Wash and quarter garden tomatoes. You only need to core them if the core seems large to you. Add the tomatoes to the onions and put the pot over medium heat. Cook the tomatoes until they have broken down and cooked through. The time depends on the size of your pot and the amount of tomatoes. Stir occasionally to make sure the tomatoes don't stick to the bottom of the pan.

Now, here's my new trick: to make room in the pot for more tomatoes, I start a full pot cooking. When the tomatoes have begun to break down and give up their juice, I ladle it out into another pot and put it over high heat to reduce. Keep cooking until the juice is nearly a syrup. It develops a delicious caramelized, sweet, and intense flavor. And there is more room in the original pot to stuff in more tomatoes.

Once the tomatoes have fully softened, discard the bay leaves and put the tomatoes through a food mill or puree them in a food processor and then put them through a large-mesh strainer. Return the sauce to the pot, add the reduced juice, and simmer until the mixture is the thickness you like your sauce. Taste for seasoning and adjust with salt, pepper, lemon juice, or a touch of sugar. Freeze in 2-cup batches.

I keep the sauce simple, omitting garlic and going light on the herbs. Then it can take on Mexican flavors by adding chili and oregano for an enchilada sauce or, with some sautéed garlic and sausage, it turns into a sauce for pasta, etc. You could also puree some roasted sweet red bell peppers and add them to your sauce.

Next up: Nuts, seeds and grains—herbed nuts and Effie Taylor's favorite oatmeal. Please send us any ideas you have for healthy snacks.

Our motto: Eat Well to Stay Well

FROM IWMF-TALK

BY MITCH ORFUSS

It is with sadness that I begin this issue's IWMF-Talk column with a few words in praise and in memory of **Rob Selden**, who prepared this column for the last issue. Rob, whom I was fortunate to get to know traveling to and from our bi-monthly support-group meetings and frequently bumping into each other and sharing stories in the waiting room of New York Presbyterian Hospital, was a giving and courageous patient and friend. His battle with WM over nearly four years was an inspiration. Rob took on the challenge of managing his illness (recently transformed to diffuse large B-cell lymphoma) with the same intensity and humanity that he brought to his numerous and varied interests. His sudden passing from a heart attack this summer was a shock to all who knew, enjoyed, and respected him. Rob Selden will be missed.

Over these last few months, IWMF-Talk raised an especially wide variety of topics. The use of Rituxan is always a major topic of interest. **Karen Grimsley** asked about the number of readers who experienced "extreme reactions" to Rituxan and whether the discomfort, nausea, and shaking are worth it. **Shirley** was one responder who said that she'd not had severe reactions and that the minor reaction she did experience with the first infusion was well managed by attentive infusion nurses with meds such as Tylenol and Benadryl. **Guy Sherwood** further expanded the discussion by saying that minor side effects ("minor" being a debatable descriptor) are well worth it, bearing in mind, of course, that Rituxan winds up not helping some patients. In fact, some patients have no problem with Rituxan, others are troubled only with the first infusion, while yet others develop an allergy "to the mouse component." For those folks Rituxan is out of the question, and we must look for future "humanized" CD-20 antibodies to be effective in such cases. Lastly, there are anecdotal reports that Rituxan can cause pneumonitis or inflammation of the lung, a rare, but serious, and likely transient side effect. **Ron Draftz** wrote that patients receiving Rituxan should be tested by a simple blood test for both hepatitis B and C. One review showed hep-B or C to be present in nearly 1 in 12 patients receiving Rituxan. If hepatitis B or C is present, Rituxan can stimulate a lethal reactivation. Ron added in a separate post that progressive multifocal leukoencephalopathy (PML) may also be linked to the use of Rituxan with chemo. **Colin Perrott** added that Rituxan can increase the chance for infections.

With respect to another treatment of interest, namely Velcade, **Dean Johnson** wrote of his experience with a once-weekly Velcade/Rituxan trial that was completed in May of this year. Though initial results were good, by the fifth cycle improvement stopped; at the 6-month mark the numbers had worsened; and four months post-treatment conditions, including shingles involvement, warranted further treatment. **Martin Rozenman**, a WM patient since 1985 when diagnosed at age 32, has been on Velcade/Prednisone for 30 months, and for him it continues to work well, without neuropathy but with a couple of infections (including MRSA) along the way.

James Mahood weighed in on what he called pesky skin problems associated with WM. After chemotherapy (5x CVP, followed by Rituxan) Jim developed red areas on his face, ears, scalp, back, and elsewhere. They occasionally formed into small pimples or peeled and turned into small pink or red areas that don't bother him so much except for his social life. Jim hastened to add that eight months prior to his WM diagnosis his dermatologist had treated him–face, ears, and scalp–with Efudex and Desonide to prevent the development of skin cancer from sun exposure.

Lon Tanner offered that while playing pickle ball he took what he deemed a simple fall that caused massive bruising. Because Lon's blood counts were so good at the time his oncologist could not explain it—and Lon was not taking aspirin. He ended his post by saying that he now realizes he just doesn't heal as quickly with WM as he did before diagnosis. **Ken** too wrote of unusual bruising, which he attributes to IgM's sweeping out of his blood some of the thirteen coagulant factors we have, facilitating the bleeding.

Ron Draftz referred to a call **Don Brown** received from a woman whose 77 year-old husband suffers from both WM and Parkinson's. She was frustrated that the chemo her husband takes for the WM apparently interferes with the meds that treat his Parkinson's. The woman further said to Don that her husband's neurologist has no fewer than10 patients who, like her husband, have *both* conditions—all from an area limited to the northwest suburban Chicago area alone. Ron found this coincidence of Parkinson's and WM surprising and wondered "if the [patient] database will show more pockets of this double dose of disease." **Daniel** was skeptical that a single neurologist would be treating 10 patients who have both Parkinson's and WM. The neurologist was contacted to shed some light and was kind enough to reply. She did not claim to be treating 10 Parkinson's patients with WM; she said simply that both diseases were typically associated with aging and that though she does have a number of patients that do, indeed, have both diseases at the same time, there is no association between the two other than chance.

