

# MYELOMA TODAY

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION



## HIGHLIGHTS

Dear Reader

Page 1

IMF Support Group Leaders Retreat

Page 2

Ask the Expert:

The Pathogenesis and Treatment of Multiple Myeloma Bone Disease

Page 3

The Good, the Bad, and the Ugly of Cancer Public Policy

Page 5

IMF Calendar

Page 6

Scientific Advisor Profile:  
Meet New Members of the IMF  
Scientific Advisory Board

Page 6

IMFer Profile:

Terry Herman Shares Her Story

Page 9

News & Notes

Page 12

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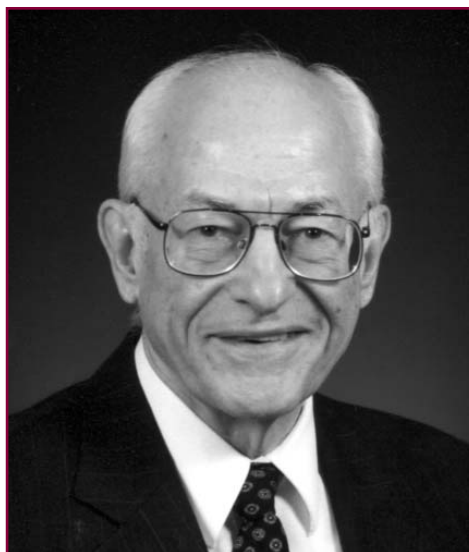
Dear Reader,

August promises to be a very busy month for the IMF and the myeloma community. The 2<sup>nd</sup> Annual Myeloma Awareness Week will take place August 10<sup>th</sup> to August 17<sup>th</sup>. Several events are scheduled across the country during the week itself and during the days preceding and following this week.

On August 2<sup>nd</sup>, the IMF will honor Dr. Robert Kyle for a lifetime of service to the myeloma community. The IMF has established the Robert A. Kyle Lifetime Achievement Award to recognize doctors for outstanding contributions to the field of myeloma. Dr. Kyle is

founder of the myeloma and related diseases research group at the world-renowned Mayo Clinic. I first heard the name Dr. Robert A. Kyle, fifteen years ago, when Brian Novis was searching for the best myeloma doctor possible. It would be hard to find someone else with more experience, knowledge, and expertise than Dr. Kyle. I could hardly have imagined that one day he would become

the very good friend that he is today. Bob is a true gentleman, whose kindness and caring is felt by patients and colleagues alike. Bob was the first person that Dr. Brian Durie contacted when he and Brian Novis came up with the idea to start the IMF. And true to his nature, Bob jumped right into the project, and became a founding member of the IMF Board of Directors and Chairman of the IMF Scientific Advisory Board. Thirteen years later he maintains those positions - that's dedication. I look forward to continuing to work with Bob, who brings together doctors, researchers, nurses, and healthcare providers to help the myeloma community. It is an honor and a pleasure for the IMF to present him with the Robert A. Kyle Lifetime Achievement Award. There is no one more deserving. The presentation will take place in Rochester, Minnesota, in the presence of family, friends, associates, and fellows.



Robert A. Kyle, M.D.

During the week of August 10<sup>th</sup> to August 17<sup>th</sup>, all over the country, people just like you will be mailing letters to their friends and relatives asking for their support of myeloma research and other important IMF programs which benefit the myeloma community. The Mail For The Cure campaign is already well on its way, with IMFer Terry Herman leading the way (please see page 9 for an interview with Terry).

On August 9<sup>th</sup>, the Charity Golf Outing at Stone Creek in Omaha, Nebraska, will feature two person teams and 27 holes including a 9 hole scramble, 9 hole alternating shot, and 9 hole individual ball. Proceeds from this event will go to support IMF programs.

On August 15<sup>th</sup> and 16<sup>th</sup>, the Atlanta IMF Patient & Family Interactive Seminar will take place at Emory University in Atlanta, Georgia. This two-day intensive seminar is designed to meet the changing needs of today's myeloma patients and their families, providing up-to-date practical and useful information pre-

sented by the top practitioners from around the country. The seminar will feature guest speaker Dr. Nancy Lee of the CDC.

On August 16<sup>th</sup>, the Mile High March for Myeloma will take place in Lake Arrowhead, California. The walk-a-thon is being organized by Lisa Doyle in honor of her father who has myeloma.

The Donate-A-Phone program is also being rolled out during Awareness Week. There is an estimated 30 million used cell phones lying around in America's homes, just waiting to be reprogrammed, refurbished, or recycled. IMFers will be setting up collection boxes around the country to help with this exciting new program. The funds raised will benefit local myeloma support groups as well as the myeloma community at large.

Susie Novis  
President

*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.*

**IMF SUPPORT GROUP LEADER RETREAT**

By Chuck Koval

Forty support group leaders, co-leaders, representatives, and IMF staff participated in the fourth annual IMF Support Group Leader Retreat, held June 27-29 at Duke University in Durham, North Carolina. The retreat lived up to the expectations of regular attendees of past retreats. This was the first retreat experience for nearly half of the group. Judging by their reactions, we expect to see them regularly at future IMF retreats.



Susie Novis and Mike Katz

The Friday evening kick-off started with a first class welcome reception. A wonderful dinner served in the tradition of a fine hotel followed. In a lively welcome address, Susie Novis gave us details on the new IMF initiative, 'Bank On A Cure™'. This may prove to be one of the most significant contributions to the future management of myeloma. After much excitement, the travelers were ready to retire and prepare for the Saturday schedule.



(L-r) Bill Hollowell, Sharon Madagan, Deborah Eller, Nancy Baxter, Cindy and Bob Feltzin

On Saturday morning, Susie set an upbeat tone for the meeting with a brief history of the retreats, progress in the management of myeloma, a look at new programs, and the role of support groups. She highlighted the availability of VELCADE™, the first new drug for myeloma in many years, and how IMFers



(L-r) Judith Hartig-Osanka, Roger Buffett, Pat Koval, Chuck Koval, Jane Buffett

helped gain rapid approval of this drug.

