MYELOMA TODAY

WINTER 2006
VOLUME 7 NUMBER 1

A Publication of the International Myeloma Foundation

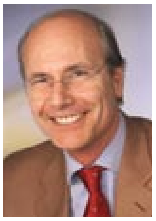
Dedicated to improving the quality of life of myeloma patients while working towards prevention and a cure.

In this issue…

Scientific & Clinical

REPORT FROM ASH

Read about some of the most significant myeloma-related news from the 48th annual meeting of the **American Society of Hematology (ASH)**. Information includes updates on Revlimid®, VELCADE®, and IMF's Bank On A Cure® research initiative. ***PAGE 6***



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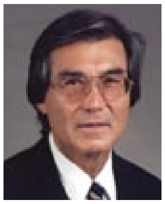
INVESTING IN THE FUTURE



This new section features profiles of IMFers who are making profound investments in the myeloma community and the path to a cure. Read about how and why **Gary & Louise Takata** have chosen to commit so significantly to the fight against myeloma. ***PAGE 21***

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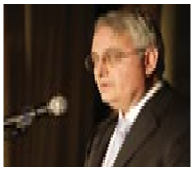

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LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP?

If you are interested in joining an existing group please access the website at www.myeloma.org "Finding Support" or call the IMF at 800-452-CURE (2873).

This issue of Myeloma Today is supported by Celgene Corporation and Millennium Pharmaceuticals.

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International Myeloma Foundation

Dear Reader,

Winter is typically a time when everything goes into a deep slumber. But not the IMF! We've never been busier. This past year was a monumental year for us as we added key members to our team. Diane Moran, most recently with Millennium Pharmaceuticals, came to us after a 22-year career in the pharmaceutical industry and has helped the IMF realize new programs that help broaden our reach to patients, caregivers, and the medical community. Greg Brozeit took on a new role, becoming the IMF's European Director. He has spent the past year participating in numerous seminars in Europe, meeting with doctors and support group leaders, and launching the Myelom Merkur, a German version of the Myeloma Minute.

The IMF added 20 new publications to our already extensive library, including translations into French, German, Italian, and Spanish to provide our members in other countries with access to information on treatment advances. The IMF also launched the Mensajero, a Spanish edition of the Myeloma Minute. IMF Latin America and IMF Israel also were extremely busy, putting on seminars, meeting with patients, updating their websites, and translating publications into Portuguese and Hebrew.

The IMF launched another new and exciting program with the formation of the Nurse Advisory Board (NLB). The first meeting was held in November and brought together 20 oncology nurses from leading centers treating myeloma patients. The inaugural meeting of the NLB was structured to accomplish objectives that include: defining the needs of the myeloma nursing professionals and their patients; establishing a baseline awareness of novel therapies and associated side effects; developing management guidelines for nurses who treat myeloma patients; facilitating information flow between the IMF and oncology nursing organizations; sharing best practices and lessons learned in myeloma advocacy; and supporting the identification and implementation of key nursing educational programs.

The IMF's Bank On A Cure® team was equally busy developing custom SNP chips. They researched over half a million genetic variations that can affect cancer and targeted 3,400 genes that specifically influence myeloma. And at ASH the important advances that were presented included the discovery of specific genes that identify patients at highest risk for developing DVT's with thalidomide and/or Revlimid therapy, as well as genetic correlations with different type of myeloma disease patterns. These findings will be in the next issue of Myeloma Today and will be available on our web site, but as we go to print, this information is still embargoed.

Our Support Group team, Kelly Cox, Robin Tuohy, and Andy Lebkuecher, crisscrossed the country visiting with groups from coast to coast, providing them with materials, information, and a helping hand when needed. Four extremely successful conference calls were held with the Support Group Leaders that focused on important topics such as Medicare Part D, new clinical trial design, and novel therapy updates. And this year 15 Support Group Leaders were invited to attend ASH – something that had never been offered before – so that they could attend the important sessions; gain first-hand knowledge; and take that information back to share with their groups.

I realize that I've now run out of space… and there is so much more to tell! So please go to the IMF's website and read about all the other innovative programs and activities the IMF has been up to this year that help myeloma patients and their families around the world.

I'd like to express our deepest gratitude to you and thank you for your belief in and support of the IMF – we couldn't do it without you!

Happy New Year!
Susie Novis

Letters to the IMF

To Susie Novis and Brian G.M. Durie, MD:

The advocacy efforts of the IMF are just extraordinary. Thanks for your commitment to your patients and to those who simply need support and direction. I so appreciate your post-show follow-up. See you for new programs in 2007!

Selma R. Schimmel
Founder & CEO
Vital Options International

Editor's Note: Dr. Durie and Susie Novis participated on the Vital Options International radio program, The Group Room®, on July 30 and August 27, 2006. These programs (#547 and #551, respectively) are now available online at www.vitaloptions.org.

To Susie Novis:

Thank you and your staff for inviting me to the Gala. I enjoyed it very much. The food was excellent and the desserts "tres bien."

I know how hard you have worked. Certainly those of us who have MM enjoy the fruits of your labor to the Nth degree. I have seen how the IMF has grown and has taken on its own speed. I know that I would be bereft without the IMF doing what it does. The culmination of the research has been to the benefit of all of us with MM, so thank you for being there. I hope to have more years because of what you do and because of Dr. Durie's wisdom in the cause of a cure.

Nancy Sorrenti

MYELOMA TODAY IN CONVERSATION WITH RICHARD SALETAN

Myeloma Today: ***Please tell us a little about yourself.***

Richard Saletan: My wife Suzanne and I have been married for over 40 years. We have two children. My son and daughter-in-law live in South Carolina, and have two boys, ages 5 and 7. My daughter and her husband live in Massachusetts, and have a 4-year-old daughter and a 2-year-old son. I take enormous pride in my family and get the greatest joy from my grandchildren!

Professionally, I have over 40 years of experience in business management, strategic planning, and marketing for Fortune 100 companies. I founded Weston Group Inc. and, as its chairman and CEO, built it into a world-class consulting organization with over 75 employees. Our clients included Dow, Coca-Cola, Pepsi, General Foods, Chase Manhattan Bank, American Express, Keebler, Nabisco, Bristol-Myers, Shell Oil, and AT&T among others. I also served on the Board of Directors of a NYSE company.

How did myeloma enter your life?

One day, while playing golf, I felt a pain in my back after I made a swing. The pain was so bad that I could no longer lift the club. I went home and called my doctor. Because I had previously experienced problems with my spinal discs, my doctor suggested I visit a chiropractor. The chiropractic adjustment did not offer relief. In fact, I collapsed at home the next day. In the emergency room, when the doctor tried to sit me up, I went numb from the middle of my chest down. A neurosurgeon rushed me into an MRI machine, then into surgery, where it was revealed that a compression of the T6 vertebra produced a blood clot that had landed on my spinal cord. A laboratory examination of the bone from the compression confirmed the myeloma diagnosis. That was 16 years ago.

What medical treatment did you receive?

I spent 10 weeks in the hospital, then a year in physical therapy. My wife happened to have worked for a hematologist, and he put me on a regimen of melphalan and prednisone. After a year of treatment with my counts below normal, he sent me to a local myeloma specialist who told me I had three years to live. I didn't like what I heard, so I sought out the most experienced myeloma doctor I could find. That man was Dr. Robert Kyle at the Mayo Clinic. I remained a patient of Dr. Kyle's until he retired from clinical practice. I still go to Mayo every six months, but now I see Dr. Morie Gertz. Over the past 16 years, I have received a variety of treatments for myeloma. Now I take prednisone and low-dose Cytoxan®.

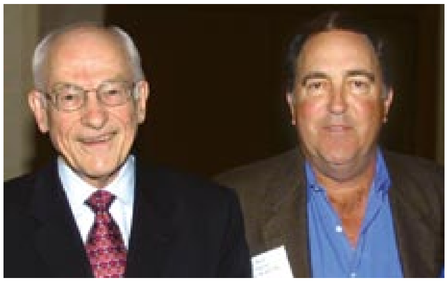
Saletan at the IMF Gala with wife Suzanne and Susie Novis.

When did you become involved with the IMF?

Right after 9/11, I decided that I wanted to contribute in some way to the myeloma community – by then, I had retired from my business career – so I called Susie Novis at the IMF. Immediately, she saw how my business experience could be of service to the Foundation and its members. I began working with Susie and Dr. Brian Durie in the business planning area of the IMF. Soon thereafter, the "positioning line" – "Until There is a Cure… There is the IMF." – came into being. Next, we developed an annual plan for the IMF. Then I became a member of the IMF Board and, a few years later, a member of its Executive Committee.

Can you tell us about your work on behalf of the Foundation?

I work closely with Susie and the Board. The annual business plan is one project to which I continue to contribute every year. IMF progress has been remarkable – I have seen the Foundation triple its revenue in the last five years! This growth in funding has allowed the IMF to create and to launch many new programs and services for patients around the world, caregivers, and professional members of the myeloma community. We have expanded our educational programs and increased our overall funding for research.



Saletan at an IMF Patient & Family Seminar with Dr. Robert Kyle

Probably the most significant research project being funded by the IMF is the innovative Bank On A Cure® initiative. In 2002, Susie Novis called me after the IMF Scientific Advisory Board's annual retreat, and shared with me an idea of founding a collaborative DNA databank to provide doctors with access to DNA data that could help move our understanding of myeloma forward. In my opinion, Bank On A Cure holds out tremendous promise, both for patients and the medical community. Cancer treatment that is customized for the patient's individual DNA profile will facilitate more effective and less toxic healing. This concept also assists pharmaceutical companies in developing, engineering, and refining drugs.

What is your outlook for the future of the IMF?

Frankly, I look forward to the day when the IMF goes out of business! The bottom line is that the IMF is here to help patients; when a cure for this disease is found and myeloma becomes history, our job will be done. But the only way the IMF will be able to achieve extinction is if we are successful in continuing to increase our funding for research, while we help today's patients and their doctors deal with the disease. **MT**

BRIAN G.M. DURIE, MD

Myeloma Today: ***Please tell us a little about your background.***

Brian G.M. Durie: I was born in Scotland, where I graduated from the University of Edinburgh Medical School in 1966. My internship was served at the Edinburgh Royal Infirmary working as assistant to Professor Sir John Bruce, a prominent orthopedic surgeon, and Professor Sir James Fraser, one of the leading internal medicine physicians in Scotland. I completed my residency and fellowship in Hematology and Oncology at the Mayo Clinic in Rochester, Minnesota. It was there that I first worked under the direction of Dr. Robert Kyle. At the Mayo Clinic, I conducted several research projects including special analyses of the impact of computers on medical research and medical practice.

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Upon completion of my fellowship training, I moved to Tucson and began working in the Department of Hematology/Oncology at the University of Arizona. In my first year there, I worked on a computer project utilizing new statistical methods to calculate the number of myeloma cells in the body at different stages of disease. This project led to the development of the Durie/Salmon clinical staging system for myeloma, with Dr. Sydney Salmon, which was published in 1975 and has been used worldwide for the evaluation of patients with myeloma. In 1981, I earned the appointment of Professor of Medicine.

In 1989, I assumed the chair as Professor of Clinical and Laboratory Hematology, Chairing Cross and Westminster School of Medicine, University of London. I served as Chairman of the European Oncology Research and Treatment Group (EORTC) Myeloma Committee when the randomized trial comparing stem cell transplant with standard chemotherapy was planned and subsequently implemented by Dr. Michel Attal for the IFM group. In 1992, I came to Los Angeles to chair the IMF and work at the Cedars-Sinai Medical Center as Director of Myeloma Programs.

What are your current professional activities?