Peter DeNardis made us aware of a future development in cancer research—human cells have been found to house electric fields as powerful as lightning bolts. Using new nano-tools (such as voltage-sensitive dyes), scientists hope to learn more about disease states by understanding cellular changes on a very local level.

The pros and cons of stem-cell transplantation for WM patients is an area of perennial interest on IWMF-Talk. **Hank Stupi** wrote that after several rounds of treatments–including Rituxan, Cytoxan, and perifosine–he is once again considering the need for re-treatment and asked which treatments would be optimal prior to stem cell harvest in order to preserve the option for a potential future autologous transplant.

Finally, there was a burst of IWMF-Talk regarding the three-network news collaboration "Stand Up To Cancer [SU2C]." This program was billed as a groundbreaking television event. It aired simultaneously on all three over-the-air networks (NBC, ABC and CBS), live and commercial free, in prime time on September 5. Some of the biggest names in news and entertainment (actors, musicians, athletes and journalists)

From IWMF-Talk, cont. on page 14

From IWMF-Talk, cont. from page 13

were on hand to raise awareness and money for the fight against cancer—though of course not specifically for WM or even for blood cancers as a large sub-category. Funds raised as a result of this program will purportedly help advance and accelerate cancer research as well as bring new therapies to patients more quickly. Several IWMF-Talk readers asked in the days that followed if fund-raising for SU2C competes with, is neutral to, or indirectly supports our own specific WM fund-raising efforts. Treasurer **Bill Paul** represented the IWMF at the SUC2 event. Look for his report in the next issue of the *Torch*.

IWMF RECEIVES CONGRATULATIONS

IWMF President Judith May received the following letter from Sue Bliss, President of the Lymphoma Research Foundation.

Dear Judith,

What an honor and joy it is to send you this congratulatory note recognizing the 10th year that the IWMF has been an incorporated as a non profit organization. My first introduction to your Foundation was from Ben Rude who greeted me with his wonderful smile and a hug at the first American Society of Hematology Meeting that I attended as the new head of the Lymphoma Research Foundation in December 2001. We met on the floor of the exhibit hall, and that initial greeting soon blossomed into a wonderful friendship and a strong professional relationship.

Because of his insight and willingness to cooperate over the years, I know that both of our organizations grew stronger and it has been a pleasure to formally collaborate with you and the IWMF in recent years at the LRF's annual North American Educational Forum. All of us at LRF look forward to on-going opportunities to work together to eradicate the blood cancers that we all care about so passionately!

Again, congratulations from LRF on your 10th Anniversary!

Sue Bliss
President
Lymphoma Research Foundation

MEDICAL NEWS ROUNDUP

BY SUE HERMS

Soluble CD27 May Be Good Marker of Disease Burden in WM – Treon et al. reported in the American Journal of Clinical Oncology that soluble CD27, elevated in WM patients, supports tumor cell growth and can potentially be used as a marker of disease burden. It may be especially helpful in patients who are undergoing plasmapheresis or who have Rituxan-induced IgM flare because IgM levels are not accurate disease indicators in these situations.

Brain Disorder Reported in Some Patients Receiving Rituxan Therapy – A brain disorder called progressive multifocal leukoencephalopathy (PML) has been reported in a retrospective study of 35 patients receiving Rituxan therapy. PML represents a reactivation of latent JC polyoma virus, especially in patients who have abnormal T-cell function because of chemotherapy, transplantation, or other immunosuppressive conditions. PML is a serious disease with survival for one year after diagnosis reported in just three patients (9%).

Genasense in Combined Therapy Increases Overall Survival in CLL – A Phase 3 trial of Genasense (oblimersen sodium), manufactured by Genta Inc., showed a statistically significant increase in overall survival of chronic lymphocytic leukemia patients with relapsed or refractory disease. Genasense was included in a regimen with fludarabine and cyclophosphamide and increased overall survival from 38 months for chemotherapy alone to 56 months when Genasense was included. Genasense inhibits production of Bcl-2, a protein made by cancer cells that is thought to block chemotherapy-induced cell death. The company has requested a meeting with the U.S. Food & Drug Administration to review this new information.

Medical News Roundup, cont. on page 15

INTRODUCING TORCH TOONS

BY SUE HERMS

What do CD20 antibodies and cows have in common? More than you might think! There's a "moo—vement afoot" to produce anti-CD20 antibodies from cows milk. One of the alert members of IWMF-Talk, **Peter DeNardis**, spotted the following: it seems that Chinese scientists have bred a genetically altered cow that may be able to produce CD20 antibodies in its milk. The cow was born in Beijing on August 2, and a dozen more mab-yielding bovines are due next month. Researchers are hoping that mass breeding of the animals will enable China to produce the antibodies cheaply by purifying the milk of the cow. Thanks to Peter, **Christopher Court**, and others who saw the humor in this and "milked" it for all it was worth, inspiring this cartoon created by IWMF member **Linda Pochmerski.**

The *Torch* would like to present *Torch* Toons as an occasional feature and hopes that other IWMF members will be similarly inspired to submit examples of hematological humor.

Radioimmunotherapy Results Reported by Immunomedics – Immunomedics Inc. has reported that its monoclonal antibody epratuzumab (anti-CD22) labeled with radioisotope yttrium-90 produced significant clinical results when given in small fractionated doses to non-Hodgkin's lymphoma (NHL) patients. An objective response rate of 64% and a complete response rate of 49% were achieved. By splitting the radioactive dose over 2-3 fractions, higher radioactivity can be delivered without increasing toxicity to the bone marrow.