In keeping with the successful format of previous retreats, the first half of the morning was dedicated to group introductions and expectations each group brought to the retreat. After the open discussion, "What Works – What doesn't", it was time for the first of the invited speakers.

Patty Delaney of the Food and Drug Administration described her role within the FDA. Due to plane difficulties, Patty had to use the telephone to share her message. Thanks to the quick



Ken and Mary Makowka, Robin and Michael Tuohy

work of Mike Katz and staff, the PowerPoint slides Patty prepared were easily shared with the attendees. The presentation was an insightful look at the role of the FDA from the start of the drug approval process, through approval, and follow-up post-approval drug use. She clarified some of the limitations faced by the FDA throughout the process, particularly the inability to respond due to many legal restrictions.

Next, Dr. Brian Durie provided an update on the International Myeloma Workshop held in Salamanca, Spain. He was able to place a perspective on the hot issues in myeloma research as well as those areas that appear to be losing favor as additional information

*Please see page 4*

## The Pathogenesis and Treatment of Multiple Myeloma Bone Disease



Robert A. Vescio, M.D.  
Associate Director, Multiple Myeloma/Bone Metastases Program  
Cedars-Sinai Medical Center  
Los Angeles, California

By Robert A. Vescio, M.D.

One of the most common symptoms that lead patients with multiple myeloma to first seek medical attention is bone pain. This pain is caused by the destruction of bone material induced by myeloma cells within the center of the bone. The bones can then become weak and eventually result in small or more substantial fractures most commonly within the spine or ribs. Fortunately, there are now medications that can limit this process. In addition, other treatments such as radiation therapy or new surgical procedures such as kyphoplasty can alleviate or even correct some of these complications.

One might think that there would be evolutionary pressure to produce bones as strong as possible. This is not the case nor is it in your body's best interest. While it is important to have bones strong enough to not break during normal activities, it is not in one's interest to have bones so heavy that limbs become inefficient to move. To accomplish this balance, the body somehow senses the shocks and stresses transmitted throughout the bones and lays down new bone matrix material in areas that are structurally stressed, and dissolves away material in areas which are not needed. This is why it is very important for patients with multiple myeloma to keep active. The stresses incurred by even seemingly non-strenuous activities such as walking, can keep the bones of the legs and spine strong. As an example, astronauts returning from the space

station have been found to lose significant bone mass due to prolonged weightlessness. The first astronaut to Mars will likely be taking a bisphosphonate on the way! One can see that prolonged bed rest could also induce similar reductions in bone mass.

If one looks inside the femur, the largest bone in your leg, you can see a strong outer shell with a scaffolding matrix in the middle. The outer portion of the bone is called the bone cortex, while the center of the bone is called cancellous bone. It is in the center of the large bones of the body where blood cells are produced. This area is called the bone marrow. This is where normal plasma cells reside and, consequently, where the malignant version (myeloma cells) also prefers to grow. The smaller bones of the hands and feet do not have bone marrow; hence patients with multiple myeloma typically do not develop fractures or bone lesions in these areas.

The cells within the bone marrow that are responsible for bone remodeling are called osteoblasts (the cells that produce bone material) and osteoclasts (the cells which dissolve bone). In patients with multiple myeloma, the osteoclasts are overactive. The myeloma cells secrete hormones that can stimulate the osteoclasts to break down bone inappropriately. One of these hormones produced by myeloma cells is called RANK Ligand. It attaches to a receptor called RANK on the surface of the osteoclast and stimulates its activation. In addition, other hormones (also called cytokines) are overproduced in the multiple myeloma environment such as IL-6 and TNF. These cytokines may also indirectly stimulate osteoclast overactivity. This is why areas of increased bone breakdown (lesions or lucencies on X-rays) often occur in the regions where myeloma cell proliferation is particularly prominent. When osteoclastic activity is severe, the bone in that area can become weak and calcium (present within the bone matrix) comes out of the bone and into the bloodstream. That is why multiple myeloma patients can have hypercalcemia (high calcium blood levels) when their disease is not well controlled. The pattern of bone involvement differs from patient to

patient. Some patients have multiple myeloma diffusely spread throughout their bone marrow. These patients may not have individually identifiable lesions on X-ray but are instead noted to have diffuse osteoporosis (thinning of the bone). Other patients will have discrete collections of tumor cells in their bones that result in what looks like holes on X-ray. One of the problems with multiple myeloma is that the bones do not readily repair these holes even when the multiple myeloma is controlled. This is because the osteoblasts don't rush in to repair these areas of weakness for unknown reasons. It should be remembered that a lesion on X-ray does not mean that there is multiple myeloma still present in this spot. The myeloma cells could have been destroyed by treatment such as radiation but the bone just hasn't filled in the weakened area.

Fortunately, there are now new treatments for multiple myeloma bone disease which have made skeletal related complications such as fractures less common. Treatment of the myeloma itself is one of the most effective ways of controlling further bone breakdown. Often patients at diagnosis will be discovered to have hypercalcemia. With successful treatment, the calcium levels often fall, indicative of less calcium release from resorbed bone. As this occurs, the patient's pain often improves as well. It is likely that much of the pain experienced by multiple myeloma patients comes from some of the cytokines and inflammation that exists around these nests of tumor cells within the bone marrow.

Another important treatment for multiple myeloma directly attacks the overacting osteoclasts. Bisphosphonates are a class of drug known to suppress osteoclastic activity. The initial studies completed in multiple myeloma used relatively weak agents such as etidronate and clodronate. In the Canadian study involving etidronate, 166 patients were randomized to etidronate (5 mg/kg) or placebo in addition to primary chemotherapy with melphalan and prednisone. No significant difference in clinically mean-

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## SUPPORT GROUP RETREAT – continued

is compiled. Several very hopeful concepts were presented that we will likely hear more about in the near future.

The first afternoon session focused on loss and grief issues facing support groups. Since most myeloma support groups do not have professional facilitators, it can be difficult to handle the loss of fellow members. Joanna Parker, LPC, Bereavement Services Coordinator, Duke University, led a discussion helping understand the various kinds of grief and loss. She assisted the group in defining grief and the ways it might be expressed. She explained ‘Anticipatory Grief’, a type that occurs when individuals focus on future fears, i.e., debilitation, loss of ambulation, economic problems, etc. She stressed the importance of healthy anticipatory mourning by outlining the factors necessary for it to be a healthy experience. Joanna offered some coping ideas for support groups at times of loss.