At Cedars-Sinai Comprehensive Cancer Center, I evaluate and treat from five to ten newly diagnosed myeloma patients each week, totaling several hundred new patients each year. I direct a variety of research projects, including imaging with PET scans, molecular studies, virus culture research, and a range of myeloma treatment studies involving novel agents. In my role as National Director for Hematologic Malignancies for Aptium Oncology, I coordinate clinical trial activities and set up sponsored research. I am co-Chairman, with Dr. Bart Barlogie, of the Myeloma Committee for the Southwest Oncology Group (SWOG), which conducts major national clinical trials to evaluate new myeloma therapies.

How did you become involved with the founding and growth of the IMF?

The original ideas for the International Myeloma Foundation were laid out in November of 1989 in a coffee shop in London. Brian Novis, Susie Novis, and I were talking about what we could do to help make a difference for myeloma patients. Little did we realize at the time how that conversation would not only change our own lives but the lives of so many people around the world. IMF officially opened for business in October of 1990, with Brian Novis working out of the basement of his home.

At that time, there had never been a "Myeloma Hotline" or a "Patient & Family Seminar." Public knowledge about myeloma was at a very low level. There was a critical need to improve day-to-day diagnosis and treatment for myeloma patients, as well as to promote new research. The IMF brought together, for the first time, world experts in myeloma, working together in a collaborative effort to improve the quality of life for myeloma patients, while working towards prevention and a cure.

Within the IMF's first year of existence, plans were made to publish Myeloma Today, to host the first Gala Benefit to raise money and awareness about myeloma, and to hold both the first Patient & Family Seminar in Los Angeles and the first Clinical Conference on myeloma in Phoenix, Arizona. Since then, there have been over 100 IMF Patient & Family Seminars around the world, and regular clinical conferences of different types.

Through these meetings, the IMF website, and numerous publications, the Foundation reaches out to millions of people per year, including the over 20,000 newly diagnosed myeloma patients around the globe. Today, there is much more myeloma research and many new drugs that offer hope for myeloma patients faced with a dangerous disease.

What is your outlook for the future of the myeloma community?

I have served as Chairman of the Board of the IMF, as well as a Scientific Advisor, since the IMF was founded. The Scientific Advisory Board is chaired by Dr. Robert Kyle. Currently, I also serve on the Scientific Advisory Boards of IMF Latin America, IMF Japan, and Myeloma Canada. I am very proud of the work that the IMF has done and continues to do around the globe to fulfill its mission.

In my work with myeloma patients, I have seen their average life expectancy double, thanks in part to the education, advocacy, and research funding of the IMF. New approaches to myeloma therapy have not only improved the overall survival of patients but also their quality of life. Clinicians and scientists are continuing to expand knowledge of myeloma and how it responds to treatment. This work results in an improved outlook for myeloma patients. To this end, my latest projects include guidelines for bisphosphonate use to avoid ONJ as well as guidelines for DVT prevention related to the use of thalidomide and Revlimid.

In the scientific and clinical communities, there has been an outstanding show of collaboration between the members of the IMF Scientific Advisory Board, the Bank On A Cure® Advisory Board, and the International Myeloma Working Group. These experts represent all major myeloma research facilities and hospitals around the world. Since I have been working in the myeloma field, we have never before been so firmly on the path to a cure. **MT**

Editor's Note: Dr. Durie has achieved many honors and awards. He is the recipient of the Leukemia Society of America Scholar Award, and received the US Hematological Research Foundation annual award, among many others. He is a Marquis member of "Who's Who in America" and "The Best Doctors in America." Dr. Durie holds an international patent for scintillation autoradiography. He has published more than 600 research papers and abstracts, as well as numerous book chapters, articles, and published books. The second edition of his textbook Multiple Myeloma and Related Disorders was published in 2005. Major recent published articles include the new International Staging System in 2005 and the new Uniform Response Criteria for Multiple Myeloma in 2006.

48TH ANNUAL MEETING OF THE AMERICAN SOCIETY OF HEMATOLOGY

An overview of myeloma-related news

Introduction

The mission of the American Society of Hematology (ASH) is to further the understanding, diagnosis, treatment, and prevention of disorders affecting the blood, bone marrow, and the immunologic, hemostatic, and vascular systems. Since 1958, the ASH annual meeting has provided a forum for discussing critical issues in the field of hematology. The 48th Annual ASH Meeting and Exposition took place on December 9th-12th at the Orange County Convention Center in Orlando, Florida. Nearly 20,000 attendees from around the world participated in the four-day meeting. Oral and poster presentations, chosen by peer-reviewers from abstracts submitted prior to the annual meeting, contained exciting developments in scientific research. Plenary symposia and named lectures on specialized areas of hematology were also presented throughout the meeting program.

The advances in the treatment of myeloma caused much excitement at the 48th annual meeting of ASH. A large number of abstracts presented dealt with novel agents such as Revlimid®, VELCADE®, and thalidomide. For the first time at ASH, a whole session of the annual meeting was devoted to the new paradigm of using novel therapies as the first approach to the treatment of myeloma. Novel agents have been previously studied in relapsed myeloma, so the current emphasis is on investigating their use in the frontline setting.

Revlimid® Updates

Multiple significant studies presented show that Revlimid is helping a growing range of myeloma patients by extending its utility. In some cases, the data significantly build on previous studies to show long-term response in newly diagnosed patients. In one study of Revlimid plus dexamethasone as frontline therapy, conducted by Drs. S. Vincent Rajkumar, Martha Q. Lacy, and colleagues (Mayo Clinic, Rochester, MN), the overall response rate was 91%. With a low rate of disease progression after more than two years, 67% of patients achieved a complete or very good partial response based on the International Myeloma Working Group's new uniform response criteria for multiple myeloma. The relapse rate at two years was only 18%. At the very least, these results are equivalent to what had been achieved in the past with autologous transplantation, but without the transplant-associated risks and toxicities.

Other studies presented at ASH show that: Revlimid plus dexamethasone may "overcome the poor prognosis" of patients with certain chromosome abnormalities (such as 13q deletion); Revlimid plus melphalan and prednisone provides a complete response or very good partial response in nearly half of the elderly patients newly diagnosed with myeloma; Revlimid combined with VELCADE is producing durable responses even in patients who have already failed on each drug alone; earlier use of Revlimid results in a more favorable response in myeloma patients who have already failed another treatment.

Researchers have learned that Revlimid has multiple mechanisms of action, some still unknown, but many of which have been identified and characterized. The drug blocks the growth of tumor blood vessels, sensitizes the cancer cells to natural killer cells, and suppresses the TNF-alpha growth factor associated with inflammation. Combining the activities of these and possibly other mechanisms is allowing physicians to attack the cancer at its source, and to expand the use of Revlimid.

Bank On A Cure® Updates

In another significant ASH session, researchers working with the IMF's unprecedented global, collaborative Bank On A Cure® initiative presented data identifying genetic pathways that may explain why some patients suffer from blood clots when undergoing thalidomide therapy for myeloma. The pathways may shed new light on individual differences in the response to cancer and its treatment, and may lead to the development of screenings and tailored interventions to prevent these side effects.

The findings specifically involve thalidomide, a widely prescribed treatment that has been shown to extend and improve the quality of life for myeloma patients. An estimated 15% to 30% of patients treated with thalidomide and dexamethasone without aspirin prophylaxis suffer a venous thromboembolic event (VTE) as a major complication. The research team looked at genetic differences between patients who suffered from blood clots and those who remained event-free, and attributed the VTEs to gene clusters responsible for rapid drug metabolism, inflammation, and the rate at which the tumor responds to treatment. This means patients with genes that can be identified for rapid thalidomide metabolism and rapid tumor breakdown were most likely to experience blood clots.

"We were surprised that we did not find genes involved with the blood coagulation cascade as a differentiating risk factor, but instead we identified genes associated with DNA repair, drug metabolism, inflammation, and tumor lysis," said Bank On A Cure co-director Dr. Gareth Morgan (Royal Marsden Hospital, London, UK). "While rapid tumor lysis is a frequent problem in cancer care, in this case it affects only specific individuals – patients we believe we can now identify in advance." In all, seven genes were validated using a custom chip developed for Bank On A Cure. "Identifying these pathways tells us who is at risk, why they're at risk, and how we should approach intervention," said co-director Dr. Brian Van Ness (University of Minnesota), a developer of the custom myeloma chip. "Our objective is not just to develop biological markers so we can anticipate a patient's response, but to increase our understanding of the mechanisms of cancer, the drugs we use against it, and how that should vary from one person to another." IMF chairman Dr. Brian G.M. Durie (Cedars-Sinai Comprehensive Cancer Center, Los Angeles, CA) said, "Our next step is to build this genetic data into a clinical risk model so we can develop screens to predict how an individual patient will respond to treatment, and apply appropriate intervention strategies."

In a separate presentation — Deep Vein Thrombosis In Myeloma: Estimate Of Problem And Recommendations For Therapy Based Upon A Survey Of Members Of The International Myeloma Working Group — aspirin was recommended as a prophylactic treatment for blood clots in myeloma patients who are treated with thalidomide or Revlimid®, a novel immunomodulatory drug approved in 2006 in the US for myeloma patients who have failed at least one previous treatment. The Bank On A Cure finding that genes related to inflammation are involved in this pathway helps explain why aspirin is effective in reducing the occurrence of VTEs in these patients.

Bank On A Cure researchers are also using the custom chip to identify potential prognostic markers of survival outcomes. Early analysis presented at ASH — SNP Associations with Event Free Survival in Myeloma from Two Phase III Clinical Trials using the Bank On A Cure Chip — is

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ANEMIA IN MULTIPLE MYELOMA

Myeloma Today in conversation with Prof. Heinz Ludwig

Myeloma Today: ***What is anemia?***

Prof. Heinz Ludwig: Anemia is not a single disease but a condition with many forms and multiple possible causes. It can occur either because of the increased destruction of red blood cells (RBCs, erythrocytes) or from their loss (from bleeding) and/or insufficient production. The most important component of the RBC is hemoglobin (Hgb). The process of manufacturing, recycling, and regulating erythrocytes is called erythropoiesis. Most of the work of erythropoiesis occurs in the bone marrow. Low blood oxygen triggers kidney cells to release the hormone erythropoietin (EPO), which acts in the bone marrow to increase RBC production.

What can you tell us about anemia in multiple myeloma?

Anemia is a common complication of myeloma. As in other situations, the anemia in myeloma patients can have multiple causes. In myeloma patients, anemia may be caused by the myeloma itself, by active anti-myeloma treatment, and/or by iron deficiency. It is hoped that as the efficacy of available myeloma treatments improves, the incidence of anemia cases caused by the disease itself will decrease.

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The adverse impact of anemia on physical functioning, quality-of-life, and long-term outcome is well documented. It can cause disabling symptoms. Therefore, the investigation and treatments of anemia should be an integral part of patient care. In fact, the majority of present-day myeloma patients are likely to experience this condition at some point.

Please tell us about the European Cancer Anemia Survey.

I participated in the recent European Cancer Anemia Survey (ECAS), which evaluated anemia in patients with myeloma and lymphoma in order to define anemia prevalence, incidence, and treatment patterns, as well as to identify anemia risk factors in European patients. Data for a subgroup of 2,360 patients were analyzed; variables included age, sex, tumor type/stage, cancer and anemia treatment, World Health Organization (WHO) performance status, and Hgb levels. There were 704 myeloma patients in the group of 2,316 total evaluable patients. Anemia rate at enrollment was 52.5%, and Hgb levels correlated with WHO scores. Anemia prevalence during ECAS was 85.3% for the myeloma patients. The overall incidence in chemotherapy patients was 55.4%. Only 47.3% of anemic patients received anemia treatment during ECAS. The overall Hgb nadir for initiating treatment was 8.9g/dL. In summary, myeloma and lymphoma patients had a high prevalence and incidence of anemia; however, anemia was not optimally treated. We hope that the predictive factors identified by ECAS will help clinicians develop optimal anemia treatment strategies for both myeloma and lymphoma patients.