Oral Agent Effective Against Multiple Myeloma Cell Lines – EntreMed Inc. announced preclinical data for its angiogenesis kinase inhibitor ENMD-981693, which exhibited toxicity against multiple myeloma cell lines. The drug is an orally active agent and will be used in a Phase 1 study with hematological malignancies later this year.

Phase 2 Results Presented for Perifosine and WM – Keryx Biopharmaceuticals presented Phase 2 results of perifosine (KRX-0401) in patients with relapsed/refractory WM. Thirty-six patients were evaluated, with an overall response rate of 33% and an additional 61% of patients achieving stable disease. Toxicity was manageable. Perifosine is a novel oral anti-cancer agent that modulates Akt and other pathways associated with cell survival and differentiation. Patients were scheduled to receive 150 mg of perifosine daily in a 28 day cycle for at least six cycles.

Perifosine and Bortezomib Both Impact Nuclear Factor-KappaB Pathway – The Dana-Farber Cancer Institute has reported that the nuclear factor-kappaB pathway has been implicated in tumor B-cell survival, growth, and resistance to therapy. Both perifosine and bortezomib impact this pathway through their targeting of Akt and proteasome inhibition, and combining these drugs has led to synergistic cytotoxicity in WM cell lines. Combining these with Rituxan further increased their activity. Thus, effective WM therapy may require combination regimens targeting this pathway.

Favrille Announces Disappointing Results for Specifid and Follicular Lymphoma – Favrille Inc. announced disappointing results from its Phase 3 trial of Specifid following Rituxan therapy in patients with follicular lymphoma. Specifid is a so-called idiotype vaccine, based on the patients' specific tumor cells. Analysis of time to progression failed to show a significant improvement over the control arm of the trial, and the company plans to discontinue development.

Possible Link Between Certain Drugs and Lymphoma in Children and Young Adults – The U.S. Food & Drug Administration (FDA) is investigating a possible link between drugs used to treat juvenile arthritis and Crohn's disease and the development of lymphoma and other cancers in children and young adults. The FDA is looking at Remicade, Enbrel, Humira, and Cimzia and reports of 30 possible associated cancer cases. The FDA hopes to complete its study in about six months.

Update of Phase 1 Trial of Anti-CD19 Antibody – Micromet Inc. provided an update of its ongoing Phase 1 trial BiTE antibody for relapsed NHL patients. The antibody, called blinatumomab, targets the CD19 antigen found on B-cells and achieved either partial or complete responses in all the patients completing this particular arm of the study. BiTE antibodies are designed to direct the body's own cytotoxic T-cells to attack the tumor cells.

New Drug Improves Chemotherapy-Related Cancer Fatigue – A large Phase 3 clinical study showed that the drug Provigil (modafinil) alleviated severe fatigue for many cancer patients receiving chemotherapy, thus paving the way for a reliable treatment of this common and debilitating side effect. The trial of 642 patients at the University of Rochester Medical Center was reported to the American Society of Clinical Oncology. Cephalon Inc. manufactures Provigil.

Phase 2 Results for Combined Anti-CD80 and Rituxan – A Phase 2 clinical trial of galiximab, an investigational anti-CD80 antibody, combined with Rituxan achieved a 70% response rate in previously untreated follicular lymphoma patients. The CD80 molecule is found on the surface of cells of various subtypes of NHL. This trial was sponsored by the National Cancer Institute.

Investigational Drug Blocks Both B-Cells and Mast Cells – Pharmacyclics Inc. reported a pre-clinical study of its drug PCI-32765, which causes a block of both B-cell and mast cell activation in lymphoma cell lines. PCI-32765 is orally available and targets an enzyme called Btk, which is critical to B-cell activation and mast cell function. A Phase 1 clinical trial is anticipated to begin in the fourth quarter of 2008.

Nanoparticle Drug to be Used in Clinical Study of Lymphoma Patients – Calando Pharmaceuticals is collaborating with City of Hope in California to initiate a Phase 2 clinical trial using Calando's nanoparticle drug candidate IT-101 in patients with relapsed or refractory B-cell, T-cell, and Hodgkin's lymphoma.

Statin Use May Decrease Rituxan Effectiveness – A study from the University of Warsaw, Poland, suggests that taking cholesterol statin drugs concurrently with Rituxan therapy may decrease the anti-tumor effects of Rituxan. Statins appear to cause shape changes in the CD20 molecule that result in impaired binding with Rituxan.

Small Molecule Drug Enters Phase 1 Trial – Calistoga Pharmaceuticals Inc. has initiated a Phase 1 trial of its small molecule compound CAL-101 in patients with hematologic cancer. This drug targets PI3K-delta, which mediates critical pathways that promote proliferation, growth, metabolism, and survival of blood cell lineages.

Carfilzomib Advances to Phase 1b and Phase 2 Trials – Proteolix Inc. has begun a Phase 1b clinical trial to evaluate carfilzomib (PR-171) in combination with lenalidomide (Revlimid) and dexamethasone in patients with relapsed

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multiple myeloma. Carfilzomib blocks proteasome activity, causing death of cancer cells. In addition, Proteolix is evaluating carfilzomib as a single agent in Phase 2 studies.

Phase 2 Results Released for TREANDA – Cephalon Inc. published results of its Phase 2 study of relapsed NHL patients treated with its drug TREANDA (bendamustine hydrochloride) plus Rituxan. The overall response rate was 92% with a complete response rate of 41%.

New Oral Drug in Phase 2 Lymphoma Trials – Researchers at the University of Rochester's James P. Wilmot Cancer Center are reporting that an oral investigational drug called fostamatinib disodium shows promise against several types of lymphoma. The drug targets a common protein, SYK, found in normal B-cells and lymphoma cells. A Phase 2 study of 53 patients with recurrent lymphoma showed 44% had positive responses.