Jon Seskevich RN, BSN, BA, CHTP Nurse Clinician, Duke University Health System focused on, “The Vital Quartet: Safe, Sane Complementary Therapies for Inquiring Patients”. Jon focused on the negative impacts of stress and identified a variety of stress management techniques. Stress management gains increased importance when we realized that 50% - 80% of all diseases are stress related. A ten-minute relaxation was said to have the impact of a half-hour nap! You can access much of what Jon presented by visiting his website at [www.managestressnow.com](http://www.managestressnow.com).

The pre-dinner cocktail reception provided a nice transition between the work of the day and the anticipation of a relaxing dinner. Following dinner,

Greg Brozeit presented an interesting discussion on “Cancer and Public Policy: The Importance of Advocacy”. His remarks were punctuated with a variety of experiences in his years working in the offices and hallways of Washington. He pointed out the value of advocacy, particularly if done at the right time and in support of a visible project. A good share of the viability of a project lies in the eyes of what congressional representatives and senators feel they can support. His best example of this is the IMF participation with more than forty groups in the One Voice Against Cancer coalition.

Our retreat ended late Sunday morning after an exceptionally well-prepared and presented discussion on the development of VELCADE™ by Millennium Pharmaceuticals Medical Director, Dr. Beth Trehu. Her many years of experience as a practicing oncologist nicely complemented her new role.

I am now at the point of gathering our thoughts from the retreat, thinking about applications of what we shared on return home, and looking to next year with great anticipation for the fifth annual IMF Support Group Leader Retreat. I hope that more multiple myeloma support group leaders will plan to join us in 2004. Special thanks to Nancy Baxter and the IMF staff who worked on arrangements for this retreat. We are grateful to the IMF for this helpful and generous support. 🌸

**Note:** Chuck Koval, a co-leader of the Wisconsin Multiple Myeloma Support Group, can be reached via email at [cfkoyal@wisc.edu](mailto:cfkoyal@wisc.edu). For a list of multiple myeloma support groups throughout the U.S. and around the world, please contact the IMF.



# THE GOOD, THE BAD, AND THE UGLY OF CANCER PUBLIC POLICY

By Greg Brozeit

Excuse me if I seem to exhibit a bit of schizophrenia. I'm not sure whether to be optimistic or pessimistic. On the one hand, the state of the science of cancer research and patient care is the brightest it has ever been. On the other hand, the politics and policy impacting the cancer world seem to be moving in the exact opposite direction.

So what are we to believe? More importantly, what will we do?

## THE GOOD NEWS

Last week I attended the National Dialogue on Cancer (NDC) meeting on behalf of IMF's Susie Novis. Susie is the only representative of the myeloma community who is a member of the NDC. Chaired by former President George Bush and his wife Barbara, the NDC is a unique entity that brings together members of the private, public, and non-profit sectors of the cancer community for biannual meetings to with the goal of significantly reducing cancer incidence and mortality within the decade.

As a member of the NDC Cancer Research Team, I have learned first hand about the real potential for significant advances in cancer research through targeted therapies of genomic and proteomic medicine development. I have learned that we may soon see a future free of chemotherapy drugs. Drugs that target cancers at their genetic and molecular roots will replace them. I have seen glimpses of future that will put chemotherapy into the outmoded category of the medicinal use of leeches.

At the last NDC meeting, NDC founding member and vice chair Andrew von Eschenbach, the director of the National Cancer Institute (NCI), unveiled his 2015 initiative. Its ambitious goal is the elimination of suffering and death due to cancer by the year 2015. This may be audacious, but it is not nearly as unthinkable as it was just five years ago. And just like President Kennedy's challenge to the nation in 1962 that we would be on the moon by the end of the decade, Dr. von

Eschenbach's initiative goal should focus our efforts in ways we find it difficult to imagine. But it can be achieved if we make the national commitment and sacrifices needed to get there from here.

The 2015 initiative may be the most ambitious scientific goal of our lifetimes. Imagine a world without death and suffering due to cancer. If you're reading this, you know how audacious a goal that is. You've seen far too much of cancer and its consequences to take this seriously. It might even seem cruel.

But the truth is that it is within our grasp. The investment our nation has made into cancer research since President Nixon signed the National Cancer Act into law in 1971 is now beginning to pay off in remarkable ways. In the past two years we have seen the approval of the first three molecularly target drugs. As many as 300 more are currently in development. Over the course of the next decade, the science may drive this number well past 1,000.

While we have had steady growth in our understanding about how the mechanisms of cancer work, we will now need exponential growth. That will mean a need for more researchers, more public and private investment, more participation of patients in cancer trials, more engagement of policy makers and citizens in the decision-making process, and, most importantly, more public understanding of the cost of cancer and why it matters that cancer should be our nation's most important health care priority.

Whether or not we achieve the goals of the 2015 initiative by the year 2015, one thing is clear: we can realistically anticipate a world in which our children and our children's children will not suffer and die because of cancer. Let's not quibble about dates, but let's use them as incentives to speed up the achievement of the goals.

## THE BAD NEWS

Juxtaposing the grand vision of the 2015 initiative, Congress and the president have decided to dramatically reduce their previous commitments of funding for the National Institutes of

Health. Additionally, access to and funding for cancer treatment took a hard blow in the proposed Medicare reform bills passed by the House and Senate.

After the relatively giddy 5-year process of doubling NIH budget—an average 15% per year—President Bush recommended slightly more than a 2% increase for fiscal year 2004. This small increase barely keeps pace with the rate of inflation and translates into a flat funding scenario at best. Within those amounts, the request for NCI totaled just \$170 million for a total of \$4.77 billion.

In late June 2003, the fate of the funding was sealed when the congressional appropriations committees largely followed the funding recommendations for medical and cancer research laid out in the president's fiscal year 2004 budget. For NCI each chamber recommended the same amount as the president.