Which patients are at particular risk of developing severe anemia?

Factors found to significantly increase anemia risk were low Hgb levels prior to start of myeloma treatments, female gender, persistent/resistant myeloma despite active anti-myeloma treatment, and the use of platinum as part of therapy. Myeloma patients above age 70 had an approximately 90% risk of developing anemia. In females, normal Hgb levels are lower than in males, so women are at greater risk of developing anemia. Chemotherapy, which is designed to target and destroy the myeloma cells, can also destroy healthy cells and reduce bone marrow function, causing a drop in Hgb levels and increasing the risk of anemia. Patients who show a low initial Hgb level prior to starting chemotherapy are at particular risk of developing anemia that may be severe enough to require transfusions.

Are myeloma patients more at risk of developing severe anemia than others?

Yes. In comparison with patients who have other cancers, myeloma patients are at particular risk of developing severe anemia because, as a group, they have reduced production of erythropoietin by kidney cells and, consequently, low blood levels of erythropoietin. Although overall reduced kidney function occurs in only 5-10% of myeloma patients, the reduced EPO production occurs in as many as 50%. Even very slight renal impairment can cause reduced erythropoietin production that will lead to anemia.

What can be done to combat anemia in myeloma?

Exogenous recombinant human erythropoietins (epoetins) have been used successfully to treat anemia caused by myeloma itself and/or active anti-myeloma treatment. In our high-dose therapy study (involving autologous stem cell transplant), 1 out of 3 patients below age 70 received epoetin during treatment. They received mainly epoetin alpha, although all three epoetin agents are available (epoetin alpha, epoetin beta, and darbepoetin). Through a combination of clinical studies and extensive experience in the real-life clinical setting, epoetin has been shown to be efficacious and well tolerated, increasing Hgb levels, reducing the need for transfusion, and improving quality of life. This favorable profile has been demonstrated across a broad range of cancer types, irrespective of the treatment used. The effect of erythropoietin treatment is rapid, being seen as early as 4 weeks following the start of therapy. As for dosing, it has been found that the once-weekly regimen of epoetin alpha or beta may result in improved treatment compliance due to greater convenience than the three-times weekly regimen. Darbepoetin can be given weekly or as infrequently as every three weeks.

How well do patients respond to erythropoietin therapy?

Approximately 70% of myeloma patients with anemia respond to treatment with epoetins. The question that we have been asking is: How can we increase the response rate? There has been one trial, involving a small number of patients, which has shown that non-responders to erythropoietin become responders when intravenous (IV) iron is given in addition to the erythropoietin. Iron supplementation can convert a non-responder to a responder. This is a new field which may change the way we treat myeloma patients who have anemia.

How does iron supplementation work, and how is it used?

Iron is the critical component of Hgb in RBCs which enables oxygen to be picked up in the lungs and carried throughout the circulation to sites where oxygen is required. Iron absorption from dietary intake and utilization from bodily stores are severely altered in cancer-related anemia. Insufficient

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ASH OVERVIEW — continued

showing that there are detectable genetic differences between short- and long-term survivors. From these findings it may be possible to better predict which patients will need more aggressive therapies, and then to integrate genetic markers for adverse effects, along with recommendations for prophylaxis, to help optimize treatment on an individual basis for patients with myeloma.

VELCADE® Updates

One significant study by Aptium Oncology Research Network (Los Angeles, CA) and Cancer Research and Biostatistics (Seattle, WA) focused on long-term follow-up of patients treated with VELCADE alone and in combination with dexamethasone as frontline therapy for myeloma. Forty-eight patients were evaluable and, at the end of treatment, the overall response rate was 90%. Response to VELCADE alone was rapid. Dexamethasone, which was added for 36 patients, improved responses in 23 patients. In summary, VELCADE alone and in combination with dexamethasone is an effective frontline therapy for myeloma. The treatment is well tolerated and toxicities were manageable and reversible. Stem cell harvest and engraftment were successful in all patients proceeding to transplant. This regimen is now being compared to VAD in a phase III study comparing these two regimens as induction therapy prior to transplant.

Myeloma Education Programs

As part of the ASH special education programs, Dr. Philip R. Greipp (Mayo Clinic, Rochester, MN) chaired a program on multiple myeloma. Program presentations included Treating Patients Who Are Not Candidates for Transplant by Dr. Robert Z. Orlowski (University of North Carolina at Chapel Hill, Chapel Hill, NC), Thrombotic Complications of Myeloma Therapy by Dr. Jeffrey Zonder (Wayne State University School of Medicine, Detroit, MI), and Bisphosphonate Complications Including Osteonecrosis of the Jaw by Dr. Bhoomi Mehrotra (Long Island Jewish Medical Center, New Hyde Park, NY). A chapter based on this special session will be published in the Education Program Book, Hematology 2006.

Conclusion

With the introduction of new myeloma therapies, the responses being achieved have already translated into significantly improved average overall survival of patients. Even in the relapse setting, these new therapies have doubled patients' life expectancy. "The many studies being presented at ASH confirm the good news we have been experiencing first-hand in our work with myeloma patients," said Dr. Durie. "As we gain experience using new therapies alone and in combination with other new and existing myeloma treatments, we are learning more about how blood cancers respond to treatment, and which are the most critical pathways we need to block in order to stop the cancer. The wide range of presentations at ASH should enable us to continue to improve the outlook for an expanding range of patients. This is perhaps the most encouraging meeting of ASH since I have been working in the myeloma field." **MT**

ANEMIA IN MULTIPLE MYELOMA — continued

availability of iron for erythropoiesis is the major limiting factor for RBC production, in spite of the presence of normal or increased storage iron.

Although the ASH/ASCO guidelines recommend iron substitution "when indicated," specific information on the mode of iron therapy and its indication is not provided. There is little information on the efficacy of oral iron supplementation and the only randomized trial comparing oral iron with no iron or IV iron did not reveal a benefit for the oral application mode. It did, however, show a significant increase in response rate and quality of life in the group treated with intravenous iron. Recently, additional evidence for the benefit of intravenous iron therapy in addition to treatment with erythropoiesis- stimulating substances was provided at the meeting of the European Hematology Association. A Scandinavian group (Hedenus et al.) presented results of a small study on 69 patients with myeloma or lymphoma that were randomized to weekly erythropoietin beta with or without intravenous iron. The patients on IV iron experienced a higher response rate and responses occurred faster. The other study that was presented (Vandenbroek et al.) showed reduced transfusion need and slightly higher response rate when darbepoetin was combined with bi- or thrice-weekly IV iron supplementation.

The role of intravenous (IV) iron supplementation is of increasing interest as a possible means of improving response. Recent studies evaluated the impact of IV iron supplementation in comparison with oral iron therapy and with control in anemic cancer patients treated with epoetin (alfa, beta, or darbepoetin). Two studies presented at ASH in December of 2006 show that concomitant treatment with IV iron is superior to oral iron or no treatment.

What are the type, dose, and schedule of IV iron in these studies?

One of these was a randomized, open-label, multi-center study designed to evaluate the safety and efficacy of IV iron versus standard practice in chemotherapy-induced anemia patients receiving darbepoetin alfa. Interim efficacy analyses showed a higher response rate for darbepoetin alfa with IV iron, with no difference in the safety profile. Eligible patients with chemotherapy-induced anemia and a baseline Hgb value < 11g/dL received darbepoetin alfa 500 mcg administered every 3 weeks. Patients were randomized 1:1 to IV iron 200 mg (administered as a single dose at the same time as darbepoetin alfa or in two doses of 100 mg within 3 weeks) or standard practice (oral iron or no iron). A total of 400 patients were randomized. In summary, the combination of darbepoetin alfa and IV iron appeared to be associated with a trend toward increased mean serum ferritin (protein that stores iron in the body) levels compared to the standard practice control arm. The findings presented suggest the need for additional exploration of iron uptake and demand in cancer patients treated with darbepoetin alfa.

Are the data sufficient to support offering IV iron as a current treatment option?

In the patients studied who received IV iron, the benefits of IV iron supplementation included higher response rates, shorter time to increase of Hgb, lower need for RBC transfusions, and improved quality of life better as compared to patients treated with oral or no iron at all. It is also important to note that there is a financial benefit to the reduced need for erythropoietins because patients require lower doses to achieve equal or greater benefit. Severe side effects were rare and tolerance was good in most patients. Concomitant IV iron supplementation is not standard treatment at this time, and information on long-term safety is not available, but IV iron administration seems likely to evolve as an important adjunct to treatment with erythropoietic agents. **MT**

2007 IMF RESEARCH GRANT RECIPIENTS ANNOUNCED

The recipients of the 2007 IMF Research Grant awards were announced at the gathering of the Foundation's Scientific Advisors, held at the 48th Annual Meeting of the American Society of Hematology (ASH) in Orlando, Florida.

2007 Brian D. Novis Senior Research Grant

William Matsui, MD
Sidney Kimmel Comprehensive Cancer Center
Johns Hopkins University
Baltimore, Maryland

"Hedgehog Signaling in Myeloma Cancer Stem Cells"

Many agents produce complete remissions in multiple myeloma, but most patients experience disease relapse and progression. Dr. Matsui and colleagues have studied the cells responsible for myeloma growth and have found that myeloma "stem cells" resemble B cells rather than plasma cells and share several characteristics with normal stem cells. Therefore, strategies that target these specific stem cell pathways may be able to prevent myeloma growth and relapse. Dr. Matsui and colleagues have found that the Hedgehog signaling pathway that is required for stem cell regulation during normal embryonic development is active in myeloma cells, and they propose to examine its potential as a target against myeloma stem cells.

2007 Brian D. Novis Junior Research Grants

Roberto Bellucci, PhD
Dana-Farber Cancer Institute
Boston, Massachusetts

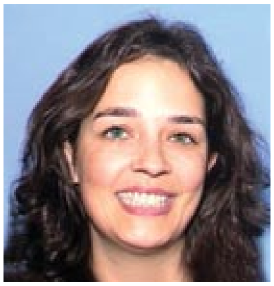
"Genetic Screening for Myeloma Cell Susceptibility to NK cell mediated lysis using shRNA libraries"

At present, allogeneic stem cell transplantation is the only approach that is potentially curative for patients with myeloma. The effectiveness of this therapeutic approach is in large part due to the graft versus myeloma effect. A compelling example of this effect is provided by donor lymphocyte infusion, where 40-50% of patients with myeloma can achieve a response in the absence of any other therapy. However, when compared to other chronic hematological malignancies, graft versus myeloma effect is less powerful: only 10-20% of myeloma patients can achieve a long-lasting complete response. Although several studies have shown that tumor rejection is a coordinated immune response involving both the adaptive and the innate immunity cells, the molecular mechanisms are not yet fully understood. Dr. Bellucci and colleagues propose to study the effects of kinase genes on NK lytic activity.

Nicola J. Camp, PhD]
University of Utah School of Medicine
Salt Lake City, Utah

"The Familiality of Multiple Myeloma and Related Phenotypes"

The causes of multiple myeloma are largely unknown, but it is likely that genetic mutations caused both by environmental and internal factors are involved. Dr. Camp aims to identify the gene defects involved in myeloma. This may lead to helpful information about the cause and progression of myeloma, and to improvements in diagnosis and treatment of this disease. If genes are involved in myeloma, family members have a higher chance of having genetic mutations involved with myeloma than would a random person in the population. Results from familiality analyses immediately provide information about which family members should be screened and more closely followed. Familiality analyses also provide the information needed to design studies to find the genes for myeloma. Beyond investigating myeloma by itself, the same types of analyses can be used to investigate the relationship between cancers of different types. For example, are the relatives of an individual with myeloma at increased risk of only myeloma or other blood cancers or solid tumor cancers as well? Dr. Camp and colleagues will use the Utah Population Database to perform familiality studies for myeloma and other blood and solid tumor cancers.



