



MYELOMA TODAY

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

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Dear Reader,

As the year drew to a close, I heard from so many people about how relieved they were that 2001 was finally over. The past year was one of enormous upheaval and grief. But, strangely, in the world of multiple myeloma it was also a year of hope.

Evidence of this was apparent at the recent meeting of ASH where there were over 200 abstracts on myeloma. Currently, exciting drugs such as PS-341 and the new iMid Revimid® are moving through clinical trials. These drugs hold much promise for improving the outlook for myeloma patients.

Important work in myeloma research is taking place in labs around the world. Numerous studies are being conducted, including projects on molecular genetics, bone metabolism, and cytokines to name a few. More and more pharmaceutical and biotech companies are developing drugs and technologies that may have an application in the treatment of myeloma.

When Brian Novis was diagnosed in 1988, the drugs available to treat myeloma were melphalan and prednisone, dexamethasone and interferon as a maintenance therapy. What a choice. Today, the myriad of new treatment possibilities challenges both patients and physicians to stay abreast of emerging options in order to attain the best outcome possible.

Knowledge is power! Our thanks to Geraldine Ferraro who made myeloma a household word. She too recognizes how powerful education is. As she so aptly stated in her letter to the IMF, **"The International Myeloma Foundation has been a source of information and hope not only for me but for many other myeloma patients. It has educated and provided support to our families and most importantly has been at the forefront of raising public awareness and money for research."**

If we've learned one lesson this past year, it's that even in the darkest hour there is a glimmer of hope. All of us at the IMF hope that we have been able to provide you and your family with that beacon of light. And remember –

"Until there is a cure... There is the IMF."

Susie Novis

ASH 2001

A PLETHORA OF NEW INFORMATION ABOUT MYELOMA



Twenty-four participants from around the world attended the IMF Scientific Advisory Board meeting held at ASH 2001.

by Brian G.M. Durie, M.D.

This year 5,453 abstracts were submitted to the American Society of Hematology (ASH), of which over 200 dealt exclusively with myeloma plus more including myeloma as part of a larger study. In addition, there was a "Myeloma: Corporate Super Friday" event on Friday, December 7th, as well as a Physician Education Session for myeloma on Saturday, December 8th (full text accessible on IMF website at www.myeloma.org).

The presented abstracts specifically on myeloma included 1 plenary session oral presentation (the "top" submitted abstract as judged by the program committee), 49 oral presentations, as well as 152 poster presentations distributed December 8th-10th. Detailed commentary on the sessions is available via a special ASH edition of the *Myeloma Minute* on the IMF website. The following is an overview of highlights from the various sessions.

PLENARY ORAL PRESENTATION

"Combining an Allogeneic Graft-vs-Myeloma Effect with High-Dose

Autologous Stem Cell Rescue in the Treatment of Multiple Myeloma" (Abstract #1822) was presented by David G. Maloney, Firoozeh Sahebi, Keith E. Stockerl-Goldstein, et al. This study involved 32 previously treated patients who had relapsed. The "mini-allo" or non-myeloablative allogeneic transplant protocol consisted of first a typical auto stem cell transplant using high dose melphalan (200mg/m²) followed by total body irradiation and immunosuppressive therapy, along with the non-myeloablative graft of immune cells from an HLA identical sibling. The excitement is that the added graft-vs-myeloma effect resulted in 53% complete remissions plus 31% partial remissions, giving an 84% overall response rate. The caution is that 6/32 (19%) of patients have died with follow-up of about 1 year, although not all from direct transplant complications. This is less than the 30% or greater mortality possible with a full allogeneic transplant, but still substan-

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The IMF is dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

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The information presented in *Myeloma Today* is not intended to take the place of medical care or the advice of a physician. Your doctor should always be consulted regarding diagnosis and treatment.

PROGNOSTIC FACTOR IMWG MEETS AT ASH

The IMF was proud to sponsor the fourth meeting of the International Myeloma Working Group (IMWG) at the time of ASH 2001. There was participation from all of the major myeloma groups around the world. This project was initiated by the foundation at the IMF Scientific Advisors retreat in May 2000, in collaboration with Profs. Jesus San Miguel (Salamanca, Spain) and Philip Greipp (Mayo Clinic, USA). Since then, the group has met at ASH 2000 and at the 2001 Banff International Myeloma Workshop. Based on the results and further plans presented at ASH 2000, major progress has been made.

Dr. Durie (Cedars-Sinai, USA) provided an overview of the initiative to be followed by Dr. Kyle (Mayo Clinic, USA) who summarized plans for the new classification and staging system. The proposal covered MGUS, "smoldering myeloma" (name to be changed!), symptomatic myeloma, non-secretory myeloma, plasmacytomata and Waldenstrom's. There was much discussion about criteria for active or symptomatic myeloma versus MGUS or inactive/asymptomatic disease. Remarkably, a clear consensus was reached – the full details will now be brought together and written up by the working group for publication. Since all major myeloma groups have been involved,

it is hoped that for the first time ever an accepted international classification system can be introduced. This is enormously important for the evaluation of all new treatments. This project will help not just investigators, but pharmaceutical companies with drugs under development and of course patients who need clear guidance for diagnosis and treatment decisions.

Dr. Greipp, who chaired the session, asked Dr. Joan Blade (Barcelona Hospital Clinic, Spain) to present details of accepted myeloma response criteria. A report was previously published by the working party of the International Bone Marrow Transplant Registry (IBMTR) in the *British Journal of Haematology* (102: 1115-1123, 1998). It was

“Remarkably, a clear consensus was reached – the full details will now be brought together and written up by the working group for publication.”

agreed to adopt most of these recommendations with minor revisions and publish the criteria along with

the new classification system as soon as possible in 2002.

The final session dealt with the establishment of a new prognostic index using historical data from all of the collaborating myeloma centers. The data to be used for analysis was clarified and plans made to proceed with data gathering, collation and statistical analyses. This whole project is supported by an unrestricted grant from the IMF. The year 2002 should see major strides both in publishing results and in developing the new index. The working group will reconvene at the time of the Oxford Trialists meeting in Oxford, England in March 2002 and proceed from there. It was clear that all participants were extremely pleased with the progress and look forward to completing this important project, which serves as a benchmark for all future myeloma clinical trials. 🌸



IMWG participants at ASH 2001 included:

Drs. Kenneth Anderson, Bart Barlogie, Regis Bataille, Joan Blade, J.A. Child, Joth Jacobson, Meletios Dimopoulos, Brian Durie, Rafael Fonseca, Philip Greipp, Vania Hungria, Mohamad Hussein, Robert Kyle, Jesus San Miguel, Paul Richardson, Chaim Shustik, Kazuyuki Shimizu, Pieter Sonneveld, Ingemar Turesson, Keith Wheatly, and David Vesole



IMF GRANT PROGRAM CELEBRATES 8 YEARS OF RESEARCH FUNDING



IMF Scientific Advisory Board Chairman Dr. Robert A. Kyle with fellow IMF Directors Rich Saletan, Mike Katz and Don Springer

by Robert A. Kyle, M.D.

The IMF has played an important role in research support for multiple myeloma since the first Brian D. Novis Award was given in 1995. The number of awards has gradually increased and now currently funds nine new investigators annually. These awards are given to junior faculty members who we hope will develop an on-going research interest in multiple myeloma. The size of the grants is rather modest at \$40,000 per year, but this provides seed money for the investigator to obtain preliminary data which will lead to success in extramural funding.



IMF Scientific Advisor Dr. Joan Blade with Senior Research Award recipient Dr. Herve Avet-Loiseau

During the past three years the IMF has awarded senior grants in the amount of \$80,000 to \$100,000 annually. These are given to senior investigators who are already established in the field of multiple myeloma.