These recommendations were approved despite the fact that NCI only funds 28% of its approved grants. In other words, 72% of the approved, peer-reviewed grants NCI reviews never get funded. This perverse situation will only get worse under the fiscal year 2004 funding recommendations.

The news gets worse. In the recently passed Medicare reform bills funding for cancer treatment took a big hit. According to an analysis by the American Society for Hematology, "...it is projected that the House and Senate proposals would reduce payment for cancer drugs by about \$700 million per year, but would add back only about \$190 million in improved reimbursement for the administration codes. Thus, a net reduction in excess of \$500 million per year is under consideration for chemotherapy services."

So, while the science and treatment for cancer has never looked better, our policy makers have responded by limiting the funding stream to realize the opportunity. To exacerbate the problem, they have recommended a reduction in the vital reimbursements needed to ensure minimal access to quality cancer care for Medicare recipients. If enacted, these proposals will

**August 2, 2003**

Robert A. Kyle Lifetime Achievement Award Dinner  
Rochester, MN

**August 2, 2003**

Steve Malone Golf Tournament  
Omaha, NE

**August 10-17, 2003**

Myeloma Awareness Week  
Nationwide

**August 15-16, 2003**

IMF Patient & Family Seminar  
Atlanta, Georgia

**August 16, 2003**

"Mile High March for Myeloma" MM Fundraiser  
Lake Arrowhead, CA

**August 23, 2003**

Ralph Ferrizzi Memorial Golf Tournament  
Allentown, PA

**August 25, 2003**

Corporate Cup Challenge Golf Tournament  
Naperville, IL

**September 6, 2003**

IMF (UK) Patient & Family Seminar  
Cardiff, WALES

**September 12, 2003**

IMF Patient & Family Seminar  
Torino, ITALY

**September 19, 2003**

IMF Patient & Family Seminar  
Paris, FRANCE

**September 27-28, 2003**

IMF Patient & Family Seminar  
Heidelberg, GERMANY

**October 1-5, 2003**

SWOG Group Meeting  
Seattle, WA

**October 4, 2003**

Ribbon of Hope - Making a World of Difference  
Anniversary Gala  
Seattle, WA

**October 17-18, 2003**

IMF Patient & Family Seminar  
Philadelphia, PA

**November 1, 2003**

IMF Patient & Family Seminar  
JAPAN

**November 7-8, 2003**

IMF Patient & Family Seminar  
Dallas, TX

**November 15-17, 2003**

ECOG Group Meeting  
Miami, FL

**December 5-9, 2003**

ASH Annual Meeting  
San Diego, CA

For more information, please visit  
[www.myeloma.org](http://www.myeloma.org) or call (800) 452-CURE.

*The International Myeloma Foundation is pleased to welcome*

**Rafael Fonseca, M.D.**  
**Mayo Clinic**  
**Rochester, Minnesota**  
**U.S.A.**

Dr. Fonseca is Associate Professor in Medicine, Mayo Graduate School of Medicine and Consultant, Department of Hematology and Internal Medicine, Mayo Clinic. Dr. Fonseca completed his Medical School education in 1991 at Universidad Anahuac School of Medicine, Mexico City, Mexico.

Dr. Fonseca is a member of American College of Physicians, American Society of Hematology, American Society of Clinical Oncology, Mexican Society of Internal Medicine, North Central Cancer Treatment Group, Eastern Cooperative Oncology Group, and a Fellow of International Society of Hematology.

A member of the Dysproteinemia Clinical Group, Dr. Fonseca has developed an expertise in the management of the plasma cell disorders. His clinical practice is primarily composed of patients with multiple myeloma, primary amyloidosis, monoclonal gammopathy of undetermined significance and Waldenstrom's macroglobulinemia.

In the laboratory, Dr. Fonseca concentrates on the genetic and cytogenetic nature of the clonal cells of the plasma cell disorders.



Rafael Fonseca, M.D.

**John Gibson, M.D., Ph.D.**  
**Royal Prince Alfred Hospital**  
**Camperdown, NSW**  
**Australia**

Dr. Gibson is deputy director of the Institute of Haematology, head of the blood and marrow transplantation

program, and a senior member of the Myeloma Research Group at Royal Prince Alfred Hospital in Sydney. He is also associate professor in medicine at the University of Sydney.

After graduating in medicine at the University of Sydney, Dr. Gibson worked at Sydney Hospital before commencing advanced training in hematology at Royal Prince Alfred Hospital. He gained fellowships of both the Royal Australasian College of Physicians as well as the Royal College of Pathologists of Australasia and subsequently a Ph.D. from the University of Sydney. Since 1986, he has been a senior member of the Institute of Haematology at RPAH. In 1995 he also spent some time as a visiting scientist at the Fred Hutchinson Cancer Research Centre in Seattle.

Dr. Gibson's main research interests are myeloma, as well as the therapy of hematological malignancies in general, in particular the role of stem cell transplantation. He is a member of the joint myeloma subcommittee of the International Bone Marrow Transplantation Registry and Autologous Blood and Marrow Transplantation Registry and the representative of the Australian Leukaemia and Lymphoma Group on the International Myeloma Trialists' Group. Non-myeloma interests include undergraduate and postgraduate teaching as well as patient education, having been a contributor to the IMF Patient & Family Seminars held in Australia.

The RPAH Myeloma Research Group has an active interest in the molecular genetics of myeloma as well as myeloma tumor immunology and the potential application of immune based therapies such as vaccination. In addition, active clinical research programs include the investigation of new approaches to primary therapy,



John Gibson, M.D.

# Meet New Members of the IMF Scientific Advisory Board

ome Drs. Fonseca, Gibson, Shimizu, and Westin to its distinguished Board of Scientific Advisors.

reduced intensity allogeneic transplants, management of advanced disease and early detection of skeletal disease. It is one of the co-ordinating centres for the Australian Leukaemia and Lymphoma Group myeloma trials.

The RPAH Myeloma Research Group is also the proud host of the 10<sup>th</sup> International Myeloma Workshop, which will be held in Sydney in April 2005. Dr. Gibson is co-vice-president of the organising committee and a member of the national planning group for the scientific program.