Claire M. Edwards, PhD
Vanderbilt University Medical Center
Nashville, Tennessee

"Effects of VELCADE on the protein expression profile at the myeloma-bone interface in vivo"

VELCADE®, a proteasome inhibitor, represents an important advance in the treatment of multiple myeloma. In addition to inhibition of myeloma cell growth, proteasome inhibitors also affect bone cells, resulting in an increase in bone formation. Therefore, the effect of proteasome inhibition in bone cells may play a role in the therapeutic effects of VELCADE in myeloma. Dr. Edwards and colleagues will use a pre-clinical model of myeloma and state-of-the-art proteomic techniques to determine the effect of VELCADE on the protein expression profile of myeloma cells and bone cells at the myeloma-bone interface in vivo. These studies will further our understanding of the mechanism of action of VELCADE in multiple myeloma, and may lead to the identification of novel therapeutic targets for the treatment of myeloma bone disease.

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RESEARCH GRANT RECIPIENTS — continued from page 9

Silvia Ling, MD
Centenary Institute of Cancer Medicine and Cell Biology
Newton, Australia

"Predicting Response of Multiple Myeloma to Proteasome Inhibitors"

Multiple myeloma is currently incurable by chemotherapy. However, about a third of relapsed multiple myelomas respond to a new class of drugs, the proteasome inhibitors. It would be very helpful to identify those patients who will benefit from the drugs in order to expedite their treatment. If patients who will not respond to the drugs could be identified, then the expense and unpleasant side effects of a needless treatment could be avoided. In addition, treatment with therapies that are more likely to work would not be delayed. At present, there is no known way to predict which myelomas will respond to proteasome inhibitors. Dr. Ling and colleagues think they have found a molecular marker that can do so. The aim of this project is to confirm that the marker predicts responsiveness to proteasome inhibitors in human myeloma patients and to investigate related factors that determine sensitivity to the drug.

2007 IMF Japan AKI Award

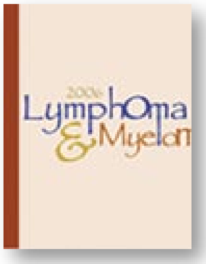
This myeloma research grant is awarded in memory of IMF Japan founder Akira Horinouchi.

Akira Sakai, MD, PhD
Research Institute for Radiation Biology
and Medicine
Hiroshima University
Hiroshima, Japan

"Analysis of the aspects induced by Cyclin D1 overexpression in myeloma cells leads to a new strategy of treatment of multiple myeloma"

Myeloma cells in the bone marrow are a heterogeneous cell population. Dr. Sakai reports that phenotypic analysis of mature myeloma cells correlates with the cells' sensitivity to chemotherapeutic agents. A recent study analyzing gene expression in myeloma cells showed that the cells fall into 7 groups. Two showed a high expression of cyclin D1 together with a low expression of cyclin D2, and they belong to the low-risk group based on event-free and overall survival. Dr. Sakai also reported that cyclin D1 over-expression was detected in about 40% of myeloma patients, and no chromosomal abnormalities were detected in half of them. It is not clear whether the down-regulation of cyclin D2 in myeloma cells might offset cyclin D1 over-expression in cell biology, and it is not clear how expression of these cyclin Ds are regulated. Since cyclin D1 promotes the cell cycle progression, and cyclin D1 over-expression is a marker of high-grade malignant cells in breast carcinoma or colon carcinoma, Dr. Sakai and colleagues sought to explain why cyclin D1 over-expression appears to be a favorable prognostic variable for myeloma patients treated with high-dose chemotherapy and single or double autologous transplantation. Recently, Dr. Sakai and colleagues have established a myeloma cell line with cyclin D1 over-expression to analyze biological changes in these cells. They plan to analyze characteristics of myeloma cells with cyclin D1 over-expression purified from the bone marrow of myeloma patients, and to confirm the aspects found in the cyclin D1 transfectant. **MT**

2006 LYMPHOMA & MYELOMA CONFERENCE



The Center for Lymphoma and Myeloma at Weill Medical College of Cornell University hosted the Fourth Lymphoma & Myeloma Conference on October 19–21, in New York City. Since 2000, this conference has provided a broad update and overview of rapidly expanding knowledge in lymphoma and myeloma. As of 2006, the conference has moved to an annual schedule. Dr. Morton Coleman of the Center for Lymphoma and Myeloma at New York Presbyterian Hospital, Weill Medical College of Cornell University, chaired the Lymphoma & Myeloma Conference. His colleague, Dr. Ruben Niesvizky, co-chaired the Myeloma Session.

On October 19th, the first day of the conference, Session I opened with a discussion of the biology of myeloma. This session also covered topics such as Cytogenetics and FISH, genomic characterizations, animal models and imaging, angiogenesis, and cell cycle control in myeloma. Session II covered the pathogenesis and treatment of myeloma bone disease. Next, a luncheon symposium addressed the clinical application of current and future directions in myeloma therapy, especially for newly diagnosed patients. Diagnosis, staging, and effective management strategies for the various types of myeloma were discussed in Sessions III & IV. These sessions also addressed relapsed and refractory myeloma, and the use of VELCADE® and Revlimid® as initial therapy for myeloma.

Next day started with a session that debated the issues associated with high-dose chemotherapy and transplantation. After lunch, an update on immunomodulators in myeloma was followed by an immunotherapy update, with included presentations on the role of vaccines in myeloma. Most of the sessions on the closing day of the conference focused on lymphomas, with the exception of the final session of the day, which included a presentation on PET scanning for both lymphoma and myeloma.

Drawing on the expertise of more than 50 leaders in the fields of molecular biology, pathology, immunology, and translational and clinical research, the 2006 Lymphoma & Myeloma Conference presented a thorough understanding of the evolution of thought and therapy of the topics under discussion. The integrated, interdisciplinary approach of the conference made for a stimulating, interactive setting for continued medical education for physicians, physicians-in-training, nurses, and pharmacists interested in lymphoma, myeloma, and related plasma cell disorders and their management. **MT**

GROUNDBREAKING RETREAT FOCUSES ON NOVEL THERAPIES

The first meeting of the Nursing Leadership Board (NLB) took place November 4–5, in Dallas, Texas. The scope of this project is to develop broad recommendations for nursing care for myeloma patients, and at the initial NLB Retreat the focus was on Novel therapies. The NLB is an exciting new initiative of the International Myeloma Foundation. The first goal for the Board is to develop guidelines for nurses on the management of side effects associated with the novel therapeutic agents used in treating myeloma patients in order to help nurses in the community to optimize care.

Twenty nurses from the leading centers treating myeloma patients in the US were selected to participate in the NLB. The NLB will expand to include nurses internationally, to ensure that patients around the world receive the best care possible.

At this inaugural meeting the founding nurse members were:

Beth Faiman, Cleveland Clinic; Stacey Sandifer, Cancer Center of the Carolinas; Bonnie Jenkins, Myeloma Institute/UAMS; Elizabeth Billoti, St. Vincent's Comprehensive Cancer Center; Emily McCullagh, Memorial Sloan Kettering Cancer Center; Ginger Love, H. Lee Moffitt Cancer Center & Research Institute; Jeanne Westphal, Meeker County Memorial Hospital; Joseph Tariman, formerly of Northwestern University (currently a PhD. candidate at University of Washington); Kathleen Curran, University of Pittsburgh; Kathy Lilleby, Fred Hutchinson Cancer Research Center; Katy Rogers, Sidney Kimmel Comprehensive Cancer Center; Kena Miller, Roswell Park Cancer Institute; Maria Gavino, MD Anderson Cancer Center; Patricia Mangan, Hospital of the University of Pennsylvania; Sandra Rome, Cedars-Sinai Medical Center; Teresa Jahns, Mayo Clinic; Page Tertolotti, Samuel Oschin Comprehensive Cancer Institute.

The IMF was honored to have Deborah Doss from Dana-Farber Cancer Institute acting as the Chairperson for the task force committees, along with fellow members of the executive committee Kathleen Colson, also from Dana-Farber, and Lisa Smith, from the Cancer Center of the Carolinas. Special thanks go to Kathleen and Lisa for their participation as faculty facilitators at this inaugural meeting.

The weekend began with a welcome from Susie Novis, President of the IMF, and Diane Moran, Senior Vice President Strategic Planning of the IMF, who presented the vision, charter, and meeting focus of the NLB.

Dr. Brian Durie provided an excellent review of novel therapies to set the stage for the important work that the outstanding team of nurses had in front of them. He focused on the new agents Revlimid®, Thalomid®, and Velcade®, alone and in combination, and in the various indications for their use.

Lisa Smith presented the spectrum of side effects with novel therapies, which opened the discussion among the participants on their experience. This discussion became the framework for developing the management guidelines. The objective of this session was to present an overview of common side effects often associated with novel therapies. The nurses then reviewed the NLB comprehensive needs assessment survey that had been completed by each participant prior to the retreat, for insight into nursing clinical practice experience, and to explore gaps that may exist between protocol and practice-evident side effects.

The needs assessment survey showed that the treatment protocols with which nurses have the most experience are: Revlimid/dex, Velcade, and

Founding members of the Nursing Leadership Board

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NURSING LEADERSHIP BOARD — continued

Thalomid. Of the common side effects observed by the nurses as indicated on the survey, deep vein thromboses (DVTs) are the most challenging to manage. The NLB identified which side effects impact quality of life and which are life-threatening. The Board then identified which were the top five side effects and "the survey said…"

Top five side effects:

- Peripheral Neuropathy
- Thrombocytopenia/neutropenia/myelosuppression/infection/fever
- DVT
- Steroid related
- GI related

Dr. Durie then led an interactive discussion on enhancing patient quality of life, focusing on current trends in supportive care. The objective of this session was to provide an overview of commonly used methods of supportive care, to describe trends in protocol-based supportive care, to discuss the NLB members' experience, and to identify and explore gaps that may exist between protocol-based supportive care trends and nursing clinical practice.

Kathleen Colson and Lisa Smith

Lisa Smith followed Dr. Durie with the discussion on Enhancing Patient Quality of Life. This session's objective was to highlight NLB survey-identified treatment protocols, to discuss NLB side effect management approaches identified in the survey, and to enumerate their experience with specific side effects that occur with the Revlimid/dexamethasone, Thalomid/Velcade, and Velcade/Melphalan regimens, respectively. These experiences and those with other commonly used protocols will become the framework for the guidelines.

After lunch Diane Moran led a discussion outlining some of the major consequences associated with side effects. Of major importance were the questions she posed:

- What are the current side effect management consensus and guidelines?
- What are the nursing needs associated with improving the management of side effects?

Diane then discussed how the NLB would develop and define position statements along with strategic recommendations.

Dr. Durie then led the group through a series of interactive questions focused on needs assessment, such as: "What is the primary role of oncology nurses in management of patient side effects during treatment for myeloma?"

Katy Rogers and Sandra Rome

The first day of the retreat ended with Dr. Durie leading the last interactive session. In this session, he presented three case studies. Case one was an older patient on Revlimid who was experiencing neutropenia. Case two was that of a younger patient who had had a transplant. After two years of remission he showed increased IgG levels, so he was now being treated with Velcade. This patient also had chromosome 13 deletion. After four cycles of Velcade with an excellent response, he experienced thrombocytopenia (low platelet count). Case three was a patient on frontline Thalomid/dex, with multiple risk factors who was experiencing numerous treatment related side effects. Following each case the question was asked, "How would you manage this patient?"