2002 BRIAN D. NOVIS JUNIOR GRANTS

The Brian D. Novis Junior awardees for 2002 include **Jaime O. Claudio, Ph.D.** from the Toronto General Research Institute, Toronto, Ontario, Canada. The development of microarray platforms for gene expression analysis is important in multiple myeloma. New gene discovery will be useful for the

future. Dr. Claudio and his group have developed a first generation myeloma chip containing 4,300 myeloma-enriched genes. There is a genetic heterogeneity in the genesis of multiple myeloma and in the gene expression profile. This heterogeneity may account for varied responses of patients to current treatment regimens. He is developing a more gene-focused myeloma chip that may lead to the development of a molecular diagnostic test for myeloma therapy. Thus, this study aims to design a second generation myeloma chip with a smaller but a well-defined subset of gene markers from their first generation myeloma enriched cDNA microarray. The



Dr. Amit Nathwani

results of these cDNA microarrays will be used for patient stratification, assessment of validation of therapeutic interventions, and molecular profiling of myeloma patients.

Amit C. Nathwani, MBChB, Ph.D., University College, London Medical School, London, England, will attempt to deliver the relevant genes for anti-angiogenesis rather than utilizing anti-angiogenic drugs for the treatment of multiple myeloma. He plans to use the lenti-viral system to deliver the genes. He has already transferred sFIK-1 and TiMP-3 genes in Raji cells which resulted in a marked reduction of tumor



Dr. Klaus Podar



Dr. Elliot Epner accepts the Senior Research Award from IMF President Susie Novis.

growth in SCID mice. He has developed a murine xenograft model that replicates many of the key features of multiple myeloma. He has constructed three lenti-viral vectors that encode different anti-angiogenic genes. He will eventually test the combined efficacy of cytotoxic drugs and anti-angiogenic agents.

The next project will define the novel signal pathways of c-KIT in myeloma cells by **Atanasio Pandiella, M.D., Ph.D.** at the Spanish National Research Council, Salamanca, Spain. He will infect c-KIT in multiple myeloma cell lines that have previously been shown to be unresponsive to c-KIT ligand. He will then utilize Gleevec™ since



Dr. Ivan Van Riet

it specifically inhibits c-KIT. A novel MAPK pathway, Erk5 has been implicated recently in proliferative responses. He proposes to study the role of the Erk5 pathway in the regulation of myeloma cell proliferation. He will also study the Erk1-2 and the p38 pathways to determine the relative contribution of each to the growth of myeloma cells. He plans to use both established cell lines and myeloma cells isolated from patients. Erk5 activation will be correlated with the activation status

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2002 CALENDAR OF EVENTS

January 25-26, 2002	Myeloma Conference (scientific meeting)	Bombay, INDIA
January 30, 2002	Cancer Care Teleconference: Understanding Anemia & Fatigue, Part I	*see below
February 8-10, 2002	Annual IMF Board of Directors Retreat	Pasadena, California
February 15, 2002	Semi-Annual IMF Staff Retreat	Pasadena, California
February 20, 2002	Cancer Care Teleconference: Understanding Anemia & Fatigue, Part II	*see below
March 8-9, 2002	IMF Patient & Family Seminar	Atlanta, Georgia
March 12, 2002	Cancer Care Teleconference: New Approaches to Managing Pain	*see below
March 20, 2002	Cancer Care Teleconference: Understanding Anemia & Fatigue, Part III	*see below
April 18-21, 2002	ONS Annual Meeting (Oncology Nursing Society)	Washington, D.C.
January 30, 2002	Cancer Care Teleconference: Understanding Anemia & Fatigue, Part IV	*see below
April 27-28, 2002	IMF Patient & Family Seminar	Vienna, AUSTRIA
May 11-15, 2002	IMF Scientific Advisory Board Retreat	St. John, USVI
May 18-21, 2002	ASCO Annual Meeting (American Society of Clinical Oncology)	Orlando, Florida
June 7-8, 2002	IMF Patient & Family Seminar	Washington, D.C.
July 11, 2002	IMF Fundraising Event	Ann Arbor, MI
August 9-10, 2002	IMF Patient & Family Seminar	Miami, Florida
August 16, 2002	Semi-Annual IMF Staff Retreat	Pasadena, California
September 13-15, 2002	IMF Patient & Family Seminar	Sydney, AUSTRALIA
October 5, 2002	IMF Ribbon of Hope Annual Gala	Washington, D.C.
October, 2002	IMF Support Group Leaders Retreat	Durham, NC
November 9-10, 2002	IMF Patient & Family Seminar	Seattle, WA
December 6-10, 2002	ASH Annual Meeting (American Society of Hematology)	Philadelphia, PA

For more information about IMF events, please check the IMF website at www.myeloma.org or contact the IMF at (800) 452-CURE.

*To register for a Cancer Care teleconference, please call (800) 813-4673 at least 2 weeks in advance.

ASK THE EXPERTS: Cautions About Kidney Effects of Pamidronate

Dear IMF,

I am a 42-year-old woman who was diagnosed with multiple myeloma in September 1999. I had four VAD treatments, total body radiation and additional chemotherapy and then had an allogeneic bone marrow transplant from my HLA-matched brother in January 2000.

I started Aredia treatments the day after my diagnosis and received treatments every four weeks until June 2001. I had many ups and a few downs in my first year but was feeling well when I went in for my one-year post-transplant checkup. The only thing that was worrisome was that my creatinine level was not stable – it changed every month and went as high as 1.7. My transplant doctor was not too concerned but encouraged me to continue drinking water in great quantities to try to bring down the level.

At my one-year checkup, my bone marrow biopsy showed no myeloma cells, which was great news. **Only one test from that check-up was discouraging – the 24-hour urine collection.** The protein level was measured at 5.63 – so high that my doctor thought something might have happened in the lab while processing the test. So I collected for another 24 hours and brought in the test. The results came back just as bad.

The kidney biopsy pathology report came back showing the diagnosis of “Focal and Global Glomerular Sclerosis”. According to the report: “Such changes have been described following bone marrow transplantation, though it is not certain whether so-called bone marrow transplant nephropathy is caused by radiation or chemotherapy.”

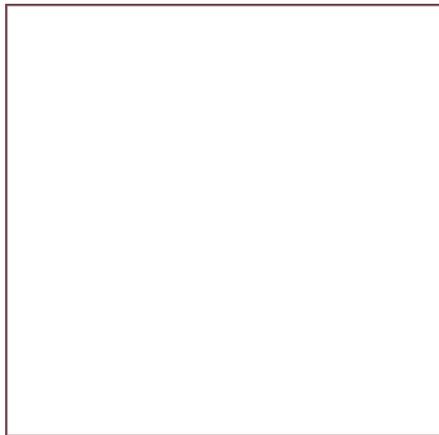
The nephrologist did not know how to treat a myeloma patient with this disease. She contacted my transplant doctor who referred her to the Medical College of Wisconsin. I was encouraged to see Dr. Eric Cohen, a nephrologist known for helping patients with kidney problems as a result of chemo and radiation.

When I saw Dr. Cohen in July, I had with me a list of questions and copies of all my tests since the transplant. Dr. Cohen said that he had a lot of reading to do to go through the paper work that I had brought, but that he had a very simple answer. That answer was “Stop Aredia”!

My doctors had told me I needed to take Aredia to strengthen my bones. To find out it had caused irreparable damage to my kidneys left me speechless. Apparently this is a new discovery. Dr. Cohen is now treating several patients that this has happened to and knows of others.

I am concerned that other patients not go through what I will be living with for the rest of my life. When I received my latest Myeloma Today, I read the article by Dr. Brian Durie and that sparked a thought. I'm hoping that by getting my story to you I can prevent other people from getting this kidney disease from Aredia.

Sincerely,
Patricia A. Smith



Eric P. Cohen, M.D.
Professor of Medicine, Division of Nephrology
Froedtert Hospital, Medical College of Wisconsin
Milwaukee, Wisconsin

by Eric P. Cohen, M.D.

A flurry of recent cases and reports have appeared in which the use of pamidronate (Aredia®) has been linked with kidney damage, high levels of urinary protein, and loss of kidney function.

There are 13 published cases, and several more that are unpublished.