**Kazuyuki Shimizu, M.D.**  
**Nagoya City Higashi General Hospital**  
**Wakamizu, Chikusa-Ku, Nagoya**  
**Japan**

Dr. Shimizu is a Vice President at Nagoya City Higashi General

Hospital in Nagoya, Japan, a visiting professor at Nagoya University School of Medicine, the President of the Nagoya Myeloma Cooperative Study Group, and is on the Board of

Directors for the Japan Society of Hematology and for the Japan Society of Clinical Hematology, a member of Myeloma Trialists' Collaborative Group of MRC, UK, the representative of Japan for the International Myeloma Working Group of the IMF, and on the Advisory Boards for the IMF (Japan).

Dr. Shimizu is the President of the 29th annual meeting of the Japan Myeloma Study Group, to be held in Nagoya in 2004. Dr. Shimizu elaborated "Guidebook" for patients with myeloma in Japan and has been playing a central role in the establishment of "Guideline for multiple myeloma in Japan."

Dr. Shimizu received his M.D. degree from Nagoya University School



Kazuyuki Shimizu, M.D.

of Medicine in 1972 and completed his clinical immunology fellowship at Memorial Sloan-Kettering Cancer Center in 1977.

**Jan Westin, M.D., Ph.D.**  
**University Hospital**  
**Lund, Sweden**

Dr. Westin was educated and began his career in medicine at the University of Göteborg, Sweden. From 1990, he has practiced at the University of Lund, Sweden.

Dr. Westin started with scientific interest mainly in myeloproliferative disorders, cytogenetics, and other clinical aspects. He later switched interest to plasma cell disorders and specially multiple myeloma. Since 1985, he has mainly published papers in this field.

In 1987, started the Nordic

Myeloma Study Group (NMSG), as a network of clinicians and scientists in the Scandinavian countries, with the primary goal to carry out large population-based phase III clinical trials. The scope of the group has

widened to include other types of studies, a multitude of spin-off projects, development of common Nordic Guidelines for diagnosis and treatment of multiple myeloma (1995, revised edition 2002) and patient education efforts. Today, 17 university clinics and 95 county hospital clinics in Denmark, Norway and Sweden are associated with NMSG. The group has so far initiated 12 study protocols. Three randomized studies are at present running (comparison of two doses of IV pamidronate, melphalan-prednisone vs. melphalan-prednisone-thalidomide to patients > 65 yrs, VAD vs cyclophosphamide-dexamethasone as induction before high-dose therapy of patients < 65 yrs). The group



Jan Westin, M.D., Ph.D.

has put special focus on quality of life-issues and health economics and included these aspects in all later studies

During the years, Dr. Westin held a number of clinical and management positions in Gothenburg (Head of Hematology Section, Östra and Sahlgrenska Hospitals; Medical Director Östra Hospital; Medical Advisor to the Health Care Administration of the City of Göteborg) and Lund (Head of Department of Internal Medicine; Medical Advisor to the Region Skåne County Council, especially in R&D issues; Deputy Director Stem Cell Center, Faculty of Medicine, Lund University)

Currently, Dr. Westin is Clinical Hematologist Assistant Professor in Internal Medicine/Hematology at University Hospital in Lund, Sweden. His main interests are:

- to further strengthen the Nordic Myeloma Study Group by running well-designed, population-based clinical trials with high accrual rate, giving generalizable results; to stimulate spin-off projects using the material from the main studies; to elucidate the role of patient information and patient participation in clinical decisions.
- to expand the Nordic network into a European multinational Network of Excellence.
- to stimulate and support younger colleagues to get involved in the clinical and experimental research focusing on plasma cell disorders, and in the clinical care of myeloma patients.

The IMF is fortunate to have the support and cooperation of its distinguished Board of Scientific Advisors, comprised of 54 world recognized experts in the field of multiple myeloma. The IMF Scientific Advisory Board provides valuable counsel and assistance to the IMF in its service of the myeloma community through education, research, support, and advocacy. We look forward to introducing you to other IMF Scientific Advisors in future issues of *Myeloma Today*.

ingful events such as new fractures, hypercalcemic episodes and bone pain were noted between the two arms. Clodronate is an oral agent, available in Canada and Europe, which has shown some beneficial effects in multiple myeloma. Treated patients developed less hypercalcemia and non-vertebral fractures. However, back pain and poor performance status were not significantly different between the two groups except at one time point (24 months) and the proportion of patients requiring radiotherapy was similar between the two arms. Similar studies suggest that oral clodronate has a mild to modest beneficial effect on bone pain and fracture development in multiple myeloma. It should be noted that Fosamax (alendronate) and Actonel (risedronate) oral bisphosphonates useful in the treatment of osteoporosis, have not been studied in multiple myeloma. The doses of drug needed to impede bone breakdown in multiple myeloma is significantly higher than that needed for osteoporosis treatment. This is demonstrated by the fact that a recent study showed a single 5mg dose of Zometa per year may be sufficient treatment for osteoporosis.

The first bisphosphonate demonstrated to reduce the bony complications in multiple myeloma patients was pamidronate (Aredia). A randomized trial was performed in which 377 patients with Durie-Salmon Stage III multiple myeloma received either Aredia or placebo (salt water infusion). The proportion of myeloma patients having a skeletal complication (fracture, need for radiation, hypercalcemia, spinal cord compression) was 41% in patients receiving placebo but only 24% in pamidronate-treated patients ( $p < 0.001$ ). In addition, the number of skeletal events/yr was cut approximately in half in those patients treated with pamidronate ( $p < 0.001$ ). The patients randomized to receive pamidronate also had significant decreases in bone pain, and, in contrast to patients receiving the placebo, showed no deterioration in performance status and quality of life at the end of nine months. These benefits continued for the remaining twelve months of the study. In fact, although overall survival was not significantly different between the two treatment groups, the median survival time for the patients

with more advanced disease was 21 months if they received pamidronate vs. 14 months for those on the placebo arm ( $p = 0.47$ ).