Erythropoiesis-Stimulating Drugs May Decrease Survival of Multiple Myeloma Patients – Treatment with erythropoiesis-stimulating drugs may not be safe for multiple myeloma patients, according to a recent study published in the American Journal of Hematology. A 20 year study from the Theagenion Cancer Center in Greece of 323 multiple myeloma patients found an association between exposure to these drugs and a reduction in progression-free and overall survival rates. The median survival rate was 31 months for patients receiving these drugs, compared to 67 months in those who did not. Such drugs include Procrit, Aranesp, and Epogen. Additional studies are being suggested to confirm these results.

New Phase 1-2 Study in Canada Targets Inhibitor of Apoptosis – Aegera Therapeutics Inc. has announced a Phase 1-2 multicenter study of AEG35156, a second generation antisense therapeutic drug targeting a key member of the protein family that inhibits apoptosis. The study is funded in part by the Leukemia & Lymphoma Society and is based in Toronto, Ontario, Canada.

Memorial Sloan Kettering Cancer Center Participates in Phase 2 Trial of Novel Therapy – Memorial Sloan Kettering Cancer Center participated in a Phase 2 trial of Ixabepilone in patients with relapsed/refractory indolent NHL and mantle cell lymphoma. This drug is part of a novel group of microtubule stabilization agents that appear to retain activity even in chemotherapy-resistant cell lines and animal models. The overall response rate was 27% in the population that previously had been heavily treated. Major toxicities included fatigue, myelosuppression and neuropathy.

Preclinical Data Presented on Another Anti-CD19 Antibody – Xencor Inc. presented data from pre-clinical studies evaluating XmAb 5574, an engineered monoclonal antibody targeting the CD19 molecule. The antibody elicited complete B-cell depletion in both leukemia and lymphoma cell lines and animal models. The data were presented during the recent annual meeting of the American Society of Clinical Oncology.

Accentia Seeks Approval of BiovaxID from FDA – Accentia BioPharmaceuticals is planning to seek FDA approval for its idiotype vaccine, BiovaxID. Researchers recently completed a Phase 3 clinical trial that included patients with follicular lymphoma who were initially treated with chemotherapy followed by either BiovaxID or a control. Follow-up was 80 months. Median cancer-free survival was improved by more than one year among patients treated with BiovaxID, and median time to relapse was 33.8 months for those treated with BiovaxID compared to 21.2 months for the control group.

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

SUPPORT GROUP NEWS

EDITED BY PENNI WISNER

Arlene Hinchcliffe, the new Support Group Coordinator for the IWMF/WMFC (Waldenstrom's Macroglobulinemia Foundation of Canada), takes over the position from Karen Pindzola, who held the position for three years while running her local support group as well. Karen's commitment to WM patients has been an inspiration. Arlene's relationship with WM began with her father, who passed away in 1998. She says, "I wanted to offer the support to others that I was not able to find for myself." With help and encouragement from Arnie Smokler, the founder of the IWMF, Arlene held her first support group meeting in January of 1999. Nearly thirty people traveled from far and wide to attend. She has never looked back. She helped form the Waldenstrom's Macroglobulinemia Foundation of Canada in 2003 as an extension of the IWMF. In 2006 she became an IWMF Board member while continuing her roles with the WMFC and as a support group leader. "To all support group leaders: I want to thank you for your dedication in reaching out to others in your community in order to provide a safe and welcoming place for those who share this rare disease. I look forward to working with you."

IWMF CHAPTERS—USA

CALIFORNIA

Orange County

Since the IWMF Ed Forum was in LA this spring, the southern California support group will hold just two meetings this year. The fall meeting on November 18 will feature Stephen J. Forman, M.D., Chair, Division of Hematology, and Head of the Bone Marrow Transplant Unit at the City of Hope Hospital, one of the country's best known comprehensive cancer centers. An international expert in leukemia, lymphoma, and bone marrow transplantation, Dr. Forman has led the City of

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Hope program in the treatment of hematologic cancers to the forefront of the field. Dr. Forman will provide information about the City of Hope's programs and his experience with Waldenstrom's macroglobulinemia, including past, present and future treatments. In addition, Dr. Forman will be responding to questions to be collected before and during the meeting. As in the past, the meeting will take place at the conference room at Hoag Hospital's cancer center.

Sacramento and Bay Area

This September the Lymphoma Research Foundation held its annual educational forum in San Francisco. The program included a breakout session with Dr. Steven Treon of the Dana-Farber Cancer Institute. Since not many of the group attended the IWMF Ed Forum in May, they were thrilled with this opportunity to hear Dr. Treon in person and to attend other presentations of the LRF. The next support group meeting is planned for late February or early March 2008.

FLORIDA

Ft. Lauderdale area

The south Florida support group held their regular meeting at the end of September at Memorial Hospital West. The group plans for an expanded support group meeting including a presentation by Dr. Treon on March 21, 2009.

Southwest Florida

The southwest Florida support group will hold its next meeting in Sarasota in February or March with Dr. Steven Treon as the speaker. Further information will be forthcoming when the date is confirmed.

ILLINOIS

Chicago

Dr. Treon, well-known friend of the IWMF and WM research specialist, spoke with the Chicago area group in August. He detailed encouraging research into WM and potential combination drug treatments with promising response rates. As always, his question and answer period was especially well received by attendees. The next meeting on Saturday, October 25, will be an interactive format for both patients and caregivers to discuss issues and share stories.

MICHIGAN

Though the support group has not met since May of this year, two meetings are in the works. The first for October and the second, hopefully with Dr. Treon, in April or May 2009. The Michigan support group has converted to e-mail as the primary method of communication. Please send **Pete Boyse** your e-mail address at peterdboyse@earthlink.net in order to receive meeting notices.