Some have occurred in patients with multiple myeloma who have undergone marrow transplant. Others have occurred during use of pamidronate as protocol treatment for multiple myeloma, in non-transplanted patients. The levels of urinary protein in these cases have been high, sometimes as much as 10 grams per day. Kidney biopsies have shown a form of focal glomerulosclerosis, in some cases of the so-called collapsing variant. At least four of these patients have lost all of their kidney function and progressed to the point of needing kidney dialysis. This information raises substantial questions regarding the use of pamidronate, and its potential toxicity to the kidneys.

In patients with multiple myeloma, there can be more than one possible cause of kidney damage (See Table I). Myeloma light chains cause kidney cell damage, and can

cause light chain disease and kidney failure. Accumulation of the myeloma paraproteins can lead to amyloidosis,

which can cause kidney failure. Hypercalcemia will cause kidney damage. In addition, both testing and treatment may involve nephrotoxic agents such as radiocontrast for x-rays or cis-platinum in chemotherapy protocols. Bone marrow transplant (BMT) poses addi-

tional risks, because of its time-concentrated use of chemotherapy and its use of radiation therapy. The initial several weeks after BMT are a time of low white cell counts, risk of infection, and treatments that may be nephrotoxic. Months or even years after total body irradiation, there is a well-documented risk of kidney damage, so-called radiation nephropathy. These various risks are a veritable minefield standing between diagnosis and remission.

When kidney disease occurs after BMT, its clinical features and its timing are important in making an accurate diagnosis. For example, high amounts of urinary protein, greater than three grams per day, are in the so-called nephrotic-range, and suggest that there is substantial disease of the glomeruli, the filters of the kidneys. As an example, of the importance of timing, radiation injury is unlikely to be the culprit in the first several weeks after a BMT, but can be present six or more months afterwards. A kidney biopsy should enable an even better

“In patients with multiple myeloma, there can be more than one possible cause of kidney damage.”

diagnosis. The microscopic appearance of light chain disease is quite different from that of radiation nephropathy, for instance. In the cases of kidney disease associated with pamidronate, the kidney biopsies have shown so-called focal glomerulosclerosis (“FGS”), of the collapsing variant. There is a single case report of interstitial nephritis associated with pamidronate, but this must be considered anecdotal. The appearance of FGS is non-specific, and can be found in kidney disease associated with many causes, including severe obesity and drug abuse, but often no specific cause is found. The collapsing variant of FGS has been found in cases of kidney disease associated with AIDS, but also is often without apparent specific cause. In both FGS and its collapsing variant there are high amounts of urinary protein, but the rate of loss of kidney function is generally much faster in the collapsing variant, in which there can

be complete kidney failure within a year after diagnosis.

In the case of drugs that are associated with a complication, it is difficult to be certain that the drug is the definite cause of the complication. In the case of collapsing FGS, viral infections could be involved, and the association with pamidronate might then be fortuitous.

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IMF Research Grants – continued

of other classical MAPK pathways.

Klaus Podar, M.D., Dana-Farber Cancer Institute, Boston, Massachusetts, will continue his work on the pathophysiological relevance of VEGF (vascular endothelial growth factor) in multiple myeloma. During his 2001 Brian D. Novis Award he has demonstrated that VEGF triggers proliferation and migration by myeloma cells, proliferation by a protein kinase-C-independent pathway, and migration by a PKC-dependent pathway. He has also shown that these effects are mediated by binding of VEGF to the Flt-1 receptor which is expressed in plasma cells. He has proven that VEGF induced Erk phosphorylation is blocked by antibody to Flt-1. He has shown that stimulation by VEGF leads to Raf-1 activation in myeloma cells which may have an anti-apoptotic effect. He plans to extend his work to look at the effect of Flt-1 antibody and Raf-1 antisense on VEGF-induced proliferation and migration. He will use biological and chemical assays in a mouse model of myeloma. He will also use both myeloma cell lines and myeloma cells from patients. The actions of VEGF will be explored by looking to see if, like IL-6, it can protect against dexamethasone-induced apoptosis. VEGF is one of the most important biological mediators in the interaction of myeloma cells with the marrow stroma, and the proposed work will further advance our understanding of the biology of myeloma. It may also result in therapeutic targeting of the pathways that are involved.

Ivan Van Riet, Ph.D. was the recipient of a Brian D. Novis grant in 1999. He is a post-doctoral fellow and Director of the Stem Cell Laboratory at the Free University Brussels in Brussels, Belgium. He has utilized a mouse model, 5T2, for his work which indicated that the homing of myeloma cells comes from a combination of selective entry/adhesion of the 5T2 myeloma cells and the selective survival and

growth of these tumor cells in the bone marrow and spleen. He proved that homing to the bone marrow involves the CD44v10 molecule. He has shown that laminin-1, which is a component of the basement membrane, acts as an important chemo-attractant for myeloma cells. He has also reported that the chemokine receptor CCR2 can be demonstrated in several human myeloma cell lines. The monocyte chemotactic proteins MCP-1, 2, and 3 which are ligands for CCR-2, are produced by bone marrow stromal cells. This suggests a potential contribution of CCR-2 and MCP's to the bone marrow homing of myeloma cells. He plans to determine the function of the chemokine receptors, CCR-4, CXCR-4, and CCR-8 in the bone marrow homing of myeloma cells. He also will study the adhesion molecules VLA-4, CD44, and CD38 which are expressed by myeloma cells and their involvement in binding and migration through the bone marrow endothelium. He also plans to investigate the functional role of the metalloproteinases (MMP-2 and MMP-9) in the transendothelial migration of myeloma cells.

Michael A. Morgan, Ph.D. from Hannover Medical School, Hannover, Germany, will study the inhibition of ras signaling in multiple myeloma. Ras activation may potentiate myeloma cell growth, increase the expression of adhesion molecules, and increase the production of VEGF, MMP's, and cyclin D1. He plans to study the activation of ras and the MAP-K pathway and cell lines as well as in myeloma cells. He will compare myeloma cells with ras mutations with cells containing no ras mutations. He will also look at the therapeutic potential of the inhibition of ras signaling by looking at the effects of inhibitors on cell lines and primary myeloma cells. The expression of adhesion molecules and MMP's will be addressed. Cell viability and proliferation as well as migration and cell-cycle dependent expression will also be studied.

The IMF (Japan) awarded its first research grant to **Masahiro Abe, M.D.** of the University of Tokushima School of Medicine, Tokushima, Japan. This award was presented in memory of IMF (Japan) founder Akira Horinouchi. Dr. Abe will study the mechanism of skeletal destruction in patients with multiple myeloma. He has found that the macrophage inflammatory proteins (MIP-1a and b) are secreted by most myeloma cells. They induce osteoclast activity which leads to bone destruction. The osteoclasts also support myeloma cell growth and survival. Dr. Abe plans to investigate the possibility of the use of inhibitors of MIP-1 production or its activity. There are several MIP-1 receptor antagonists that



Midori Horinouchi presents the IMF (Japan) research award to Dr. Masahiro Abe in honor of founder Akira Horinouchi.

are currently available for study.

2002 BRIAN D. NOVIS SENIOR GRANTS

Senior research awards have been made available since 2000 when two awards were made. Two awards were also granted in 2001. The recipients of the 2002 awards are **Hervé Avet-Loiseau, M.D., Ph.D.** of the University of Nantes, Nantes, France. The other award was granted to **Elliot Epner, M.D., Ph.D.** of the University of Arizona, Tucson, Arizona.

Dr. Avet-Loiseau plans to analyze a large number of plasma cell specimens including normal, premalignant, and malignant plasma cells using DNA microarray technologies. He will attempt to define genes specifically associated with different types of normal plasma cells as well as genes associated with MGUS, and genes responsible for disease progression. He also hopes to identify genes involved in response to therapy or genes predicting patients' outcome. His ultimate goal is to develop an optimized "myeloma chip" enabling one to determine prognosis and to propose an individual patient-adapted therapeutic approach.