The Board began the Sunday session by identifying those side effects that they felt were the most crucial: those that seriously affected patients' quality of life and those that could be life-threatening. The NLB identified the following side effects: peripheral neuropathy, thromboembolic events, myelosuppression, steroids related, and GI related problems. The nurses then went into small breakout groups for in-depth discussions, with a directive to develop an issues statement, a corresponding position statement and strategic recommendations for each side effect. They focused on how to treat these side effects, and were asked to begin the process of reaching a consensus and establish guidelines.

The next steps for the Board are to develop a consensus and to write the Management Guidelines for Nurses Treating Myeloma Patients.

The establishment of the Nurse Leadership Board is truly a groundbreaking endeavor, and the consensus of the Board and the IMF is that the work that they will do will change the lives of myeloma patients around the world. Treatment and management of side effects impacts not only a patient's ability to stay on a therapy but also to gain full benefit from the therapy, and to enhance quality of life. The IMF is honored to collaborate with such an esteemed Board and we look forward to the work that lies ahead.

At the Saturday evening NLB dinner, Susie Novis was extremely pleased to make the exciting announcement that Celgene Corporation will provide a grant to the IMF to be used to enable each member of the Nurse Leadership Board to attend the XIth Myeloma Workshop, which will take place in Greece, June 25th – 29th, 2007. The room went wild! The IMF thanks Celgene for this incredible and unprecedented opportunity to bring the Nurse Leadership Board to this premier meeting – a learning experience until now not offered to nurses.

The IMF would also like to thank the inaugural sponsors of the NLB, Celgene Corporation and Millennium Pharmaceuticals. **MT**

NUTRITIONAL AND LIFESTYLE INFLUENCES ON MULTIPLE MYELOMA

Myeloma Today in conversation with Dr. Loch Chandler

Myeloma Today: ***Please tell us about your professional orientation.***

Dr. Loch Chandler: I am a naturopathic doctor and a licensed acupuncturist. The two areas of emphasis in my practice are cancer and clinical nutrition. I enjoy working closely with the other practitioners who are a part of a person's healthcare team, and helping people minimize the side effects of cancer treatment. By helping to relieve side effects, we can help improve the patient's quality of life and help support their recovery process.

Acupuncture can help people with cancer before, during, and after treatment. It helps to optimize the flow of energy, or Qi, in the body and is used to treat pain, nausea, peripheral neuropathy, and fatigue. Naturopathy blends ancient, pre-modern, and current philosophies and therapies. Its roots are in European "nature cures," which focus on diet, hydrotherapy, herbal medicine, and lifestyle changes.

Loch S. Chandler, ND, MSOM, LAc
Providence Integrative Medicine Clinic
Portland, Oregon

What is integrative medicine and how can it help during cancer therapy?

Integrative medicine is a healthcare model that blends individualized, evidence-based complementary and alternative medicine (CAM) together with conventional medicine in a patient-centered and whole-person approach. Examples of CAM therapies include acupuncture, naturopathic medicine, nutritional and supplement assessment, herbal medicine, homeopathy, massage, and mind-body therapies.

Integrative medicine can help mobilize a person's natural healing ability, improve tolerance of conventional therapy by decreasing side effects, decrease risk of cancer recurrence, and address a range of quality of life issues, such as sleep, fatigue, poor appetite, stress management, weight loss, and constipation.

Some patients and caregivers who think that they've never tried mind-body therapies might actually be benefiting from such therapies already! Mind-body work includes activities such as individual and family counseling, and participating in support groups. The benefits include stress management and relaxation, and connecting with other people affected by cancer. Examples of other mind-body therapies include meditation, relaxation, hypnosis, and visual imaging.

What role does nutrition play?

Certain food groups can help the body detoxify from cancer-causing substances, decrease levels of hormones that stimulate cancer cell growth, reduce blood supply to cancer cells, better balance the immune system, and improve the body's healing and recovery capabilities. I recommend the Mediterranean diet, which is high in vegetables, beans, fruits, nuts, whole grains, olive oil, and fish. It includes some dairy — mostly as cheese and yogurt — and moderate alcohol. The diet is low in red meat, poultry, potatoes, and refined sugar. Studies show many benefits to this diet: less obesity and heart disease, and a 60% reduced incidence of cancer. In particular, studies have shown that cabbage family vegetables are associated with lower rates of many cancers; one study indicated that more frequent intake may reduce risk for myeloma[1]. Green tea has many benefits, and one study has shown that it can cause myeloma cell death[2].

Should myeloma patients take supplements?

Nutritional deficiency is common during cancer treatment, but nutritional supplements should be chosen with great care. Supplements can benefit and harm. Using vitamins and/or herbs may increase or decrease the toxicity and/or effectiveness of chemotherapy. For example, Vitamin C may interfere with VELCADE®. It is best to seek professional advice and to take an individualized approach based on situation and needs.

What about lifestyle choices? Why is exercise so important?

Exercise improves blood counts, energy, mood, quality of life, sleep, immune function and weight regulation, while decreasing blood pressure and reducing nausea. Exercise is important for both cancer patients and caregivers. While physical activity is vital, an individualized plan is best, since each person's needs and abilities vary.

Can naturopathy reduce the effects of peripheral neuropathy?

Peripheral neuropathy (PN) can be a side effect of cancer and cancer treatment, nutritional deficiencies, diabetes, and cholesterol-lowering medications. It is most commonly described as numbness, pain, tingling, and weakness in hands and feet. PN can adversely affect sleep and the overall quality of life. Conventional treatments for PN can include non-steroidal anti-inflammatories, tricyclic anti-depressants, SSRIs, anticonvulsants, and implant devices. There are naturopathic approaches that can help in preventing or reducing the effects of PN. The history of PN shows a strong correlation to nutritional deficiencies so improved nutrition, an individualized supplement program, acupuncture, and drinking plenty of water can significantly reduce the severity of symptoms. In one study, 27% of patients who used CAM therapies (supplements, acupuncture, magnets, herbal remedies, and chiropractic) reported an improvement in neuropathy symptoms[3].

What should we look for in an integrative medicine practitioner?

Choose a qualified integrative medicine practitioner who has experience treating people with cancer. When interviewing prospective practitioners, seek out individuals who are licensed naturopathic doctors (ND) and acupuncturists (LAc) with a degree from a 4-year accredited school, licensed counselors or social workers (LCSW, MSW, LPC) with a Masters degree, and certified graduates of accredited mind-body programs (e.g. Harvard Mind-Body Program or Center for Mind-Body Medicine). Also, tell your oncologist and other conventional care providers about any use of CAM treatments and supplements, and ask all members of your healthcare team to consult with one another. **MT**

[1] Brown, Cancer Causes & Control, 2001;12(2):117-25.

[2] Nakazato, Clin Can Res, 2005;11(16):6040-9.

[3] J Neurol Sci, 2004 Mar 15;218(1-2):59-66.

IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

The IMF Hotline 800-452-CURE (2873) is staffed by Debbie Birns, Paul Hewitt, and Nancy Baxter.
The phone lines are open Monday through Friday, 8am to 4pm (Pacific Time).
To submit your question online, please email TheIMF@myeloma.org.

Question:

I have compression fractures in my back that are extremely painful. I have heard other myeloma patients mention a procedure called "kyphoplasty" that may help this problem. What can you tell me about it?

Answer:

Hotline staff: Debbie Birns, Paul Hewitt, and Nancy Baxter

Myeloma is a cancer that affects the plasma cells of the bone marrow. This rare and complex disease replaces healthy bone marrow with malignant plasma cells (myeloma cells), often causing widespread development of lesions and destruction of bone. Lesions occur most commonly in the bones of the spinal column. Most myeloma patients experience pain, especially in the back and the ribs. Sudden severe back pain can indicate that the vertebral body of a vertebra has fractured or collapsed. Fractures of the bones of the spinal column are called vertebral compression fractures (VCFs) or simply, spinal fractures. Treatments to alleviate the pain associated with VCFs range from over-the-counter medications to major open spine surgery.

Kyphoplasty is a procedure designed to help patients who have "intractable spinal pain secondary to vertebral body fractures." In lay terms, that means pain that does not respond to bed rest, pain medications, or back braces, and is caused by breaks in the vertebrae.

The vertebrae, when fractured, often compress nerves, resulting in unremitting pain. These fractures can also cause problems in addition to pain, depending upon which vertebrae are affected. For example, when the thoracic (mid-back) spine is compressed, a patient can have decreased lung capacity. When the lumbar (lower back) spine is compressed, a patient can have decreased lung capacity and even loss of appetite due to a reduction in abdominal space. And vertebral compression often leads to significant loss of height.

Previously, the only procedure available to help support collapsed vertebrae was vertebroplasty, which involves injecting a semi-liquid plastic cement called polymethylmethacrylate (PMMA) under high pressure into a fractured vertebral body through one or two bone biopsy needles. After injection, the PMMA hardens. This technique was developed to stabilize the spine, increase mobility, and decrease the pain from vertebral compression fractures. It does not, however, help with the spinal deformity, and there is a danger of leaks of PMMA into surrounding tissues.

Kyphoplasty involves inserting (under image guidance, using a radiocontrast medium) two balloons, one in either side of the vertebral space. The balloons are then inflated. By inflating the balloons, the doctor forces the "cancellous" or soft, central part of the bone outwards toward the outside of the vertebral body. The balloons used in kyphoplasty may allow some correction of the deformity by re-expanding the compressed vertebra. The expansion of the balloons also forces the soft, central bone tissue out toward the harder, outer bone of the vertebra, where it "dams up" the cracks and fissures in the fractured vertebra. The balloon is deflated and withdrawn after it is inflated, leaving a void or cavity. PMMA is then inserted into the cavity under low pressure. Because the walls of the vertebra are dammed up, the placement of the cement is more carefully controlled than in vertebroplasty, and the cement is therefore less likely to ooze out. With kyphoplasty, doctors are, in many cases, able to restore some portion of a patient's lost height. This depends largely on the state of the fractured bone tissue and how much time has passed since the fracture. Balloon kyphoplasty has been performed since 1998.

Results from the first multicenter long-term, prospective clinical study evaluating the benefits of balloon kyphoplasty treatment of spinal fractures were published in the September 2006 issue of Spine. The study evaluated 155 elderly patients with 214 spinal fractures caused by primary osteoporosis, secondary osteoporosis, or multiple myeloma. Multiple outcomes were evaluated over two years following balloon kyphoplasty, and the results demonstrated that patients experienced improvement in back pain, back function, and quality of life. In addition, the study documented improvements in restoring vertebral height.

In order to determine if kyphoplasty would be an appropriate option for you, you should speak to your oncologist, who may refer you to an orthopedic surgeon, neurosurgeon, or interventional radiologist. Kyphoplasty requires special training; it is especially important that the doctor who performs the procedure have experience in dealing with myeloma patients, since bones affected by myeloma are more fragile than those of people who undergo kyphoplasty for osteoporosis. If your oncologist thinks that kyphoplasty may be a viable option but doesn't have a referral for you, you may call us here at the IMF Hotline at 800-452-CURE (2873) or visit the Kyphon Inc. website, www.kyphon.com, which lists specially trained doctors by area and zip code.

The IMF has published a booklet, Understanding Balloon Kyphoplasty and Myeloma-Induced Vertebral Compression Fractures, which may help you be better able to discuss your condition with your physician and formulate a treatment plan that's best for you. This publication is available online at www.myeloma.org. You can also request a free of charge printed copy from the Foundation. **MT**

UPDATES FROM AROUND THE GLOBE

GERMANY


Dr. Orhan Sezer confers with Dr. Robert Kyle

As part of the mission of the IMF to provide the best in patient education and to increase collaboration between myeloma specialists throughout the globe, two members of the IMF Scientific Advisory Board (SAB) participated in patient meetings in Germany this year.