After this study was completed most patients with bony lesions and multiple myeloma began treatment with Aredia. Recently, a newer more potent agent, zoledronic acid (Zometa) has become available. This drug was noted in animal models to be 100-800 times as potent on a mg per mg basis. This led to a trial comparing Aredia to Zometa in the treatment of hypercalcemia. Zometa was approved for use because a dose of 4 or 8 mg corrected hypercalcemia ~90% of the time vs. only 70% of the time with 90 mg of Aredia. Subsequently, a large randomized trial was performed comparing Zometa to Aredia in patients with multiple myeloma and breast cancer. This was done to see if Zometa was at least as effective as Aredia at preventing the bony complications that these patients develop. The final results demonstrated that the zoledronic acid was at least as effective at preventing bony complications as Aredia in multiple myeloma and slightly more effective than Aredia for patients with breast cancer.

The bisphosphonates are relatively safe drugs. They can cause a flu-like illness and even exacerbate bone pain the first couple of times they are received. All bisphosphonates can cause kidney problems (usually reversible) if given too quickly intravenously. In the above trial, Zometa was given at two different doses (8 mg and 4 mg) each over 5 minutes (compared to the 120 minute infusion time for Aredia). It was then discovered that at this rapid infusion time, some patients receiving Zometa developed kidney damage particularly when the higher dose was used. Because of this, all patients randomized to receive Zometa, received the lower 4mg dose and over a longer period of time (15 minutes). After this modification, the incidence of kidney problems with Zometa matched that seen for patients receiving Aredia. At the present time, either of these drugs (Aredia or Zometa) can be used to prevent bone problems. Zometa is more convenient since it takes only 15 minutes to give versus 120 minutes for Aredia. Since it is likely that these drugs prevent bone disease from getting worse (by impeding osteoclasts), but do not necessarily reverse damage already done, these drugs work best as a

preventative treatment. Although never definitively proven in a long-term study, most patients with multiple myeloma and bone disease should receive these medications indefinitely with careful monitoring of kidney function. In addition, it has never been proven that patients with earlier stages of multiple myeloma require treatment with a bisphosphonate. My practice, however, is to treat most patients with these drugs since they work best as preventative treatment, and because there is also laboratory evidence that these drugs can kill myeloma cells in the culture dish. Furthermore, reducing osteoclast numbers and activity by bisphosphonate administration may indirectly slow myeloma cell growth since the osteoclast is the greatest producer of IL-6 in the body and IL-6 is the primary growth factor for the myeloma cell.

Several new agents are under development, the most promising being a synthetic homologue to the naturally occurring osteoclast inhibitor (OPG). This drug AMG-162 has been given to patients with multiple myeloma and appears to be safe and inhibit bone resorption at least comparable to that achieved with pamidronate. Comparative phase III trials are being formulated right now and should start shortly.

Finally, a new procedure has been developed which can help patients who have already developed fractures within the spine causing chronic pain. Unlike fractures elsewhere in the body, once a vertebrae collapses it will never regain its normal height and shape. Many times, this is not a major problem. Patients will lose some height and may lean forward (due to kyphosis of the spine) but eventually, the pain will resolve. Unfortunately, some patients will develop chronic pain due to the non-healing vertebral fracture. If the offending vertebrae can be identified and the collapse is not too severe, a balloon can be inflated into the vertebrae and filled with cement. This procedure is called a kyphoplasty and is being done by more and more orthopaedists. Although not always successful, the procedure itself is relatively safe requiring only an overnight stay in the hospital and can often achieve instant pain relief in suffering patients with vertebral compression fractures of the lower spine. 🌸



## IMFER PROFILE: Terry Herman Shares Her Story



Terry and Howie Herman

### **Myeloma Today:** Please tell us a little about your life before myeloma.

**Terry Herman:** I had an average life. I am married. I have a son who is going to be 33 and a daughter who is going to be 31. Both of my children have children of their own. I have a business – I own a travel agency with a partner. I've always thought I was extremely healthy. I exercised, took all the right vitamins and antioxidants, and ate all the right foods. I used to laugh because my husband Howie was always running to the doctor, always thinking that something was wrong with him. I used to say, "All you have to do is take care of yourself!"

### **MT:** When were you diagnosed?

**TH:** In April, 2002, I had a stint in the emergency room because of some pain in my side. It turned out to be irritable bowel syndrome and acid reflux. But the blood tests revealed a high protein level. Of course, at the time I didn't understand what that meant. I had an endoscopy and a colonoscopy. Then I got pneumonia, followed by bronchitis. My family doctor had been monitoring me very closely ever since the elevated blood protein level was discovered and he told me that as soon as I got better, I needed to go see a hematologist. He was hoping I had MGUS and had discussed it with me but I just wasn't paying attention. I didn't even bother to look up MGUS on the Web so I never realized that this could be something serious. After all, I felt healthy! But my family doctor just wouldn't let the matter drop. When I got over the bronchitis at the end of August, he insisted that I see a hematologist.

The hematologist wanted to do some blood work, a 24-hour urine collection, a bone scan, and a bone marrow

biopsy. I said, "I am going to humor you. I'll give you some blood and all the urine you want. You can even take x-rays. But as far as doing a biopsy, that's out of the question." When the hematologist called me with the test results, I happened to have been playing around on my computer. He said, "You definitely have to come in for the bone marrow biopsy." I said, "What are you looking for?" He said, "I am not looking for anything. You have myeloma." So of course I type in the word "myeloma" into the computer and the search comes back "cancer of the plasma cell." I told the doctor that he had the wrong person. This couldn't be! Yes, I was anemic and I had a benign protein in my blood, but how can that be malignant? He tried to explain it to me but at that moment I was so stunned that there was no way I could deal with this kind of information. This is why, in my opinion, you always need to bring someone with you when you go see a doctor. It's important to have someone else there to listen to the information. A patient really can't process it all.

### **MT:** What did you do?

**TH:** I called my husband. I kept saying, "I don't understand. The doctor is telling me that I have cancer. He must have thought he was talking to somebody else. Or maybe he mixed up the charts..." I couldn't get it through my head. My husband told me to call our family doctor. I received the diagnosis on Friday, October 15, 2002. Our family doctor was on vacation but called me back and spent at least 45 minutes trying to calm me down. I spent the whole weekend crying. I thought I was a healthy human being. This was a very rude awakening.