Dr. Epner points out that the majority of B-cell malignancies including multiple myeloma contain translocations involving the immunoglobulin heavy chain (IgH) locus. These translocations result in deregulated expression of target genes such as cyclin D1, c-maf, and FGFR3 by regulatory elements from the IgH locus located up to several hundred kilobases away. He has developed homologous recombination approaches to study the mechanisms involved in long-distance, deregulated gene expression in B-cell malignancies. He also plans to determine the functional requirement for the expression of these deregulated genes in malignant B-cells. The identification of the sequences and proteins involved in long-range deregulation will be used to develop and test new therapies for multiple myeloma. 🌸



Dr. Keith Stewart accepts the Brian D. Novis Award on behalf of Dr. Jaime Claudio from IMFer Sheila Field

A PATIENT'S EXPERIENCE: My Anniversary



Joseph Lerner, Ph.D.
Professor Emeritus
Tennessee Technological University
Cookeville, Tennessee

by Joseph Lerner, Ph.D.

I have multiple myeloma. This past October, I celebrated my 15th year since diagnosis. Had I not ruminated about waging a war of chemotherapy and dying, I might have spent a lot of time doing other things since 1986. During the first ten years following diagnosis no harsh chemicals were used to fight the dragon. Instead, I went from test to test, watching, waiting and worrying about when it would attack. I even did a frenzied search of the medical literature to find answers to the best treatment protocol. Then in the tenth year, completely out of my control, the disease changed for the worse, and I was forced to beat back the monster by undergoing tandem stem cell transplants.

During my pre-transplant period (1986-1996) I had some anemia which was not treated, some lumbar back pain, two collapsed vertebrae, and a moderate, but rising, myeloma protein level; ultimately, I had to be treated with pulsed Decadron. During this time I had significant anxiety that responded to Valium; but this treatment enhanced my depression which remained untreated. Furthermore, I was susceptible to respiratory infections due to a lack of normal background immunoglobulins and was treated with antibiotics for such episodes. Moreover, I made a fruitless attempt to control my emotions. My reading of the myeloma literature was obsessive; and I played a game with my oncologist by following the blow-by-blow reports of the myeloma protein "numbers" while I ruminated over my symptoms. I thought each and every pain I had was associated with the disease. I even checked the color of my fingernails and my cheeks to see if they were still pink.

During this period of my life, I worked

full time in a pressure-cooker, lawsuit-ridden, stressful job as a liberal arts college dean at a state university. I resigned this position as myeloma began to attack and returned to my tenured position as a full-time professor of chemistry, a job that regrettably included working in the laboratory with chemicals that might fuel the disease. I took for granted my relationships with significant others. And I continued to attend social events despite my vulnerability to infections. Among my activities, I listened to classical music, read periodicals and some tedious non-fiction books, all in a perfunctory manner. The affliction colored my view of the world.

The transplant period (1996-1997) beckoned a time to begin to smell the roses. I underwent two stem cell transplantations, a half-year apart, followed by radiation treatments to my lumbar spine. Subsequently, I spent two weeks in a psychiatric ward where I began my treatment for depression; this involved solo and group counseling sessions – a total immersion process. The post-transplant period (1997-present) was, and continues to be, a time of further personal transformation, and a time of improvement of my general physical condition, including pain management. I have been fortunate in having a low and relatively stable myeloma protein level. Hence, I have been off chemotherapy since having the transplants. I was prescribed maintenance –interferon, but could not take this medication due to severe side effects. Over this period, I have been successful at diverting negative thoughts, at finding consolation in daily prayer, and in striving to make every day a joy. Working with my oncologist, I have been able to reduce the symptoms of myeloma. For example, I have moderate anemia that has been treated with Epoprostenol. This protein has been quite effective in restoring my energy level and in giving me a sense of well-being. My depression has been treated successfully with Paxil and Zyprexa along with maintenance psychiatric help. My internist has prescribed Claritin D and Nasacort nasal spray which appear to reduce my susceptibility to sinus infections. In this regard, I have avoided large social occasions and instead enjoy socializing with a few friends. I use antibacterial hand wipes when I go out to eat and use waterless hand sanitizer after opening doors.

My oncologist has treated my moderate back pain with MS Contin and Roxanol. Aredia treatments once a month have been taken to slow or stop the development of osseous lesions and potentially to reduce pain. I have taken advantage of a procedure to correct damaged vertebrae by rebuilding them with plastic cement (vertebroplasty). Since

the transplants I have suffered from a dry mouth. I have treated this nuisance by using Biotene Oral Balance mouth moisturizing gel (saliva substitute) and Biotene toothpaste, by chewing sugarless gum, and by drinking diet soda.

Since 1997, I have come to thoroughly enjoy reading both fiction and nonfiction books. In the last two years alone, I have read 81 books. This exhilaration in reading has led me to establish a home library of books. I have found great fun in identifying sources of books from the *New York Times Book Review*, from browsing in bookstores, from researching sources on the web such as sites of Nobel Prize winners and Pulitzer Prize winners in literature; as well as from visiting websites of booksellers. Furthermore, I have stopped reading and collecting massive amounts of articles from the myeloma literature – they only reinforce obsessive feelings about my disease. The one exception is that I read *Myeloma Today* to keep current.

Recently, I have greatly expanded my holdings of classical music on CDs. Thus, I enjoy listening to music while I read in the evenings and on weekends. After my transplants I refrained from asking my oncologist what the "numbers" were on my monthly blood tests. I find it hard to believe now that at one time I plotted my paraprotein levels on a graph! Several years ago I resigned my tenured position as a full-time professor, but retained my university office where I come each day to read, study, and to listen to classical music and FM Public Radio. Now I enjoy myself in teaching one course in organic chemistry each term and spending more time with my wife, family and friends. But I do not harp to them about my disease and its symptoms as I once did – I keep all of my aches and pains to myself and my oncologist.

When a person has myeloma, I believe, he or she needs to maintain in so far as possible a normal life routine. For me at least, this routine involves enjoying teaching, reading, listening to music, and in having significant others close at hand or on the phone. If you cannot get out of the home often because of your myeloma, you still can invite friends and family to join you. And you can order CDs and books on the web. An inexpensive computer can keep you connected, for a small monthly fee, to the web and other internet services such as e-mail.

I would like to close by saying that there is no substitute for having a competent, compassionate medical team that looks after your mental and physical well-being – a team in whom you can have the upmost confidence. With this armamentarium, I have been more able to fight the dragon. 🐉

IMF RIBBON OF HOPE – MAKING A WORLD OF DIFFERENCE



Guest of honor Michael S. Katz with wife Susan and sons Jonathan, Jason and Jeffrey.

by The Unknown Patient

When the Unknown Patient read the list of honorees for the IMF *Ribbon of Hope – Making a World of Difference* Cirque de la Vie gala, he knew he had to brave the post-9/11 airport chaos and get himself and his unknown tuxedo out to Los Angeles. The honorees at this year's gala have truly made a difference in the battle against myeloma and the gala was a wonderful opportunity to thank them.

Once safe and comfortable in his very nice hotel room in Los Angeles, the Unknown Patient went down to check on the preparations for the IMF gala. A quick walkabout confirmed the diligence of auction chair Carol Klein and her dedicated volunteers, working to showcase the items so generously donated to benefit the IMF and its good works. Dinner chairs Sheila Field and Ruth Gilliam were seen tending to the myriad of last minute details, trying to maintain calm as chaos threatened. It was really gratifying to see the many volunteers working so hard to make the gala very special.



Courage Award recipient Rudolf Brutoco with family and friends, including IMF Director Mike Bell.

The Unknown Patient was pleased to see Carol Troup with good friend Robin Leach, the evening's emcee. Robin graciously donated his services at last year's gala and again this year. Carol's husband Brian lost his battle with myeloma last fall. Carol and Robin remain committed to the battle against myeloma and we are most grateful for their continued dedication and support.