In June, SAB member Dr. David Vesole spoke at a patient meeting in Würzburg. The event, hosted by Dr. Hermann Einsele of the University of Würzburg and Mrs. Kleineberg, attracted more than 100 participants.

In September, Dr. Robert Kyle, Chairman of the SAB, participated in Multiple Myeloma Days at the University of Heidelberg. Hosted by SAB member Dr. Hartmut Goldschmidt, the event included more than 220 participants. The program consisted of patient meetings, special educational programs for clinicians, and a gathering of the German-Speaking Myeloma Multicenter Group (GMMG).


(left to right) Karin Kleineberg, Rolf Kunstmann, Prof. Dr. Martin Wilhelm, Dr. Kerstin Schäfer-Eckart, Dr. Robert Kyle, Dr. Tobias Schertlin, Prof. Dr. Hannes Wandt

In November, Dr. Kyle returned to Germany for patient meetings in Nürnberg and Berlin. The Klinikum Nürnberg Nord hematology/oncology staff — Drs. Wilhelm, Schäfer-Eckart, Schertlin, and Wandt — and Karin Kleineberg and Rolf Kunstmann, leaders of Myelom Hilfe Nordbayern, fit in 45 additional walk-ins to the more than 80 pre-registered attendees for Dr. Kyle's talk on the diagnosis of myeloma. Another 90-plus patients, caregivers, clinicians, and residents attended Dr. Kyle's detailed overview of myeloma and novel therapies at a patient meeting hosted by Dr. Orhan Sezer of Berlin's Charité Hospital and Elke Schutkowski, leader of the Berlin support group.

In 2007, the IMF plans to expand its program of bringing American-based experts to European patient meetings and offering speaking opportunities for European-based myeloma experts in the United States.

CANADA

Myeloma Canada, the national organization and IMF affiliate, was formed in 2004. Today, there are 14 myeloma support groups across Canada, all actively involved in myeloma awareness and education and in raising funds for research. October of 2006 was a very busy month for the Canadian myeloma community.

After attending the 2006 IMF Support Group Leaders' Retreat in Arizona, Francesca Plaster was determined to make the most out of the Myeloma Awareness Week in her home Province of British Columbia. She contacted local newspapers and radio and television stations. The response was quite favorable. Next, Francesca provided information about myeloma and the Greater Vancouver Multiple Myeloma Support Group to the local government representative and asked that an appeal be submitted to the capital to request that Myeloma Awareness Week be proclaimed officially. Then she asked, "Could we get the whole month proclaimed instead of just one week?" As a result of Francesca's efforts, the month of October was officially proclaimed Myeloma Awareness MONTH!


Myeloma Canada seminar in Montreal, Quebec

The first Myeloma Awareness Month event in British Columbia was an appearance on a morning talk show by Dr. John Shepherd of Vancouver General Hospital and Michelle Krall Wigmore. Dr. Shepherd answered questions about myeloma and Michelle related the experiences of her mother, Adella Krall, who was diagnosed with the disease in 1996. Michelle's sister is Grammy-winning jazz vocalist Diana Krall, whose concerts have raised much-needed funds for Vancouver General Hospital. Congratulations to Francesca, the Greater Vancouver Multiple Myeloma Support Group, and all who contributed to the success of British Columbia's Myeloma Awareness Month!


Dr. John Shepherd, Francesca Plaster, and Michelle Krall Wigmore

In Ontario, an interactive videoconference — Current and Emerging Therapies in the Treatment of Multiple Myeloma — was held on October 12th with the participation of five cancer centers throughout the province. The evening was hosted by the London & District Myeloma Support Group. The presentation, which was made by Dr. Donna Reece, was viewed by approximately 100 patients. The support group is planning to hold more educational videoconferences in the future. Three days later, on October 15th, the 5K Walk for MM Research at Ontario's Princess Margaret Hospital drew 200 participants. On October 26th and 29th, two radio webcast programs devoted to myeloma were broadcast in English and French, reaching a large audience throughout Canada and the US.

In Quebec, the second annual Myeloma Canada seminar attracted over 175 attendees to Montreal on October 27th. The seminar — Myeloma

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UPDATES FROM AROUND THE GLOBE — continued

Greater Vancouver Multiple Myeloma Support Group celebrates a successful Myeloma Awareness Month

Today & Tomorrow: Progress & Challenges — featured a faculty of myeloma experts from Canada and the US, including Drs. Morie Gertz (Mayo Clinic), Chaim Shustik (McGill University), Silvy Lachance (University of Montreal), Richard LeBlanc (Quebec University Hospital Centre), and Karen van Hoeven (The Binding Site). Pierre Deschamps from the Canadian Human Rights Tribunal discussed patients' rights, and IMF's David Smith provided an update on Bank On A Cure® and presented the Understanding Bisphosphonates video.

The IMF congratulates Myeloma Canada and all its members on the many accomplishments of 2006!

JAPAN

IMF Japan was founded in 1997 by Akira Horinouchi, a myeloma patient who dedicated himself to improving the quality of life of other patients in Japan. Over the last nine years, IMF Japan has grown to serve over 1,000 members. With the support of a nationwide network of more than 60 consulting physicians, IMF Japan has significantly furthered the cause of myeloma education and awareness.

In 2006, IMF Japan expanded its meeting and seminar program beyond the major cities of Tokyo and Osaka into the countryside. Such events are of the utmost importance to a patient population with more limited access to information and treatment. In an effort to further advance patient education, volunteers regularly translate the latest available medical texts for dissemination to IMF Japan members. IMF Japan also produces an original annual publication, GAMBARIMASSHOI, which is distributed to the patient community, medical doctors, and pharmaceutical companies.

As part of its advocacy effort in July of 2006, IMF Japan petitioned the Ministry of Labor & Welfare for the approval VELCADE® in Japan. In October, VELCADE was finally approved in Japan for relapsed or refractory myeloma in patients who have received at least one prior therapy. Zometa® also received approval in Japan in 2006, and thalidomide was submitted for approval. The IMF congratulates all who contributed to these positive developments for the myeloma community in Japan. **MT**

RHODE ISLAND MULTIPLE MYELOMA SUPPORT GROUP (RIMMSG)

Carol Murray-Rossi was diagnosed with myeloma in September of 2003. She felt a need to connect with other patients battling the same disease but there was no myeloma support group in Rhode Island. So, in April of 2005, Carol founded the Rhode Island Multiple Myeloma Support Group (RIMMSG). Five members attended the first meeting. The group has grown significantly since then – it even serves members who are unable to attend meetings in person. "RIMMSG enables patients and caregivers to exchange comfort and empowerment," says Carol, "I derive much of my strength from other group members, as well as from participating in community service, disseminating myeloma information, and increasing myeloma awareness. And the IMF has been very supportive of me and of the group. "


(left to right, standing) Joann & Bill Feaster, Gail & Steve Sullivan
(left to right, seated) Gary & Susan Burns,
Frank & Deb Duchala, Bob & Jo Aspri

In October of 2006, Carol and the RIMMSG took on the formidable task of organizing a Multiple Myeloma Awareness Week in her state. The RIMMSG received a tremendous outpouring of support from the local community. Scott Avedisian, the mayor of Warwick, RI, declared October 22-28 to be Multiple Myeloma Awareness Week and displayed the IMF banner on Warwick City Hall for the duration of the week to help raise public awareness. City employees donated money to the RIMMSG by sponsoring a "dress down day."


Carol Murray-Rossi selects the winning raffle ticket during RIMMSG's Money for Miracles celebration

The Rhode Island Multiple Myeloma Awareness Week included the RIMMSG's First Annual Money for Miracles fundraiser, which was held on October 27th. The event featured the unveiling of the group's new logo, which now appears on the RIMMSG banner, as well as on coffee mugs available for sale. Money for Miracles also included a raffle, a silent auction, and a presentation by Robin Tuohy, IMF's NE Regional Director of Support Groups, who traveled from Connecticut with her family to join the celebration.

"Support group members provide invaluable help to one another. But we can also do a lot in our local communities to raise public awareness and money for research. Organizing a fundraising event really isn't as intimidating as it first seems, and it's really worth the effort! We raised more funds than we thought we would, and the proceeds benefit both the IMF and the RIMMSG!" **MT**

Editor's Note: The Rhode Island Multiple Myeloma Support Group meets on the first Tuesday of every month. For more information please contact Carol Murray-Rossi at marcar@gis.net.

CHATTANOOGA AREA MULTIPLE MYELOMA SUPPORT GROUP

The Chattanooga Area Multiple Myeloma Support Group was founded by Tommy Tonkin in 2002, shortly after his diagnosis. Running the group became a joint project for Tommy and his wife, Carroll. Together, they attended the annual IMF Support Group Leaders Retreat and implemented what they learned to help their group grow and develop. Sadly, Tommy passed away in September of 2005. But Carroll was determined to carry on this part of her husband's mission. "Our group was so important to Tommy. He reached out and did so much for so many members of the myeloma community, and I just had to continue his work. The group is a big part of his legacy."

Kim Shank, Rhonda Edwards, and Carroll Tonkin.

Carroll was reluctant to attend the 2006 IMF Support Group Leaders Retreat without Tommy, but "as soon as I got off the plane, I felt as if I was surrounded by my best friends!" She now co-leads the group with oncology education nurse Kimberly Shank, RN, and oncology social worker Rhonda Edwards, MSSW, ACSW, of the Memorial Cancer Resource Center in Chattanooga. Kim and Rhonda alternate helping facilitate the group's meetings. The group includes members from Tennessee, Alabama and Georgia.

"Our meetings often feature presentations by invited guests. We've hosted speakers – physicians, nurses, a dietician, an attorney – who have addressed the wide range of topics that concern our members," says Kim, "But we regularly make time for open discussions. We are also very welcoming to newly diagnosed patients and their families. This is a very close-knit group of people who truly care about one another and encourage each other to never give up or lose sight of hope." **MT**

Editor's Note: The Tennessee support group meets on the third Thursday of each month at the Memorial Cancer Research Center. For more information, please contact Kimberly Shank, RN (Oncology Education Nurse) at Kimberly_Shank@memorial.org.

A CHANCE TO LIVE

By William F. Wheeler Jr, MD

I was born in 1943 in Blackville, South Carolina. Severe asthma in childhood kept me confined to the house for months. Nine hospitalizations and long, lonely, miserable nights sweating in a hot steam tent — a crib draped with plastic — had taken their toll. Worst of all, I had not been able to go outside to play with my friends.

One night, after mother tucked me into bed and left, my chest constricted as if strong metal bands were tightening around it. It took all my strength to barely move air in and out. I rolled closer to the copper kettle that was belching clouds of white steam and tried to call out but it was too late. There was not enough breath to make a sound. Tight with panic, my lungs closed off completely. I quit struggling and gave up.

I knew I was dying. Anger suddenly raged through my body, anger that I would never go out and play again, never run in the yellow fields of grass behind the house, never smell the flowers that grew in our garden, or marvel at the secret world of ants and butterflies. These were great mysteries of nature that I loved, and I felt cheated, angry with God for taking me away.

As the room turned grey, arms reached out and picked me up, the touch filling my body with overwhelming warmth and an indescribable feeling of love. The anger vanished. As I was taken toward the ceiling, I looked down at my lifeless body, and I knew I was going to a better place. Then a voice filled the room: "Put him back." Instantly, I was back in bed, breathing.

As a child, I regarded this as a normal experience. I never even thought to tell anyone about it until recently. Whether it was real or the delusion of a dying child I do not question, for that experience has been a guiding force in my life ever since that night. Since that moment, I have regarded life as a precious gift, each day to be lived fully and never taken for granted.

To experience as much of life as possible, I rushed the milestones of life. I quit high school for college and received my medical degree from Duke University at the age of 23, completing an internship in surgery at University of California San Diego and a specialty degree in anesthesiology at the Massachusetts General Hospital in Boston. But I dreamt of faraway cultures and civilizations.