I gathered my family. I said, "Listen, I just want to tell you all that I am going to be here for a while and I am going to take very good care of myself. I don't want you to treat me special. I want to be who I've always been. I want to be your mother. I want to be there for you. I don't want you to think that you can't talk to me because I'm going to die next week. That's not going to happen. My disease is in the early stages and every day the doctors are coming out with something new." And I am looking at my kids and they are sitting there stone-faced, and my son-in-law and daughter-in-law are crying. I said, "What's wrong with this picture? My children aren't

crying. My in-law children are crying!" That's when we all laughed.

A cancer diagnosis is very hard to come to terms with. You really don't know where to turn. It would be very difficult to have myeloma and to have to deal with it on your own. We all need help to get through this.

### **MT:** How do you cope?

**TH:** I have a great support system. I have a husband who's been just unbelievable. His mother was sick for many years and I should have known then, as I watched him take care of her, that I was going to be so lucky some day, that he was going to be there to take care of me. And he does. He makes sure I go to the doctor, and he comes with me. He's never missed an appointment. My daughter has also gone for doctor visits with me. I can email my hematologist with questions and get an answer from him within hours! We discuss my blood levels every month. He is trying very hard to keep me stable. And my family doctor still calls me all the time just to see how I am feeling. I have two wonderful doctors who work hand-in-hand.

A couple of months ago, I attended to my first support group meeting. I don't think that I could have gone earlier because I just wasn't ready. But now I find it very informative.

And I have found out that my friends are true friends, not just acquaintances. They are there for me and that is so important. They call me to before my treatments, they call after. They offer to take me to my doctor appointments, to sit with me during treatments. They browse the Internet doing research – when VELCADE™ received its FDA approval, I received so many calls from friends making sure that I had all the information. It's just unbelievable. I feel so loved and protected by everybody.

### **MT:** How did you learn about the IMF?

**TH:** I found the IMF on the web. I ordered the free InfoPack and signed up for this newsletter. Your educational materials have been most informative. They help me to ask the right questions and communicate better with my doctor and that's very important. I think that people need help learning how to communicate. They need guidance. These are things I never needed before

Please see page 11

## CANCER PUBLIC POLICY – continued

have disastrous consequences for all cancer patients, oncologists, and researchers.

All this is happening at the time of greatest scientific opportunity to make cancer a manageable, treatable, chronic condition that would eliminate suffering and death due to the disease. Where is George Orwell when you need him?

### THE UGLY TRUTH

Cancer is the number one killer of Americans between the ages of 25 and 64, i.e., the most productive years of our lives. Every day 1,500 Americans die of cancer and more than 3,000 are diagnosed.

Despite these facts, Congress and the president have decided to treat cancer as a deflated political football. What we are witnessing are the consequences of the perception that medical research was the big winner over the past five years and now it is some other constituency's turn. Why do we have to have a funding world of winners and losers?

I would argue that there are two primary reasons. First, winners and losers in the appropriations process is a direct consequence of the tax cuts signed into law over the past two years. When you take \$1 billion out of the government's resources, you have to begin to expect serious priority adjustments as Congress decides how to allocate money.

As I wrote in the August 2002 issue of Myeloma Today:

*What was needed...was an understanding and appreciation of how the political and appropriations processes were dependent on each other. How, for example, could the appropriations committees begin to fulfill the wishes of the competing funding constituencies if tax cuts diminished federal resources by \$600 billion?*

*Under these conditions, no constituency should expect to fulfill their wish lists, or, in a more likely scenario, the future of appropriations would translate into a process of perceived winners one year becoming losers in the next...*

*That might translate into education programs not being funded at the levels promised in previous years. It also may translate in reductions or stagnant funding levels for other health programs...*

*And in boom-and-bust funding cycle scenarios, it may mean that next year's medical research funding figure will barely rise while other programs, the perceived losers of the current cycle, will experience greater increases. It*

*will be the legislative metaphor of moving around the deck chairs on the Titanic...But instead of "guns or butter" the mantra for advocates may be "tax cuts or cancer research" or "tax cuts or education funding."*

*On the other side of the discussion, there would be no guarantee that research funding would automatically go up if tax cuts were defeated and the federal funding stream remained uninterrupted. Those decisions would again be left up to the various appropriations subcommittees and there are no guarantees that link tax income with funding for programs...*

*But we should expect winners and losers in the appropriations process. Although the NIH part of the equation looks promising for cancer research advocates this year, the other parts do not look as promising. The outlook for next few years is even more nebulous, especially for NIH.*

*And remember to connect the dots. At least then it is easier to explain the final results. And remember that it is more likely to be on the losing side of the appropriations process when the income of the federal government is constricted by tax cuts.*

Another reason is the fragmented and quiet nature of the cancer constituency. We still tend to focus too much on "our cancer" rather than champion the big picture of NIH and NCI research. And we expect that the sheer logic of the cancer arguments will prevail.

The reality, however, is different. In one discussion I had with a senior congressional staffer this year, she candidly admitted that she had heard much more from education advocates than from cancer advocates. And when she did hear from cancer advocates, it was usually in support of issues and funding related to "their" cancer. Since Congress does not appropriate by specific disease category, this segmenting of cancer types further undermined the overall message. It should be no surprise, then, that education funding will be a big winner in this year's appropriations cycle.

In order to reverse this trend, all cancer advocates must become more sophisticated and consistently vocal. Beginning now, we should all make our concerns about cancer research funding and potential Medicare cutbacks known.

We have to begin the process for next year's appropriations cycle now. We have to become engaged in the budget debate that follows the president's State-of-the-Union address to ensure that Congress allocates enough money for the appropriations subcommittees to

have the freedom to make decisions to lessen the need for winners and losers.

We have to work the appropriations process with messages like those of the One Voice Against Cancer coalition to increase funding for NIH, NCI, and the Centers for Disease Control and Prevention cancer programs. And we must do so in concerted voices with all the members of the cancer advocacy community.