Dinner honorees and other speakers began to stream in for their rehearsal, which proved more dramatic than planned when Unknown glitches in the audio system

threatened to blow out their eardrums and the teleprompter crew was missing in action, having gone to another hotel with the same name some sixty miles away. After some fits and starts, things got back on track and the Unknown Patient decided to sneak off for some quiet time before the big night.

After napping, the Unknown Patient and spouse helped each other into their formal duds and went up to the VIP reception. Catching a glimpse via an ornate mirror, the Unknown

Patient was glad to see Mike Katz with his lovely wife Susan and their three now very grown up sons, Jason, Jeffrey and Jonathan. The Unknown Patient feels a strong kinship with Mike, owing to their strikingly similar situations and their dedication to helping the IMF and their fellow patients. Mike has worked as a volunteer for the IMF for over eight years, having gotten involved at the

same time as the Unknown Patient. Working the room, Mike and the Unknown Patient spoke with Mary Lou and Clyde Porter, thanking them for their good work with the Los Angeles Support Group and the *Circle of Friends*, which has funded a number of research grants over the past few years. Mike and his Unknown alter-ego also got a chance to thank dinner chairs Sheila Field and Ruth Gilliam, both a bit tired but looking absolutely fabulous in their evening gowns, tastefully accessorized. Then came a few words, delivered by IMF President Susie Novis and Chairman Brian Durie. This was followed by a surprise presentation by Stephanie Colman of the IMF – an award on behalf of the Philadelphia support group to honoree Mike Katz. The group soon got back to the serious business of consuming beverages, snacking, catching up with old friends and meeting new ones. Chatting up a storm, Mike and the Unknown Patient



Robin Leach with Quality of Life Award recipient William Pearson and IMF supporters from Ortho Biotech.

seemed inseparable until it was time to go downstairs for the silent auction.

While buzzing from table to table, depositing bids here and there, the Unknown Patient was very pleased to meet two scientists from Millennium Pharmaceuticals, Julian Adams and Michael Kauffman – the brains behind PS-341, the new proteasome inhibitor in clinical trials as a promising new treatment for myeloma. While the role of PS-341 remains Unknown, the early results are very exciting and the Unknown Patient has high hopes that this new drug will be a great leap forward. The Unknown Patient thanked the dynamic duo for their good work and wished them well as they work towards approval of this new treatment.

The dinner brought with it an array of speakers, including Dinner co-chair Sheila Field. Sheila shared some of her experience as a patient with the group and

CONFERENCE GALA: A CELEBRATION FOR THE CURE!



Ribbon of Hope Award recipient James Bianco with myeloma survivor Andre Boyce, IMF Scientific Advisor James Berenson, colleagues from Cell Therapeutics Inc., family and friends.

introduced a number of the awardees. This year's *Courage Award* went to Dr. Rudolf Brutoco, who founded the LifeSaver Foundation, now part of the National Marrow Donor Program. Some years ago, Dr. Brutoco's wife had been diagnosed with an aggressive form of leukemia that required a bone marrow transplant. Finding herself without a suitable sibling donor, Rudy stepped up to found an organization dedicated to finding bone marrow donors and matching them up with people who needed transplants.

Ribbon of Hope Awards were presented to Dr. James Bianco, CEO of Cell Therapeutics, and Drs. Julian Adams and Michael Kauffman of Millennium Pharmaceuticals. Dr. Bianco is conducting trials of the drug Trisenox (arsenic trioxide) as a new treatment for myeloma. Drs. Adams and Kauffman are working on PS-341 proteasome inhibitor. The Unknown Patient is truly encouraged by the work of these talented and dedicated scientists to bring new drugs to market for myeloma patients. With each new drug comes the promise of more options and a better, longer, life.



Ribbon of Hope Award recipients Michael Kaufman, Julian Adams at the Millennium Pharmaceuticals table.

The Quality of Life Award went to William Pearson, of Ortho Biotech. Bill has had a lead role in marketing Procrit®, a drug which has made an incredible difference for so many myeloma patients, helping to restore normal blood counts and make it possible to battle the fatigue that often comes with active disease and/or treatment and to regain the energy it takes to live the

good life. We salute Bill and Ortho Biotech for their efforts and thank them on behalf of myeloma patients around the world.

The evenings last award went to the guest of honor, Mike Katz, who was introduced by a sincerely appreciative Susie Novis, who recounted a long list of Mike's accomplishments on behalf of the IMF and myeloma patients all over the globe. Mike's remarks suggested that he had gotten more than he'd given, thanking IMF founders Susie Novis, Brian Novis and Brian Durie for their wonderful contributions and sacrifices.

Dinner, a lively auction led by the effervescent and indefatigable Robin Leach, and entertainment befitting the evening's "Cirque de la vie" (Circus of Life) theme led into leisurely post-gala musings with old and new friends. And, before the Unknown Patient could catch his breath, it was time to hustle back to the room and pack for the early morning flight back home.

Good friends old and new. Dinner and dancing. Lots of money raised to support the IMF. All in all, a good weekend for the Unknown Patient and the IMFers who joined

him. Bravo to all of the honorees, to our generous donors, our hard working volunteers and the dedicated staff who made this all possible. And, a special thank you to the Unknown Spouse for being courageous enough to make the cross country trek in these difficult times. 🍷



Eddie, Sheila and Trudy Field with Mary Lou and Clyde Porter



There was no stopping Ronnie Abrams at the gala's live auction!



Esther and Herman Adler take a spin on the dance floor



THANK YOU IMFERS!

by Suzanne Battaglia

It's hard to believe that this year's *Ribbon of Hope-Making a World of Difference* 11th Anniversary Gala has come and gone! Just like Thanksgiving and Christmas, all that cooking and the meal is consumed in a flash. The good news is that the event raised close to \$400,000!

The evening began with a wonderful Silent Auction and reception, with over 76 exciting packages being bid on by the guests in attendance. They also enjoyed the amazing sleight of hand by Magic Castle magician George Tovar and had pictures taken with the cirque performers on hand to greet and entertain them. During dinner, awards were presented to William C. Pearson of Ortho Biotech, James A. Bianco of Cell Therapeutics, Inc., Julian Adams and Michael Kauffman of Millennium Pharmaceuticals, Inc., Rudolf L. Brutoco and Michael S. Katz.

A big IMF thank you goes to Master of Ceremonies and Guest Auctioneer Extraordinaire Robin Leach, who once again donated his time to making the evening the success it was. Members of the Los Angeles Support Group made up the bulk of the Dinner Committee and contributed greatly to helping the IMF obtain auction items, as well as selling dinner tickets and ads for the Tribute Journal. Many other IMFers from around the globe contributed to the success of the Gala, even if they themselves were not able to attend. Of course, we couldn't have done it without Dinner Chairs Sheila Field and Ruth Gilliam, and Auction Chair Carol Klein (who has agreed to chair next year's Gala!).

Next year's *Ribbon of Hope-Making a World of Difference* Gala is scheduled to be held in Washington, D.C. on October 5, 2002, so mark your calendars. If you would like to be involved in the planning of this event, please get in touch. I am especially looking for people local to the Washington, D.C. area to serve on the committees.

To expand our outreach potential, I am also interested in talking to IMFers about hosting smaller, regional fundraisers (e.g. a catered cocktail reception or buffet in your home; a party at a local attraction, nightclub or comedy club). I'd love to learn about your communities and tell you more about the support the IMF can provide for such events.

Let's put our heads together so that the IMF can help more patients, fund more research, and continue to raise awareness about myeloma. It is only through reaching out to one another that we can achieve our goals. Please call me at (800) 452-2873 or contact me via email SBattaglia@myeloma.org. I look forward to hearing from you. 🌸



Michael Katz with IMF President Susie Novis

"At age 37, being diagnosed with myeloma was the scariest thing that ever happened to me. Worst of all, though, was the loneliness. With all due respect to the medical profession, newly-diagnosed patients need much more than a bone marrow biopsy, a couple of bottles of pills and an IV drip. When I found the IMF, it made all of the difference. It saved my life. Volunteering for the IMF has been a ray of light for me. It has made this nightmare we call myeloma somehow more tolerable. I'm proud to have helped in our efforts to fund groundbreaking research, to bring promising young scientists into the field, to bring us closer to the day when myeloma will stop killing good people."