Africa was a natural choice for me. A continent of great extremes, it contains the world's largest desert and vast untouched rainforests. Human life began in Africa, and only there is it possible to sense what it was like for the first people to live among the exotic animals found nowhere else on earth. So, after practicing medicine for 12 years, I bought a Land Rover and began traveling through Africa.

After adding 40,000 miles to the odometer, I retired the Land Rover and began exploring the most untouched wilderness on foot, alone except for a nomad guide whose language I was not able to speak. Each journey was self-organized in the style of 19th century explorers – supplies carried on the backs of porters or pack animals, no GPS, no emergency backup, no radio, not even a watch. Nothing to remind me of my own civilized world. I kept detailed journals, with sketches and hand-drawn maps. There was adventure: Balal the Tuareg who stole my camel at sword point, abandoning me in the desert; the lion that killed my riding horse; the Cape buffalo that broke my companion's spine.

There had never been a stated purpose in my travels — no endangered species to study, no vanishing culture to document, no goals to strive for or mountains to climb. I had no desire to test myself in any way, no desire to pit myself against the forces of nature. I was not an anthropologist, professional adventurer, photographer, writer, or even physically qualified for wilderness travel. Some deep-seated instinct was guiding me.

Each contrasting landscape – desert, rainforest, grasslands – forged a spiritual awareness all its own. Each tribe encountered left me with a greater understanding of our common humanity. Finally, alone in the wilderness, I came closer to God. And that, I discovered, was what I was searching for all along.

After 24 trips to the continent, the more than 5000 photographs and videos and 400 artifacts collected during my travels are in the permanent collection of the Smithsonian Institution's National Museum of Natural History. My photographic book, Efe Pygmies, Archers of the African Rainforest, was published in 2000 by Rizzoli. My next book, ALIVE: On Foot in the Sahara, Congo, and Rift Valley, chronicles my 20 years of travel with nomads in Africa's most remote and least touched wilderness. And there have been many more unwritten adventures in Africa, the Himalayas, and South Sea islands.

Then, at 62 years old, I was told I had myeloma. With chemotherapy, I was given a 40% chance of surviving one year. My immediate reaction to this unexpected news was a warmth that spread over my body, the same comforting sensation experienced in my childhood vision. My first thought was how thankful I am to have solidified my relationship with God; my second, how lucky to have fulfilled my dreams.

I always begin my day with a prayer. I thank God for another wonderful day, for another chance to give love and compassion to everyone I meet. I am grateful for having been given the chance to live. **MT**

Editor's Note: Dr. Wheeler's photographs have appeared in books, magazines, and calendars. He has acted as consultant and ground liaison for the Discovery Channel. In 1998, Dr. Wheeler established the Efe Pygmies Medical Project to provide basic medical care in the Congo.

WHAT A NIGHT!

Report from the IMF's 16th Anniversary Gala

By Sara Israel

On Saturday, October 21st, 250 guests joined together for the IMF's 16th Anniversary Gala. The evening's festivities took place at the beautiful Regent Beverly Wilshire Hotel in Beverly Hills.


Dr. Brian Durie and Susie Novis

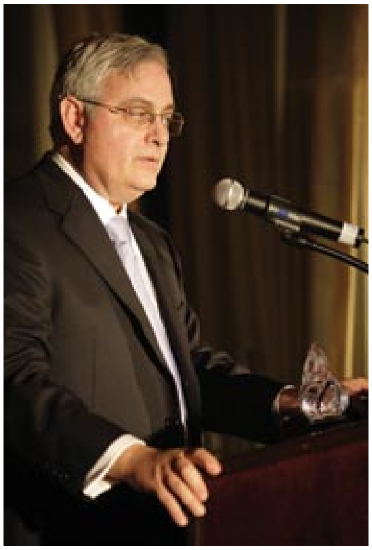
The IMF's annual gala has always been an important, spirited, and successful fundraising event for the foundation, and this year's was no exception. Due in large part to the evening's generous sponsors, including the Presenting Sponsors, Celgene Corporation and Milliennium Pharmaceuticals, this year's gala raised vital funds for myeloma research and essential programs, while encouraging attendees to celebrate the myeloma community's accomplishments.


Host Robin Leach

The evening began with a lively cocktail hour. Elegantly dressed revelers visited with old friends and made new ones, all the while vigorously bidding on the fantastic items in the evening's silent auction, ranging from fine jewelry to concert tickets to terrific trips. Many diligent guests kept a close eye on the objects they desired as the bidding progressed.

When the doors for dinner opened, Robin Leach, host of Lifestyles of the Rich and Famous and a good friend of the IMF, was there to greet everyone in the beautifully decorated ballroom. Mr. Leach set the festive tone and introduced the primary focus of the celebration — the successes of the IMF's Bank On A Cure® research initiative, and the dedicated team of scientists behind these successes.

Dr. Brian Durie, IMF Chairman of the Board, and Susie Novis, IMF President, took the podium to further extol the accomplishments of Bank On A Cure. Dr. Durie recalled the days when this major research initiative was "merely a glint in Susie's eye" and spoke passionately about the project's many collaborators who have selflessly given their time and talents to achieve a common goal. Ms. Novis extended that compliment to encompass everyone in the room, and acknowledged the evening's true heroes: the myeloma patients around the world who conduct themselves with dignity, a sense of humor, and tremendous courage.


Dr. Jerome Zeldis

During a delicious dinner, IMF Board Member Benson Klein introduced Dr. Jerome Zeldis, who received the evening's IMF Visionary Award. As Chief Medical Officer of Celgene Corporation, Dr. Zeldis has been a champion of Bank On A Cure since the beginning, and has supported the initiative's collaborative research efforts in a multitude of ways. In addressing the gala's crowd, Dr. Zeldis spoke passionately about his devotion to developing drugs and improving treatments for myeloma patients, and fondly of his affiliation with the IMF.

After honoring Dr. Zeldis, Dr. Durie and Dr. Robert Kyle, Chairman of the IMF Scientific Advisory Board, introduced the members of the Bank On A Cure research


Members of the Bank On A Cure Team: Dr. Hervé Avet-Loiseau, Dr. Hartmut Goldschmidt, Dr. Gareth Morgan, Dr. Dalsu Baris, Antje Hoering, and Dr. Brian Van Ness

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WHAT A NIGHT! — continued

team. The IMF community was thrilled that so many of these important honorees could be there in person, including Dr. Hervé Avet-Loiseau, Dr. Dalsu Baris, Dr. Hartmut Goldschmidt, Dr. Antje Hoering, Dr. Gareth Morgan, and Dr. Brian Van Ness. Each of these honorees spoke eloquently about what Bank On A Cure and their work with the IMF means to them as crusaders fighting myeloma.


Benson and Carol Klein, Dr. Robert Kyle, and Dr. Brian Durie

All of the evening's guests were called upon to participate when Mr. Leach spearheaded the gala's live auction and introduced auctioneer Mr. Grant Snyder. Enthusiastic bidders won exotic vacations, once-in-a-lifetime experiences, and two adorable puppies—both of them striking "fetching" poses for the crowd and taken home that very evening by grateful and loving new owners.


Ronny Mosston
of Millennium Pharmaceuticals


Susie Novis and Stephanie Gallagher


Lindsay and Kent Luke

The gala was also the culmination of the IMF's opportunity drawing, with all proceeds funding Bank On A Cure. Ms. Ronny Mosston, Director of Patient Advocacy for Millennium Pharmaceuticals, was the lucky winner, and will soon be off on a first-rate trip to Barcelona, Spain.

Dessert was served (and devoured), but no one wanted to leave. The band, Ric Howard Music, kept playing, and guests kept dancing.

Dr. Van Ness, co-chairman of the Bank On A Cure initiative and a member of the IMF's Scientific Advisory Board, reflected on the evening. "When patients, friends, and staff of the IMF show up for a fundraising gala, it always feels like family supporting a cause," he said. "But the IMF accomplishes this not only through a night of fun and recognition, but also through the serious mission we are all working toward, work we hope will culminate in a cure for myeloma." **MT**


(top row, L to R) Stephanie Gallagher, Igor Sill, Cynthia Sill, Dr. Robert Vescio, Elana Farquharson, Dr. Robert Kyle, Susie Novis;
(second row, L to R) Mark DiCicilia, Donna Botherton, Dr. Brian Durie, Robin Leach

MYELOMA TODAY IN CONVERSATION WITH GARY TAKATA

Myeloma Today's new section – "Investing in the Future" – features profiles of IMF members who are making profound investments in the myeloma community and the path to a cure. We hope that the stories of how and why these individuals have chosen to commit so significantly to the fight against myeloma will inspire you as much as they do us.

Myeloma Today: *Please tell us a little about your background.*

Gary Takata: I worked in the brokerage business on Wall Street. After I left Wall Street, I founded several companies in the medical business. In May of 1983, I founded OSI Pharmaceuticals Inc., a drug discovery company. The Chairman of the Scientific Advisory Board was James D. Watson, co-winner of the Nobel Prize in 1962 for his landmark discovery of the double-helix structure of DNA. Today, OSI Pharmaceuticals has several FDA-approved drugs, including one that was approved last year for cancer. The company has projected annual sales of $600,000,000.

Under what circumstances were you diagnosed with myeloma?

I was an avid tennis player — you would have found me on the court almost every day. In 1995, I began experiencing pain in my pelvis. One day in 1996, the pain became excruciating. I thought that this was due to a sciatic nerve condition, so I went to see a neurologist. MRI imaging revealed a solitary plasmacytoma on my left pelvis, and further testing confirmed the diagnosis of multiple myeloma.

How did you become involved with the IMF?

My oncologist mentioned that I should meet Mike Katz, another myeloma patient he was treating. One day, Mike and I ended up seated next to each other while receiving infusions of Aredia®. He told me about the IMF and about the work that Susie Novis and Dr. Brian Durie were doing to benefit myeloma patients. Mike and I became friendly, and I became involved with the IMF.

Gary and Louise Takata with Susie Novis

Please tell us about your involvement with the IMF.

After the pelvis was irradiated, I did not require further cancer treatment for almost two years. I returned to being fairly active – I was back to playing tennis! – and my life seemed as normal as it was before the diagnosis. At that time, I didn't have a need for the patient support that the IMF provides, but I understood and appreciated the value of the Foundation's services. So, in 1997, my wife Louise and I made our first contribution to the Foundation's scientific activities by donating stock. In addition, since my business career has been focused on drug discovery, this was one way for us to further scientific research that benefits the myeloma community. In 1999, we financed the IMF Virus Symposium that took place at the VIIth International Multiple Myeloma Workshop in Stockholm, Sweden. This satellite session featured IMF Scientific Advisors and several world-renowned researchers, including Prof. Luc Montagnier of the Institute Pasteur in Paris (who first discovered the AIDS virus). It was very exciting to be present during discussions between leaders in the field of myeloma. In 2004, Louise and I underwrote the IMF Scientific Advisors Retreat in Bermuda, which focused on molecular testing and clinical trials. We also support the Bank On A Cure initiative. We believe that this IMF project will lead to a greater understanding of myeloma, as well as the development of individualized treatments that take into account genetic variability, and drug toxicity and efficacy.

Why have you chosen to support the IMF?