NEW YORK

Northeastern NY/Western New England

Tom and Kay Zolezzi hosted the annual summer picnic at their beautiful home in August. Although the summer was a very wet one, perfect weather that day allowed the group to fully enjoy the sculpted beauty of the Zolezzi's yard. The abundance of food (featuring shrimp and other appetizers, baked salmon, chicken burgers and hamburgers, a multitude of tasty salads topped off by several homemade deserts) was surpassed only by the setting, the great conversation, and friendship. The fall meeting was in September and the next will be November 22.

NORTH CAROLINA

A new group has formed, chaired by **Ann and Don Nolan**. They will be contacting WMers in their area soon.

EASTERN OHIO, WESTERN PENNSYLVANIA, & WEST VIRGINIA

Thirteen members of the group enjoyed good wine, good food, and the opportunity to socialize at a wine tasting and pot luck dinner hosted by **Marcia and Glenn Klepac** in June. **Pete DeNardis** graciously shared many wonderful selections from his homemade wine collection, a boost for all of our resveratrol levels! In between hors d'oeuvres and dinner, Pete and **Neal Makens** presented a very informative overview of the IWMF May 2008 Ed Forum. Pete also updated everyone on the latest news of the patient database. Following dinner, members shared recent developments of their WM journey. Plans are under way for a fall meeting.

WESTERN OHIO, EASTERN INDIANA, & NORTHERN KENTUCKY

At the quarterly gathering, held this time at the Leukemia and Lymphoma Society's southern Ohio chapter headquarters in Cincinnati, the group welcomed two newly-diagnosed participants and their spouses. Viewing one of the recorded sessions from the Ed Forum and the following discussion were especially helpful to all those attending. The LLS kindly provided a healthy cheese and veggie tray that provided fortification until lunch after the meeting. The next gathering will be at Upper Valley Medical Center, Troy, Ohio, on Saturday, October 18. For those interested in carpooling to the meeting, call **Ron Payne** at 937-349-4344 for information.

PENNSYLVANIA

Central and Southeast PA and Northern MD

In May at Messiah Village the group welcomed new member **Connie Wida.** Members always encourage everyone to join in discussions of symptoms, care, and any other concerns. And this particular discussion got so involved and lively that the planned video was tabled until another meeting. August found the group at the home of **Don and Kate Wolgemuth**, who graciously hosted the pot luck meeting where new members **Dr. Jim Yeager** and his wife, **Joyce**, added to our great fellowship. **Rita Ziats** and her two sisters, **Linda and Kay,** always make for spirited and fun exchanges (and wonderful food). To join the fun, attend the group's next meeting on Sunday, November 9, at Messiah Village from 2 to 4 pm.

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Philadelphia

The Philadelphia area support group had the privilege of hosting Dr. Steven Treon at their August meeting. Despite August vacation schedules, there was a great turnout. Dr. Treon spoke about the latest research and clinical findings on Waldenstrom's. He then took questions from the audience for almost an hour, covering everything from hearing loss to Rituxan maintenance. The next meeting will be Sunday, October 12, from 2 to 4 pm.

TENNESSEE

W. Tennessee, E. Arkansas, N. Mississippi

Memphis

In May the group drew its largest turnout ever, welcoming three new caregivers (unfortunately the patients themselves were not able to attend). The group reviewed the excellent notes taken by **Colleen Casey** at the IWMF Ed Forum in Los Angeles in early May. The notes, combined with questions and concerns shared by the caregivers of those newly diagnosed, generated lively and spirited conversation. The group expects that their September meeting will be just as well attended and animated.

Central Tennessee

Nashville

Unfortunately, up to this point we have been unable to find a patient within the Nashville city limits. Instead, attendees have been traveling one to three hours to attend the central Tennessee meetings. Group leader **Bill Paul** sends meeting announcements to area hospitals and clinics in an attempt to locate more patients and generate more interest. He will keep trying!

TEXAS

Dallas & Northern Texas

Baylor University Medical Center in Dallas hosts the meetings of the north Texas WM support group. At the May meeting **Jerry and Bev Fleming** reported on the IWMF Ed Forum in Los Angeles. In August Dr. Treon, the featured speaker, presented an "Update on Waldenstrom's Macroglobulinemia and Multiple Myeloma." Marvin J. Stone, M.D., Chief of Oncology, Baylor University Medical Center, Dallas, and Director of the Baylor Charles A. Sammons Cancer Center, also gave a presentation on "Similarities and Differences Between Waldenstrom's Macroglobulinemia and Multiple Myeloma." Members of the north Texas myeloma support group and the north Texas chapter of the Leukemia and Lymphoma Society also attended the talks. Following the formal program, the north Texas Waldenstrom's macroglobulinemia group met and enjoyed lunch provided by Baylor University Medical Center.

WASHINGTON

"With mixed emotions," said long-time group leader **Peg Horton,** "I have resigned as group leader of WMSG-NW." Arnold Smokler encouraged her to start a Washington group about ten years ago, and, with help from **Deloris Morrical,** the group has grown from its original 5 people to over 150, not including spouses and caregivers. Peg and husband, Bob, have moved to a new home in Port Orchard, WA. **Malcolm Brewer** has taken over leadership of WMSG-NW, as of August 2008. Malcolm's wife, Joan, was diagnosed with WM in June 2003. Unfortunately, she died of WM in January of this year. Malcolm, 63, is retired after a career of pastoring, mostly in the Evangelical Free Church, and teaching English and Bible at North Sound Christian School. The group will be in good hands. Malcolm lives at 11541 87th Ave. S., Seattle, WA 98178. Telephone: 206-772-7430 E-mail: clanbrewer@gmail.com Co-leader Deloris Morrical has agreed to assist Malcolm and help him get started.