Michael S. Katz
Gala Honoree

"This award has a very special meaning for me and for my company, Ortho Biotech. Quality of Life is an issue on which we share such strong common ground with the IMF. Like the foundation, we understand the importance of driving the science and never wavering in the commitment to find new treatments for cancer. We fully understand and support education as one of the most powerful tools patients can use in their quest to live longer and better lives. We're excited about the success of the IMF and the number of patients who have benefited from your efforts. We respect you for your relentless commitment to helping patients live better lives. We look forward to continuing to partner with you toward this goal."

William C. Pearson
Quality of Life Award



William Pearson with Master of Ceremonies Robin Leach



Rudolf and Diana Brutoco

"Giving, helping others, being involved in the community – it's something we all learned growing up in our house. We all need others in our own times of crisis – and if there is anyone there when we need them, then we sure better be there now for someone else. Helping is contagious, and it is always the Season for Giving. The IMF is there now, and your support of the IMF is one way – one excellent way – to keep goodness circulating in our world. There is untapped power in all of us – when it is employed, it just might be what others call COURAGE."

Rudolf L. Brutoco, M.D., M.P.H.
Courage Award



Ribbon of Hope recipient James Bianco with myeloma survivor Andre Boyce

“When it comes to treating cancer, everyone at CTI knows there is not a life or a moment to lose. CTI is committed to making a measurable difference in the lives of patients with cancer. Thank you for recognizing our accomplishments. And, congratulations to the IMF for providing research support and education to myeloma patients for the past 11 years. We are privileged to be associated with such a dedicated organization.”
 James A. Bianco, M.D.
 Ribbon of Hope Award



Carol and Benson Klein



Julian Adams

“We are committed to oncology research and to providing cancer patients with much-needed treatment options as they fight multiple myeloma and other challenging malignancies.”
 Julian Adams, Ph.D.
 Ribbon of Hope Award

“One of the reasons I left medical practice to join the biopharmaceutical industry was to work with promising new drug candidates and to bring them to patients with serious diseases quickly and safely. The encouragement, recognition and support provided by organizations like the IMF reinforces that commitment. Thank you.”
 Michael Kauffman, M.D., Ph.D.
 Ribbon of Hope Award



Michael Kauffman



Robin Leach with Mary McGovern of Ortho Biotech

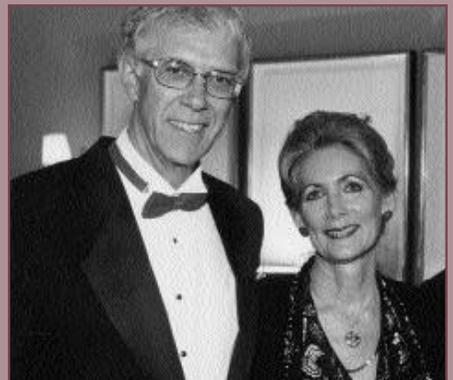


Sheila Field addresses the gala guests

“Like many of my fellow myeloma patients, I have another life. It is not quite so glamorous as this evening. In my other life, I play a lab rat. Medical treatments, and particularly those used for cancer, must be tested in humans. There are potential risks and side effects. Some in our audience, like myself, are the clinical trial patients who are currently taking these risks because the rewards are the breakthroughs that offer life saving treatments for thousands of people.”
 Sheila Field
 Dinner Co-Chair



Janet and Art Johnson and family



Lyman and Nancy Ostlund

ASH 2001 – continued

tial and very high compared to the typical very low risk (1% to 5%) of mortality from standard autotransplant.

Nonetheless, this is an important step forward in trying to develop a safer technique to achieve the clearly important graft-vs-myeloma benefit. Further refinements and studies will be required.

ORAL SESSIONS HIGHLIGHTS

The oral sessions on Monday covered numerous “pre-clinical” or laboratory based projects. Time will tell if useful therapies can emerge. A whole session dealt with genetic profiling via gene array technology and/or standard genetics or FISH. Besides chromosome 13, chromosomes 22 and 1 emerged as being prognostically important. It will take some time to assess if the molecular profiles will help in treatment decisions and/or patient outcomes. Expression patterns of genes were correlated with good and poor prognosis. The critical question is if new useful treatment targets can be identified and used to patient advantage.

The greatest excitement concerned the trials with proteasome inhibitor PS-341 (Millennium) and the new thalidomide analog, Revimid® (Celgene). Results from the first 54 patients entered into the phase II PS-341 study for relapsing/refractory myeloma were presented. Half of the patients responded by SWOG criteria with an additional 35% of patients showing evidence of benefit in this multi-institutional study.

Patient examples from St. Vincent’s Cancer Center in New York (Dr. Sundar Jagannath, Principal Investigator) were presented to illustrate dramatic benefit in patients who had received multiple prior therapies. One patient responded after 14 prior treatments. Some worsening of pre-existing neuropathy was a toxicity concern. Since the full 200 patients are still under review and follow-up is short, additional details of efficacy and toxicity will be forthcoming in 2002. The correlation between molecular profiles and response will be awaited with particular interest, as will details of remission duration.

The Revimid® (a.k.a., IMid) results were presented from both Dana-Farber and Little Rock. The numbers of patients in these Phase I evaluations were rather small (Boston, 26 patients; Little Rock 15 patients). Although responses occurred in a majority of patients, the impact of therapy was hard to assess from the data presented. Importantly, there was no neuropathy, but unfortunately there was unexpected toxicity most notably

neutropenia, which appeared to be cumulative at the 25mg and especially the 50mg/day doses. Further studies are required and planned. The full potential for Revimid® was

less clear than for the PS-341. Obviously this was the Phase I stage for Revimid® versus Phase II for PS-341. The availability of an oral agent, such as Revimid®, with the efficacy of thalidomide, but lacking the neurotoxicity is widely anticipated. Details about availability of PS-341 and Revimid® will be posted on the IMF website’s *Myeloma Minute* and the new clinical trials matrix. Currently several corporate and investigator initiated protocols are planned. For 2002, both agents will only be available through Phase II/III clinical trials. Millennium is planning a “compassionate use” protocol (#040), which should make PS-341 available for myeloma patients in need of therapy. As of now, the Revimid® will only be available as part of randomized clinical trials (i.e., less accessible to patients who may specifically need Revimid®). Hopefully, additional studies, for example evaluating the best dose of Revimid®, will make the drug more available for patients.

THALIDOMIDE

Besides the very large number of abstracts on molecular and genetic topics, one of the most popular topics was thalidomide. Twelve posters (#681-692) dealt with thalidomide. The Little Rock Group (#681) again emphasized the caution of potential deep vein thrombosis (thrombophlebitis) in patients receiving the combination of thalidomide plus adriamycin. This type of blood clotting was not life threatening and proved treatable and potentially preventable with anticoagulant therapy. The majority of abstracts dealt with issues related to the dose and scheduling in both monotherapy and combination approaches. The consensus from several posters was that a median effective dose in monotherapy was 200 mg/day. Some patients (~30%) require less (e.g., 50mg/day; #688) and most patients cannot tolerate and do not need more (#684). In combination with pulsed dexamethasone, thalidomide is very effective both as frontline therapy and at relapse. Again, 200mg/day or less is the most frequent dosing discussed or presented.

PREDICTORS RELATED TO TRANSPLANT

As the role of high dose therapy with stem cell transplant is evaluated in detail, there is increasing interest about prognostic factors in this setting. Abstracts #698 and #700 dealt with outcome and predictors in patients treated with high dose therapy and

transplant. Age less than 55 and good pre-treatment performance status (#698) predicted good outcome. When outcome was assessed by adding up the total periods of remission achieved by a patient (#700, a new term called period of “discontinuous remission”) the best predictors were serum β_2 micro globulin level and serum albumin as per a recent SWOG analysis of overall outcome.