I urge you to watch for the action alerts in the Myeloma Minute and to contact me if you have questions or advice. I urge you to engage your friends and family members around the country.

We must make Congress and the administration to understand that 1.3 million Americans will be diagnosed with some form of cancer this year. We must make them understand that more than 570,000 Americans will die of some form of cancer this year.

These are not numbers that can be relegated to a political game of winners and losers. The stakes are too high and the science is too promising.

In discussing the context of the 2015 initiative, NCI Director von Eschenbach has brilliantly put the nature of the challenge facing us into historical context. At the turn of the 20<sup>th</sup> century, the fundamental question of science was the nature of matter. At the turn of the 21<sup>st</sup> century, the fundamental question of science is the nature of life.

Looking back, it took science 50 years to move our understanding of matter from the horse-less carriage to the advent of supersonic flight. Moving forward, the development of molecularly targeted drugs that will eliminate suffering and death due to cancer is in, if you will, the horse-less carriage phase. We cannot wait 50 years to realize its promise. There are too many lives at stake, especially with the aging of the baby boomer generation.

We can only realize the 2015 initiative if our policy makers understand its implications. It is up to you and all of us to make sure they get the message. 🌸

**Note:** To contact Greg Brozeit, please email him at [greg.brozeit@sbcglobal.net](mailto:greg.brozeit@sbcglobal.net) or call (330) 865-0046.

**TERRY HERMAN – continued**

because I had never been sick before the myeloma. By the time a social worker came up to me in the hospital to ask if there was something I needed, I had already had a lot of help and information both from my doctor and the IMF. I had gone through every single page of the literature I received from the IMF. I felt that I knew what was going on and had a better view of where I stood. Even now, once every couple of months I still take out my health folder and re-read all the books because at each stage I absorb different information, even from reading the same text. As I've progressed since the diagnosis, I have been able to absorb more and more information.

**MT:** Why did you decide to participate in the IMF Mail For The Cure (MFTC) campaign?

**TH:** For years, I have been involved with a number of different causes. I lost a very dear friend on 9/11. His wife started a foundation for him and my husband and I have been very involved with it. And everyone has been extremely generous. Even my neighbors – and I've been living here for only 2

years – have donated to this foundation. Also, for years I have supported the American Cancer Society – my mother had breast cancer, as have several close friends. And my husband and I donate to several charities that my neighbors are involved with. So when I learned about the MFTC campaign, I thought that if I can donate to other causes, why shouldn't the people I know donate to a cause that's so important to me?

**MT:** How did you proceed?

**TH:** I sent in my order form to the IMF. The following week, I received a packet in the mail that contained hints on how to write a letter. So I wrote a letter and brought it home to my husband. He thought the letter was very good but I was concerned that I was asking for too much. I don't like to put people on the spot. He pointed out that the IMF does not disclose the amount of an individual donation so contributors can choose to give any amount they wish. Even if they send in just \$5... that's \$5 more than the IMF would have had otherwise. I started to figure out whom to send the letters to. First, I was just going to send them to my close friends, knowing that they would rally around me. But then I

took out my address book and went through it from one end of the book to the other and sent letters to everyone I knew. And every night I would come home and find messages on my answering machine from people saying that they wanted to participate. I even heard from people who did not receive my letters but had heard about them from others. Everyone was offering to contribute. A company I worked for 16 years ago sent in a check for \$500! I was overwhelmed that they should think enough of me to contribute to the IMF. The response has been unbelievable. I am overwhelmed with phone calls and the love and the concern and the offers of help. I know that these people will be there for me forever.

Gradually, I am finding it easier to cope with my diagnosis. I've come to understand that my health is in my hands, that I need to take it seriously, and be prepared for whatever comes at me down the line. I feel so lucky that everyone is there for me. I don't know where I'd be without my family and friends. 🌸

**Note:** To date, Terry Herman has helped the IMF raise over \$5,400 through the Mail For The Cure campaign.

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**ORDER FORM**

# News & Notes

## 2003 IMF ANNIVERSARY GALA

Plans for this year's *Ribbon of Hope* Gala are coming along well, thanks to the hard work of our busy Dinner Co-Chairs, Teresa and Glen Perez. The evening promises to be a blast for all who attend. The IMF will present awards to former NCI Director Dr. Richard Klausner, the Seattle-based support group The MM Fighters!, Mrs. John Schwartz, and the Fred Hutchinson Cancer Center. Our guests will enjoy touring EMP, a fantastic interactive museum of music history, as well as dancing, dining on great food, and dressing up in garb from their favorite decade of music. Many items have been donated to our Live and Silent Auctions, but we can always use more. If you have something you'd like to donate, or would like more information about the event, tickets, or sponsorships, please call Suzanne Battaglia at (800) 452-2873 or email her at [sbattaglia@myeloma.org](mailto:sbattaglia@myeloma.org).

## NEW TOLL-FREE NUMBER FOR CLRC

Since 1997, the Cancer Legal Resource Center (CLRC) has provided information and education to people with all types of cancer about their legal rights and the legal issues they face while battling their disease. The CLRC also has access to a panel of volunteer attorneys and other professionals willing to assist people with cancer. The CLRC can be reached through its new toll-free number (866) THE-CLRC (843-2572).

## FASHIONS 4 A CURE

The fifth annual "Fashions 4 A Cure" fundraiser was held on April 6<sup>th</sup> at the Fox Valley Country Club in Lancaster, New York. Once again, the event was organized by Ashley Barit in honor of her mother Jerra, who was diagnosed with multiple myeloma in 1998.

This year's event featured a children's fashion show, a bridal fashions show,

and fabulous auction items. The featured item was a diamond and solitaire ring generously donated by Los Angeles jewelers Adler and Co., long-time supporters of the IMF and myeloma research.

As always, guests and models enjoyed the afternoon to its fullest. This year "Fashions 4 A Cure" raised over \$23,000 to support myeloma research, bringing the total raised to over \$68,000! Our heartfelt thanks to the Barit family and to all who supported this event.



Ashley Barit with model Elena Pezzino



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