IWMF CHAPTERS—INTERNATIONAL

CANADA

Toronto

Mr. Preet Banerjee spoke on charitable giving strategies for Canadians at the Toronto group's May meeting. The group was very active in September with a meeting and a fundraiser gala organized by the three children of group leader **Arlene Hinchcliffe.** On November 8 the group will host the Third Annual One-Day Forum on WM at the Grand Hotel & Suites in Toronto. Dr. Steven Treon will be the featured speaker.

DENMARK

The Danish support group just formed and it has **one** member, namely **Steffen Stello.** The Danish support group is a subgroup formed under the umbrella of the Danish patient organization LYLE (Lymphoma and Leukemia). LYLE was formed last year and Stephen was a participating member. As a member of IWMF since 2004, he found it natural to form a sub-support group dealing with WM alone. The LYLE members with WM do not have their information needs met in the larger group, thus a WM support group is necessary. While LYLE works on becoming known in Denmark, Steffen is working to introduce the IWMF to people with WM. But there are very few WMers in Demark. "As you see," says Steffen, "the Danish WM support group has had cozy meetings where **all** members attend every time."

ISRAEL

Where just two WM patients talk together, there is a support group. And, as Steffen has shown in Denmark, even if just one person talks, a support group can flourish. **Moshe Kwart** is the IWMF Hewbrew-speaking contact in Israel. As such he fields calls from new patients and recently had a newly-diagnosed patient over for coffee. "It was an enjoyable and positive meeting," reports Moshe, who then put the patient in touch with another WMer, **Rinat Atar**, who lives in his city. So, Moshe admits, there is talk of forming a group. Stay tuned.

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THE LIFELINE

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

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

2-CdA
Norm Spector.....858-454-6313

2-CdA WITH RITUXAN
Bernard Swichkow.....305-670-1984

CAREGIVING
Lynn Bickle.....805-492-4927

Brad Alexander 972-529-2002

CHLORAMBUCIL
Dave Lively.....608-783-4552
Ronald Romeis.....610-724-3481
Jerry Berman.....416-925-6715

CLINICAL TRIALS
Tom Hoffmann.....501-868-8305
Guy Sherwood.....765-282-4377

CRYOGLOBULINEMIA
Fay Langer 973-464-6696

FLUDARABINE
Peg Horton 253-874-8820
Dave Lively 608-783-4552

FLUDARABINE with cyclophosphamide (Cytoxan)
Penni Wisner 415-552-6579

FLUDARABINE with Rituxan
Marty Kopin.....310-390-1546
Jerry Block 301-460-9799

HEARING IMPAIRED TTY FACILITY
Betty Mc Phee.....905-775-3413

LATEST RESEARCH
Bert Visheau 905-528-1789

NEWLY DIAGNOSED
Guy Sherwood 765-282-4377
Norm Spector.....858-454-6313
Sallie Moore 516-795-3746

ORAL CYTOXAN
Lou Birenbaum..... 314-961-5591

PLASMAPHERESIS
Fred Bickle 805-492-4927

RITUXAN
Charles Vassallo 201-947-6977
James Townsend 352-376-3664
Allen Weinert 603-863-5347
760-568-2918

SOCIAL SECURITY DISABILITY
Howard Prestwich 815-233-0915

SPLENECTOMY
Kathleen Ugenti.....631-470-0971
Patricia McCue.....239-348-3456 *winter*
802-468-5779 *summer*

STEM CELL TRANSPLANT
Howard Donley.....307-587-3397
Sybil Whitman 506-450-3970

THALIDOMIDE
Mel Horowitz 518-449-8817

VELCADE
Jeff Atlin 905-731-7756

VETERANS
Jerry Fleming.....972-867-2030

WATCH AND WAIT
Mel Horowitz 518-449-8817
Renee Paley-Bain.....203-744-7851
Polly Oldberg.....513-932-7486

YOUNG WM
Nobby Riedy 650-879-9104
Bob Bailey 770-664-8213

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SPANISH SPEAKER
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stonehill@earthlink.net

Betsy Beazley.....510-527-5827
betsybeazley@gmail.com

Gladys Mendieta 215-860-9216
Gladysmendieta@aol.com

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UK SUPPORT GROUP ONLINE FORUM
Raphael Altman
raltman@btinternet.com

SINCE JUNE, 2008 THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN MEMORY OF:

In memory of Deborah Abelow:
Lloyd & Sheila Hoffman
In memory of Jean-Marc Audibert:
Sarah Audibert
In memory of Mary Barnhill:
J.H. & Paula Austin
In memory of Dr. C.W. Biedel:
Suzanne Herms
Gene & Sandra Patton
Ron & Sue Reimer
In memory of Leo Bresonis:
Tom & Bev Lacey
In memory of Pauline Chester:
Lloyd & Sheila Hoffman
In memory of Edward H. Chmura:
Glitterex Corporation
In memory of John Cibiras:
Sam & Doris Mathis
In memory of Bob Crumley:
Jerry & Barb Britschgi
In memory of Craig Daughtrey:
Terry & Janet Cherry
In memory of John Lawrence Funk:
Loran & Mary Ethelyn Bosarge
J. D. & Eldora Chachere
Buddy & Mimi Clapp
Carolyn Conner
Jerry & Bev Fleming
The Halligan Family
Inquest Staffing
Ed & Ginger Jasek
Arthur & Vivian Kackley
The Kevin Lippman Family
Jim & Joyce McDaniel
Alfonse & Joycelyn Preisser
Peninnah Schram
John & Roz Sloan
Billie Straus
Henry & Barbara Vornkahl
Linda Zachry
In memory of Jacob Gowda:
Ollie Wasarab
In memory of Wayne Hodge:
Lamoine Hodge
In memory of Alan Howenstine:
Melba Howenstine
Lew & Kathy Landry
In memory of Janet Kelly:
Robert Kelly
In memory of Bonnie Koch:
Todd & Linda Kliston
Brian & Jill Koch
Charles Koch
Darren & Marian Koch
Faye Koch
Mr. & Mrs. Shaun Koch
Harold & Thelma Millen
In memory of Gregory Kryak:
Elizabeth Howanski
In memory of Robert P. Kusy:
Robert Reeber
In memory of Jeanine Laitres:
Edouard & Corine Arsenault
Michel & Marie Arsenault
Denis & Clarisse Du Salon
Jacques & Clodet Rioux
In memory of Mike Lesmister:
Gay Lesmister
In memory of Bonnie Lynch:
Earl & Judy Nolting
In memory of Merline Moran:
B. J. Fisher
In memory of Barbara Musil:
Bruce Barnett
In memory of Maureen Nelson:
Vance & Marjorie Nelson
In memory of Bill Pivorski:
Ricardo & Yolanda Ballesteros
Seth & Laura Branam
Ken Hames
Rex & Leila Hames
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Charles & Eileen Baker
Elwood & Jeanne Baker
Steven & P. Jane Barrett
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Victoria Cam
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Donald Crockford
Gordon & Lynn Crockford (Val)
Neil & Carolyn Crockford
Howard & Julie Dalal
Jake & Doreen Kyksterhuis
Echo Creek Hunt Camp
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Jeff & Pat Firth
James & Diane Flannery
Ronald & Heather French
Edward & Lynn Gerrard
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Clancey McGuire
Larry & Willie McGuire
Shane & Marie McKeen
Marian Noble (B. Crockford)
Alfred John & Sheila Russell
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Linda Semek
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Larry & Carol Spitzig
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Barry & Andrea Watson
Melanie & Helena Woodland
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Melvin & Judy Zettle
Lawrence Zimmerman
In memory of Debbie Salzman:
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Mike & Roz Bergman
Shirlee Brounstein
Michael & Shelley De Laurentis
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Deborah Finck
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Ross & Karen Karlin
Louis & Anne Katz
Arthur & Barbara Miller
Marion Perlsweig
Mike & Lee Perlsweig
Gary & Gloria Schwartz
Vivian Silver
Ernie & Nina Spinelli
In memory of Ida Schwartz:
Noah & Phyllis Fields
In memory of Rob Selden:
Susan Addelston
Esther Blieberg
In memory of Rob Selden *(cont.)*:
Sondra Brown
Linda Cantor
Cejwin Camps Reunion 2008
JoAnne Chernow
Bob & Marsha Dennis
Christopher Dial
Lynn Feinman
Joseph & Harriet Fibel
Sylvia Firschein
Honey Goldfein-Perry
Roni Green
Meg Herbig & Jeffrey Stern
Norma Kider
Roni Liebowitz
Hadassah Lipsius
Christine Longobardi
Maureen McEvoy
Paula Moss
Margaux Neiderbach
Gwen Nichols
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Eileen Polakoff
Marcia Posner
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Albert Winn & Scott
Robert Sink
Nelson & Judith Sonshine
Sheila Stein
Steve & Renee Steinig
Susan Tafler & Charles Koplik
Pete Tannen
Steven Unger
Diane Wade
William Wahler
Harold Williams & Mary Dunleavy
Saul Zalkin
In memory of Arnold Smokler:
Fred & Lynn Bickle
In memory of Mari Ellen Stoddard:
Judith Workman
In memory of Bernie Valtinson:
Al & Carol Halloran
In memory of James Walsh:
Mary Austin
Dale & Linda Bukes
Fred & Kris Davidson
Leroy & Velda Gilmoure
James & Zita Halloran
Mary Ellen & Meredith Hersberger
Arlene Johnson
Richard & Mary Kilmer
Allen & Laurie Pfeifer
Walter & Kathy Sancken
Frank Sereno
Kenneth & Joan Sereno
W. P. & Nancy Smith
Michael & Kelli Unger
Keith & Jill Vilt
R.L. & Carol Walker
In memory of John S. Ward:
Flood Control Friends
In memory of David B. Wirsching:
Jamies & Carrie Fergusson
David Ross & Shirley George
DiAnn White
In memory of Al Zucker:
Arthur & Janet Laxer
Myles & Sarah Zuckerman

SINCE JUNE, 2008 THE FOLLOWING CONTRIBUTIONS TO THE INTERNATIONAL WALDENSTROM'S MACROGLOBULINEMIA FOUNDATION WERE MADE IN HONOR OF:

In honor of Larry Bonney:
Kathy Scott
In honor of Ed Briglia:
Hillary Kindman
In honor of Jeff Eickhoff:
Bob & Tara Vincent
In honor of the wedding of Janssen Evelyn & Sonya Funna:
K. Serge Akwei
A. Linda Massougbodji
In honor of Stan Fisher:
B. J. Fisher
In honor of Jerry Fleming:
Paul Patterson
In honor of Tony Guefen:
George & Nancy Heimler
In honor of Peggy Horton:
Renate Wieler
In honor of Bob Lynch and "Row, Bob, Row":
Ida Wing & Judith Digiano
David & Colleen Forget
John & Lita Gasper
Raymond & Lorraine Lebrun
John & Penelope Paasch
In honor of Doris Mathis:
Carol Clark
In honor of Robert Murenbeeld:
Walter & Toni Murenbeeld
In honor of Mike Pennington:
Karen Blocksom
In honor of the John & Mariane Randall Bike Ride:
Erik & Wendy Bjeldanes
Daniel & Suzanne Chaply
Vaughan Johnson
Karen Maurer
In honor of Rosemary Riddell:
Jim & Charlotte Cruff
In honor of Alice Riginos:
Cynthia Riginos
In honor of Jackie Romanello:
Donna Tracy
In honor of Judy & Robert Rosencranz:
Leslie Herzog
In honor of Susan Rubenstein:
Mr. & Mrs. Jeffrey C. Rubenstein
In honor of Debbie Salzman's birthday:
Frances Salzman
In honor of Dave & Lorraine Schick:
Dorothy McAnally
In honor of the dear mother of the Sheppard Family:
Theodore, Donna & Timothy Besser
In honor of Donald Smith:
Kathleen V. Patrona
In honor of Ubaldo Vitali:
Val Iacovantuno
Emma Kabat
John & Diane Vantuno
Ralph & Nicole Wagner
In honor of Sue Wickert:
Tom Martin

TREASURER'S REPORT AS OF JUNE 30, 2008

BY BILL PAUL, TREASURER

The finances of IWMF are operated through two separate funds: the Research Fund and the Operating Fund.