ASH 2001 was a very productive and informative meeting for those interested in myeloma. 2002 promises to be a banner year for new understanding and therapeutic advances. 🐾

ASH 2001 IMF RECEPTION & DINNER

The IMF wishes to thank its Directors and Scientific Advisors for their invaluable participation at the ASH 2001 IMF events and their hard work and dedication on behalf of the foundation and the myeloma community year round.

Dr. Raymond Alexanian
Dr. Kenneth Anderson
Dr. Bart Barlogie
Dr. Regis Bataille
Dr. James Berenson
Dr. Daniel Bergsagel
Dr. William Bensinger
Dr. Joan Blade
Dr. J.A. Child
Dr. Meletios Dimopoulos
Dr. Brian G.M. Durie
Spencer Howard
Dr. Vania Hungria
Eric Low
Susie Novis
Pam Jones
Mike Katz
Dr. Robert Kyle
Dr. Jayesh Mehta
Dr. Gareth Morgan
Dr. Angelina Rodriguez-Morales
Chuck Newman
Dr. Amara Nouel
Dr. Martin Oken
Lisa Paik
Dr. David Roodman
Rich Saletan
Dr. Jesus San Miguel
Mike Scott
Dr. Seema Singhal
Dr. Brian Van Ness

Ask the Experts - continued

TABLE I: Kidney damage in multiple myeloma

FROM MYELOMA PROTEINS

- light chain neuropathy
- myeloma kidney
- amyloidosis

FROM HYPERCALCEMIA

RELATED TO TREATMENT

- chemotherapy-related
- after bone marrow transplant
- bisphosphonate-related

Stopping the drug, in this case stopping pamidronate, may result in improvement, that is, reduction of urine protein or even improvement in the kidney function. Such an evolution helps to confirm the relationship of pamidronate to collapsing FGS, and such an evolution has been seen. There appears to be a dose-response relationship, as well. That is, when pamidronate is given more frequently than once a week, the complication of proteinuria is much more common. Higher doses, for instance 180 or 360 mg monthly, appear to be more likely to cause kidney damage than the more standard dose of 90 mg monthly. In addition, the newer bisphosphonate, zoledronate (Zometa®), has been associated with proteinuria and kidney damage in 10 to 15% of subjects that receive it. These facts do tend to confirm the association of pamidronate with collapsing FGS.

Treatment for this problem should include stopping pamidronate. In addition, measures directed at treatment of hypertension and proteinuria should be used, including dietary salt restriction, use of diuretics, and use of angiotensin converting enzyme inhibitors or angiotensin II blockers. Use of prednisone does not appear to be helpful. Substitution of zoledronate would probably cause the same type of kidney damage, and should not be used. ❧

Editor's Note: The following comments in response to Prof. Cohen's article were made available by IMF Scientific Advisor Prof. Brian G.M. Durie.

As a nephrologist, Prof. Cohen focuses on the exact kidney pathology and possible causes of "collapsing focal glomerulosclerosis" (FCS) associated with pamidronate. As a hematologist/oncologist, I would like to expand upon several points:

- Serious kidney damage with pamidronate is fortunately very rare. Perhaps 20 reported patients with serious problems out of many thousand patient-years of treatment, is indeed a low rate of occurrence.
- Besides the potential risk factors for serious kidney damage identified by Prof. Cohen (See Table I), one needs to emphasize three important aspects.
 1. Most patients have had either:
 - Exposure to other nephrotoxic drugs/agents and/or
 - More than the recommended 90mg/month dosage (e.g., higher dose and/or more frequent administration) and/or
 - Shorter than recommended infusion time (less than 2-4 hours)
 2. With long-term use (such as > 3-5 years), especially with the above risk factors, there can be some effect on kidney function.
 3. Therefore, close monitoring and follow-up are recommended to avoid problems. Periodic urine protein measurement is strongly recommended for all patients in addition to the routine chemistry panel analysis with serum creatinine measurement before each treatment. With these procedures in place, I have detected small increases in serum creatinine and/or increases in urine protein in occasional patients (albumin, not Bence Jones or myeloma light chains), which have reversed to baseline upon stopping pamidronate or with adjustment in pamidronate dosage and/or scheduling.

Hopefully, with close monitoring, any risk of serious kidney damage with pamidronate can become a thing of the past. Awareness is the most important tool for prevention. If patients or caregivers have any questions about this, please get in touch with the IMF. ❧

PRESIDENT BUSH ANNOUNCES NEW NCI DIRECTOR

President Bush has announced the appointment of Andrew C. von Eschenbach, M.D. as the Director of the National Cancer Institute (NCI), one of the 27 Institutes and Centers comprising the National Institutes of Health. Dr. von Eschenbach has served as a former Executive Vice President of the University of Texas M. D. Anderson Cancer Center and as an officer of the American Cancer Society. Dr. von Eschenbach is a cancer survivor. ❧

ADVOCACY UPDATE

CONGRESS PUTS RESEARCH PRESSURE ON AGENCIES TO RAISE MYELOMA AWARENESS

Rep. Nancy Pelosi's (D-CA) efforts to engage the Centers for Disease Control and Prevention (CDC) in multiple myeloma public awareness and education highlighted this year's reports to the House and Senate funding bills for cancer research programs. Rep. Pelosi and Sen. Kay Bailey Hutchison (R-TX) provided leadership to include a variety of provisions on multiple myeloma research to the National Cancer Institute (NCI), CDC, as well as other federal research agencies in the House and Senate Labor, Health and Human Services, and Education appropriations bill reports.

Other important provisions of the bills include \$23.7 billion to fulfill the fourth year of a 5-year congressional pledge to double funding for the National Institutes of Health (NIH). This was a high priority of the *One Voice Against Cancer* Coalition and Sen. Tom Harkin (D-IA) and Sen. Arlen Specter (R-PA).

Final action to reconcile the bills (H.R. 3061 and S. 1536) for the president's approval is expected to take place prior to the Thanksgiving congressional recess.

Both reports (H. Rept. 107-229 and S. Rept. 107-84) reflect Congress's heightened awareness about myeloma and other deadly forms of cancer by asking CDC "to plan and implement public awareness programs for orphan cancers for patients and physicians. Such cancers include esophageal, kidney, liver, multiple myeloma, pancreatic and stomach. Patients diagnosed with these cancers have the lowest life expectancy rates of all diagnosed cancers, yet community oncologists generally lack specific knowledge about these malignancies."

Additionally, both reports continue to press NCI for substantive results from the recently completed Leukemia, Lymphoma, and Myeloma Progress Review Group, including a report with a budget to be completed by next spring's fiscal year 2003 hearings. Both reports also request CDC to create better data-gathering processes to better aid diagnosis and treatment of myeloma and other deadly cancers.

In a departure from previous years, the House report also request specific collaboration between NCI, the National Heart, Lung, and Blood Institute, the National Institute of Arthritis and Musculoskeletal and Skin Diseases, and the National Institute of Environmental Health Sciences on myeloma research issues. These include bone disease involvement, the development of technologies for better monitoring, anti-angiogenesis research, and to put emphasis on translational research to speed up the lag time between discoveries in the lab and pharmaceutical drug development.

The full texts of the provisions relevant to the myeloma community will be posted on the IMF website. ❧

News & Notes



Richard and Suzanne Saletan

IMF WELCOMES NEW DIRECTOR

The IMF is pleased to announce that Richard H. Saletan has joined its Board of Directors. Mr. Saletan brings with him over 35 years of experience in business management, strategic planning, marketing, relationship marketing, digital commerce, and consumer promotion.