Contributing to the IMF is very worthwhile for all of us who have been affected by myeloma. It has meant a lot to me to see the strides that have been made in the years since my diagnosis. People who are being diagnosed now can look forward to a longer and better quality of life than those of us who were diagnosed years ago. I am an 11-year myeloma survivor and the disease is beginning to take its toll, but the scientific and clinical progress is helping me lead a relatively normal life. And the IMF's unparalleled patient services programs have made a significant difference in my quality of life. In particular, the Hotline and the online chat group have been a great source of support and information. IMF's patient education has taken on even greater importance with the availability of the newer drugs and combinations of new and old drugs. Soon, myeloma may become a manageable chronic disease. My outlook is that I am LIVING with myeloma. My support of the IMF has helped the IMF support me, and others like me, in times of need. I would like to encourage others to contribute to the IMF in support of our common cause. **MT**

IMFERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

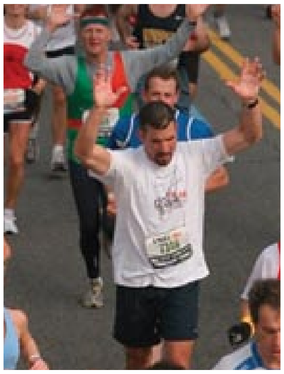
IMF represented on Celebrity Jeopardy!

A winner of 27 Emmy awards since its debut in 1984, Jeopardy! celebrated its 5,000th episode milestone with a two-week television event featuring 30 stars competing for at least $1 million to be donated to their special causes. Celebrity Jeopardy rolled out the red carpet to actors, newsmakers, and pop culture icons at New York's historic Radio City Music Hall. Each celebrity participant received $25,000 for his or her charity of choice, while each show's victor won $50,000 for charity.

On November 21, 2006, actor/writer Michael McKean appeared on Celebrity Jeopardy on behalf of the IMF. Michael played Lenny on Laverne & Shirley and has written and/or acted in many movies, such as "This Is Spinal Tap," "For your Consideration," "A Mighty Wind," and "Best in Show." Michael's Jeopardy appearance was dedicated to the memory of close friend Lee Grayson.

IING New York City Marathon

On November 5, 2006, IMF Hotline coordinator Paul Hewitt ran the New York Marathon to raise money for Team Continuum. The Team was created by myeloma patient Paul Nicholls to ease the burden that cancer thrusts upon patients and their families. This was Paul's first marathon and he spent four months training for the event. "The whole experience was magical," says Paul, "The run itself was grueling, but the good will and support the Team received was electrifying. Whatever pain I experienced during the 26.2 mile run doesn't begin to compare with myeloma patients' daily rigors. By running the New York Marathon, I was able to accomplish a life-long goal while raising money for a cause I believe in. I am so grateful to the IMF, Paul Nichols, and Team Continuum for facilitating this amazing event, and for raising funds to provide immediate help to the patients who need it most."



Scott Segar first got involved with running when he joined a cross-country team in high school. After graduation, he continued to run for exercise. Seven years ago, he ran his first marathon in Hartford, Connecticut. Another marathon on Cape Cod followed. Then, in August of 2006, Scott's wife Elise received a phone call from her aunt, Susie Novis. The IMF was looking for runners to join Team Continuum in raising funds to benefit cancer patients and their families. Before long, Scott embarked on a demanding training regimen, fitting in practice runs between his job as a West Hartford police officer and the busy life of a young family. While Scott focused on training, Elise took on the task of fundraising. "We reached out and so many people stepped forth to help," says Elise, "Some of the donations were so generous that we had to keep raising our fundraising goal!" Scott adds, "Running the marathon was an amazing experience I will never forget. I am very impressed with Team Continuum and the work they do, and am honored to have been able to help the Team and the IMF."

Walk for Myeloma

On October 15, 2006, participants in Walk for Myeloma circled Lake Oseola at the University of Miami in support of the myeloma community and the IMF. This second annual event was once again spearheaded by Denise Vidot, whose father was diagnosed in 2004. Denise, a junior at the University of Miami, is committed not only to raising funds for research but also to promoting myeloma awareness in her community. For this year's event, Denise secured the involvement of several student organizations and the turnout for the Walk more than tripled from last year to a total of 250 registrants. The Walk has now become the Annual Philanthropic Event for the Beta Sigma Chapter of Lambda Theta Alpha Latin Sorority Inc. Congratulations, Denise!

Gary C. Heuer Jr. Memorial Golf Tournament

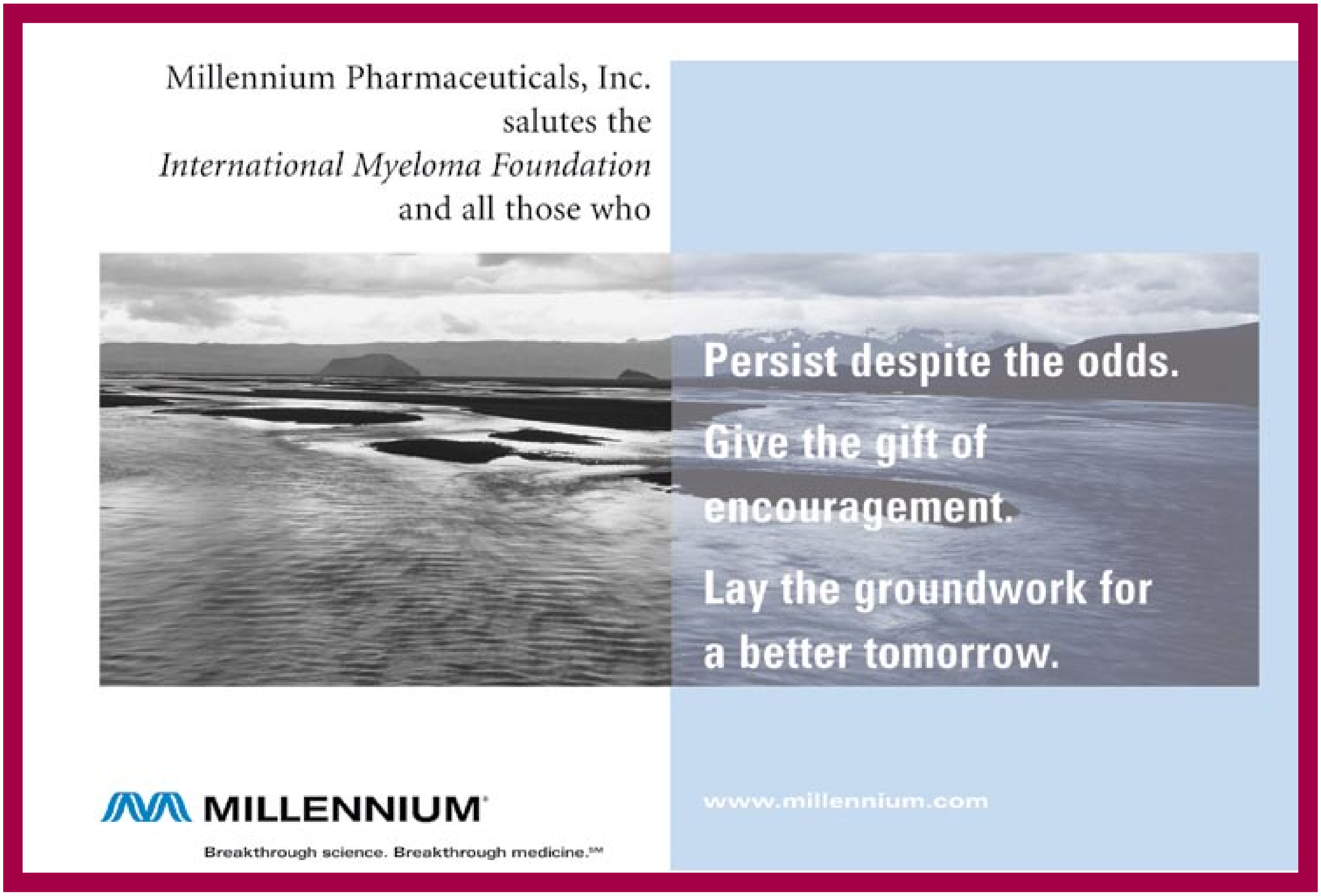
On September 9, 2006, the 5th Annual Gary C. Heuer Jr. Memorial Golf Tournament was held in Pavilion, NY. Players gathered at the Davis Countryside Meadows for the shotgun start of the exciting 18-hole round of golf. Refreshments were provided on the course, and lunch was served at turn. Later, a steak dinner awaited players and non-golfing event supporters, and door prizes were distributed to holders of winning tickets. Our thanks to all the sponsors, golfers, and family and friends who contributed to the success of this event. Special thanks go to Nancy Heuer, who established this tournament and who does such a superb job organizing it every year.

Cents for Cells

IMFer Beth Morgan is about to undergo a stem cell transplant, so she is asking family, friends, and the community to help her help the IMF by raising a penny for each stem cell that will be collected. That's about 15,000,000 cells! Won't you please help Beth reach her goal by supporting the Cents for Cells campaign? A donation of $100 represents 10,000 stem cells! "Like many other patients, I feel the need to do something to help win the war against myeloma. And I can't think of a better way – aside from discovering a cure! – to help my community other than to support the IMF." Please visit www.centsforcells.com for more information.

Join Us

We are very grateful to all IMFers who contribute their time, imagination, and hard work to benefit the myeloma community. The IMF is committed to working with you to continue to raise community awareness and funding for myeloma educational and research. Please join us in working together toward our common goal... a cure. Our FUNdraising program provides you with the tools, assistance, and expertise to make your event a success. No idea is too large or too small. For more information, please contact me, Suzanne Battaglia, at SBattaglia@myeloma.org or call 800-452-CURE (2873). **MT**



2007 IMF Calendar of Events

Feb	23–24	Los Angeles P&F Seminar – Los Angeles, CA
Mar	23–24	Houston P&F Seminar – Houston, TX
April	24–27	ONS – Las Vegas, NV
May	2–6	SWOG – Hyatt Regency, Chicago, IL
June	1–5	ASCO – Chicago, IL
	8–10	ECOG – Washington, DC
	7–10	EHA Meeting, Vienna, AUSTRIA
	7	Kyle Award Dinner – Vienna, AUSTRIA
	25–30	XIth International Myeloma Workshop, Kos GREECE
July	27–28	Teaneck P&F Seminar – Teaneck, NJ

Other events/meetings will be posted in later editions of Myeloma Today as dates are finalized.
For more information, please visit www.myeloma.org or call 800-452-CURE (2873).
IMF–Latin America, IMF–Japan and IMF–Israel events are not included above.

The upcoming **IMF Patient & Family Seminars in Los Angeles and Houston** are expected to be sold out. Reservations are taken on a first come, first served basis. Don't miss your opportunity to participate in these educational and empowering events. To reserve NOW, please call 800-452-CURE (2873) or register on the web at www.myeloma.org.

News & Notes

Planned Giving

There are many ways to support the IMF. It is important that you find the approach that best meets your needs and fulfills your wishes. In order to help start the thought process for your gift planning, we suggest the following forms of giving:

- Bequests in your Will or Trust
- Gifts of Securities (Stocks)
- Gifts of Real Estate
- Gifts of Life Insurance
- Annuity Trusts
- Unitrusts
- Term-of-year Trusts
- Charitable Lead or Remainder Trusts

Estate and gift planning requires thoughtful consideration and discussion. To learn more about any of the suggestions listed above, or other forms of giving that might inspire you, please contact Susie Novis at 800-452-CURE (2873) or snovis@myeloma.org. We also invite you to visit our website at www.myeloma.org for a more detailed explanation of these giving plans.

Imagine Moving Forward is the theme of the IMF's myeloma bracelet. Wear one in honor, celebration, or in memory of a loved one. When people ask you about it, you'll have a perfect opportunity to spread the word about multiple myeloma. These bracelets are only $1 each in sets of 10. Youth bracelets are now available, so everybody in your family who has been touched by myeloma can wear one! Order bracelets online at www.myeloma.org, or contact Suzanne Battaglia at SBattaglia@myeloma.org or 800-452-CURE (2873).

INTERNATIONAL MYELOMA FOUNDATION
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