The Research Fund accounts for all contributions received for research and is charged only for funds to be expended on approved research projects.

The Operating Fund accounts for contributions from members and others that are not designated for research, such as membership contributions. This fund is charged with all member services expenses and all operating expenses, none of which are charged to the Research Fund.

The following is a summary of the financial results for the first six months of 2008:

	Research	Operating	Total
Income	$220,000	$161,000	$381,000
Expenses	60,000	195,000	255,000
Net Income	$160,000	($ 34,000)	$126,000

Income in the Research Fund was nearly $100,000 short compared to the same period in 2007. However, the Research Fund is still in a healthy position due to the fact that no research projects were approved during the first six months of 2008. Our only expense was $60,000 to support the Stockholm Workshop in October, 2008.

The results for the Operating Fund show a loss of $34,000 for the first six months. While this might cause some concern, it should be noted that this loss is still a significant improvement compared to more than $100,000 over the same period in 2007. In addition, we should keep in mind that our annual membership campaign is held in the last few months of the year. Membership contributions will help to overcome the $34,000 shortfall and will bring us into a profitable position once again.

Please consider this shortfall when you receive a letter asking for your membership donation. Membership donations support the Operating Fund. You also received a special IWMF Bulletin in July outlining various methods you can use to contribute to both the Research Fund and the Operating Fund. As an all volunteer foundation that is almost entirely self-funded, the IWMF depends on your support.

On a personal note, I would like to thank Jim Bunton for his patience, expertise, and cooperation in helping to make a smooth transition for me into the Treasurer's position. Jim has served IWMF in an exemplary manner for eight years as Treasurer, and I am pleased that he has agreed to remain on the Board of Trustees as Secretary. Someone asked me if I would be replacing Jim, and I informed her that, while Jim can not be replaced, I will try to carry on his quality of work to the best of my ability.

Also, following Jim's lead for all these years, please know that my e-mail inbox and telephone are at your disposal should you have any questions, comments, complaints or suggestions. You can reach me at 901-767-6630, or at Billpaul1@Juno.com.

FIVE 'N FIVE

BY ARLENE HINCHCLIFFE

The International Waldenstrom's Macroglobulinemia Foundation is embarking on a FIVE year, FIVE million dollar fundraising campaign and we need you. There are 2,895 reasons to participate, the number of IWMF members worldwide who will benefit. The saying "when you need something done right, do it yourself" has never been more true than now. All the research presently under way has resulted from your generous gifts and determination to control your future. Can we achieve this goal? Absolutely!

Why?

F is for our **future** and **families**
I **innovation**
V to have a **voice**
E to **educate** and **empower**

'N the **need** to be heard is greater than ever

F **funding** is the key to unlocking this mystery
I to **inspire** researchers around the world
V to provide a **vision** for a cure
E **encouragement** for this research has to come from us

For program priorities and ways to double your dollars through the Incentive Fund, check out the IWMF Bulletin you have recently received in the mail. We ask you to join us on this journey and together we can stand as one and fight the battle of our lives. An envelope for the "The Five-in-Five Research Fund" is included in this issue. How about making a "birthday gift" to the IWMF?

THE BEN RUDE HERITAGE SOCIETY INQUIRY FORM

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

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

_____
Signature

_____
Name (please print)

_____
Address/City/State/Zip

_____
Telephone Number

_____
E-mail Address

ADMINISTRATIVE MATTERS

BY ROY PARKER, VICE PRESIDENT FOR ADMINISTRATION

Electronic Edition of the *Torch*

The *Torch* is available electronically. You can now view and reproduce the *Torch* at our web site as soon as it is in print.

Using regular mail to send out the *Torch* is extremely expensive–especially to our overseas members. If you'd like to help the IWMF save money by printing the *Torch* off your computer, please notify the office by e-mail and indicate your willingness to receive the *Torch* electronically and to save the $2.00 in postage it now costs to mail your copy.

Remember, the early *Torch* is the electronic *Torch*.

2008 Forum DVDs Coming in October

Following each Educational Forum, the IWMF produces video recordings of the sessions as a service to its members, particularly to those unable to attend in person. The DVDs from the May 2008 Forum in Los Angeles include the presentations by the outstanding doctors and researchers who spoke at the Forum. All support group leaders will receive a complimentary copy to show at local support group meetings and to loan out to their group members, especially new members and those who did not attend in person.

Although many of us attended the Forum and heard these presentations in their entirety, we can learn even more by viewing the DVDs at a support group meeting or at home. At support group meetings, for instance, those who did not attend the Forum can ask questions and ask for clarification from those who were there. Good give and take discussions can occur during such meetings.

The DVDs from Los Angeles will be ready for delivery in early October. If you would like a copy, please fill out the enclosed form and mail it to the business office in Florida using the enclosed envelope. Each set will cost US $35, including shipping. Please note: if you pre-ordered a set at the LA Forum, your order is already on record. You do not need to order again.

HOLD THAT DATE!

The 2009 IWMF Educational Forum has been scheduled for the weekend of April 24-26 in Memphis, Tennessee. See the next issue of the *Torch* for details and particulars.

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