NATIONAL CANCER INSTITUTE SEEKS NOMINATIONS FOR THE NCI DIRECTOR'S CONSUMER LIAISON GROUP

The National Cancer Institute (NCI), the federal government's primary agency for cancer research, is seeking nominations for five new members of the NCI Director's Consumer Liaison Group (DCLG) who will be appointed in July 2001. The DCLG helps NCI to identify appropriate advocates to serve on its program and policy advisory committees, and it serves as a channel for consumer advocates to voice their views and concerns. The DCLG is a federal chartered advisory committee of the NCI. It consists of 15 consumer advocates who are involved in cancer advocacy and who reflect the diversity among those whose lives are affected by cancer. NCI brings together these advocates from many communities to advise and make recommendations to the Institute Director from the consumer advocate perspective on a wide variety of issues, programs and research priorities. NCI encourages nomination of candidates reflecting the diversity sought on the DCLG. Nominations can be made by organizations or individuals, including self-nominations. To receive a nomination package for the DCLG, send your name, advocacy/voluntary organization affiliation (if any), address and phone number to: *Liaison Activities, NCI, c/o Palladian Partners, 1010 Wayne Avenue, Suite 1200, Silver Spring, MD 20910, Fax (301) 650-8676. Nominations must be postmarked by February 1, 2002.*

SAESG MEETS AT ASH 2001

The South American Epidemiology Study Group met at ASH 2001 to discuss plans to study the incidence and molecular genetics of myeloma in South America. The initiative, sponsored by the IMF, is led by Dr. Vania Hungria of Brazil with coordinating support by Dr. Jesus San Miguel of Spain for all Spanish speaking countries. Participating countries for the initial project are Brazil, Argentina, Venezuela, Chile, and Peru, with the intent to expand to include Mexico and Central American and other countries such as Spain and Portugal. From the initial data sets it will be possible to construct analytic and comparative studies linked to target genetic polymorphisms linked to myeloma susceptibility. Dr. Gareth Morgan of the U.K. will perform the genetic polymorphism studies.



IMF President Susie Novis with SAESG members Drs. Hungria, Nouel and Rodriguez-Morales

NMDP PUBLISHES DIRECTORY

The National Marrow Donor Program (NMDP) has published the 2001-2002 *Transplant Center Access Directory*. The directory is a resource for patients who are seeking to undergo an allogeneic transplant but do not have a matching donor in their family. The NMDP registry matches volunteer donors with patients who need transplants. However, in order to receive a transplant from an NMDP donor, patients must be treated at a transplant centers in the NMDP network. To request a free-of-charge copy of the *Transplant Center Access Directory*, please call (888) 999-6743. The directory can also be found at www.marow.org.

CLINICAL TRIALS GLOSSARY

Steve Dunn, a cancer patient from Colorado, has compiled a web glossary of words and phrases used in clinical trials databases and medical journals. Check it out at http://cancerguide.org/trials_glossary.html.

IMF SCIENTIFIC ADVISOR RETREAT

Plans are underway for the second IMF Scientific Advisors Retreat, to be held in May on St. John, USVI. The intent this year is to explore the impact of new technologies and novel therapies for myeloma management. The hope is to establish basic treatment algorithms based upon consensus input from the advisors and proceed from there to integrate new strategies for primary and supportive care, as appropriate at different disease stages. The IMF looks forward to another exciting and productive retreat.

2001 MAJOR MYELOMA BREAKTHROUGHS

The IMF has conducted a worldwide poll of myeloma experts, asking them to identify the 2001 studies and research findings which they deemed most important to the field of multiple myeloma. The results will be featured in the next issue of *Myeloma Today*.

SIGN UP FOR IMF E-MAIL UPDATES

To receive weekly e-mails from the IMF with important information and updates of interest to the myeloma community, send an e-mail to scolman@myeloma.org with "E-mail Update" as the subject and your e-mail address as the only text in the body of the email.

STAMFORD IMF PATIENT & FAMILY SEMINAR

The IMF returned to the East Coast with its most recent Patient & Family Seminar, held in Stamford, CT. At the Friday night reception, IMF President Susie Novis was pleased to welcome Norm & Ruth Halford into the Donor Circle. The Saturday meeting featured a cutting edge PS-341 presentation by Drs. Sundar Jagannath and Paul Richardson. We hope to see you at the next seminar – see *page 4* to learn when we are coming to your area!



Norm and Ruth Halford with IMF President Susie Novis

COPING RESOURCES

We Can Cope: When A Parent Has Cancer

A cancer diagnosis affects more than an individual. When the person with cancer is a parent of young children, an entire family must learn to cope.

We Can Cope: When A Parent Has Cancer, a video-based intervention program, shares with you stories of seven families and the approaches they used in coping with a parent's cancer. The program includes:

- **Guidebook** – Discusses how to use the program with your family and answers questions that parents frequently have about helping children cope with a parent's cancer.
- **Parent Video Tape** – The parents from seven families share practical strategies for helping children adjust.
- **Teen Video Tape** – A group of teenagers discuss their parents' cancer and how they coped, learned, and grew from facing the challenge.
- **Child Video Tape** – Children discuss their feelings and reactions about having a parent with cancer.

The program is hosted by Wendy S. Harpham, M.D., a mother, a physician, and a long term cancer survivor. Dr. Harpham provides clear and easy to follow advice on how to face the challenges of being a parent while fighting an illness like cancer.

If you have been diagnosed with cancer within the last five years and have at least one child between the ages of 6 and 18 years of age, you may be eligible to participate in the research project that is testing the effectiveness of this video education and support program.

The project is supported by a grant from the National Cancer Institute (NCI PDQ #NCI-V01-1659) and offers a modest stipend for participation. Participants will be asked to complete a short interview and answer some questions about your family's reaction to your illness. You may be asked to watch a video program and decide whether you want your child(ren) to view the program as well. Children are not required to watch the videos in order for you to participate. For more information regarding the study, please contact Sharon Meiri, Project Coordinator, at (800) 848-3895 ext. 226 or by email at smeiri@inflexxion.com.

Look Good... Feel Better

In the fight against cancer, everything counts – mind and body, appearance and self-confidence. *Look Good... Feel Better* is a free, national public service program to help women undergoing cancer treatment learn to cope with the appearance-related side effects and regain a sense of self-confidence and control over their lives. These side effects may include hair loss, changes in complexion and fingernails, and are often emotionally and psychologically traumatizing.

In *Look Good... Feel Better* sessions, volunteer cosmetologists (all certified professionals) teach women how to enhance their appearance. The program is product-neutral (no specific brand or manufacturer is recommended or endorsed) and makes no medical claims. Complimentary cosmetics and skin care products donated by the cosmetic industry are made available for use during the program and later at home.

Look Good... Feel Better has been providing information, education and support to women with cancer since 1989. To learn more, call (800) 395-LOOK. Bilingual programs are available in some areas. 🐾

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IMF PRESENTS: A PHYSICIAN'S REFERENCE



Drs. Robert A. Kyle, Brian G.M. Durie, Seema Singhal, William I. Bensinger, and G. David Roodman during the filming of "Multiple Myeloma: A Physician's Reference"

Much has changed in the approach to treatment for patients with multiple myeloma in the past decade. Produced by the IMF, *Multiple Myeloma: A Physician's Reference* is a multimedia tool designed to assist the medical community in the diagnosis, treatment, and management of patients with myeloma. Delivered via the web and CD-ROM, *Multiple Myeloma: A Physician's Reference* provides a fresh look at diagnostic criteria, new treatment options, and the best

new supportive-care strategies, including:

- **Accurate screening, diagnosis, and staging of multiple myeloma**
- **First-line treatment options for patients with multiple myeloma**
- **Minimal residula disease: maintenance strategies**
- **Management of relapsed/refractory disease and other issues related to multiple myeloma**

This innovative CME-accredited physician education program features world-renowned myeloma specialists, excerpts from scientific presentations, and discussions on controversial issues in multiple myeloma and related diseases. *Multiple Myeloma: A Physician's Reference* is scheduled for release in February 2002. To reserve your copy of the CD-ROM, please contact the IMF at (818) 487-7455 or go to the IMF website at www.cme.myeloma.org. 🍷



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