

NYELOMA SPRING 2008 VOLUME 7 NUMBER 6

A Publication of the International Myeloma Foundation

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

Scientific & Clinical News



Dr. Jesus San Miguel, IMF Scientific Advisor, board member of the Spanish Hematology and Genome Foundations, national councilor of the International Society of Hematology, and board councilor of the European Hematology Association discusses the approach to frontline myeloma therapy in Europe and summarizes his findings as the principal investigator of the VISTA clinical trial of VELCADE[®]. **PAGE 7**



Dr. Keith Stewart, IMF Scientific Advisor and multiple myeloma specialist at the Mayo Clinic, provides an overview of current clinical trials in the field of myeloma. Dr. Stewart discusses studies for newly diagnosed patients who are proceeding to transplant and for those who are not, studies in the relapse setting for refractory patients, and the new drugs that are showing promise in Phase I and Phase II trials. **PAGE 8**



Dr. Brian Durie, IMF Chairman and Scientific Advisor and multiple myeloma specialist at the Cedars-Sinai Comprehensive Cancer Center in Los Angeles, updates readers about the IMF's Bank On A Cure[®] research initiative, including his work that was singled out as part of 2007's "Best of ASH" session. The study looks at DNA single nucleotide polymorphisms that could predispose patients to myeloma bone disease. **PAGE 9**



Dr. Bharat Aggarwal, professor of Cancer Research and Experimental Therapeutics, and Chief of Cytokine Research Laboratory at the University of Texas MD Anderson Cancer Center, discusses the use of natural products in cancer therapy and their potential in prevention and treatment of myeloma. Dr. Aggarwal and his research group are currently studying curcumin. *PAGE 11*

Special Event



Prof. Mario Boccadoro, IMF Scientific Advisor and head of the hematology section of the oncology division at the University of Torino in Italy, receives the sixth annual Robert A. Kyle Lifetime Achievement Award, which honors the physician who most exemplifies a singular dedication to and compassion for myeloma patients and treatment of their disease. Among his many contributions to the field of myeloma since 1978, Prof. Boccadoro created the Italian Myeloma Study Group, the first research consortium in Italy and one of the first in Europe. **PAGE 12**

LOOKING FOR A LOCAL MYELOMA SUPPORT GROUP? If you are interested in joining a support group, please visit our website at www.myeloma.org or call the IMF at 800-452-CURE (2873).

Profiles in the News

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Mark Di Cicilia, IMF Director and long-time friend of the Foundation, talks about his relationship with Susie and Brian Novis, and how he became involved with the myeloma community. He also shares his reasons for his continued commitment to the fight against myeloma. *PAGE 4*

Dr. Alan Solomon, member of the IMF Scientific Advisory Board and professor of medicine and head of the Human Immunology and Cancer Program at the University of Tennessee Graduate School of Medicine, talks about his background as a medical scientist and about his work with primary (AL) amyloidosis. **PAGE 5**



Christine McClay, mother of four and a nine-year myeloma survivor, shares her story of challenges and miracles, optimism and gratitude, and the new "window on life" that the journey with myeloma has given her. **PAGE 19**



David Brown, a 10-year myeloma survivor, talks about the experiences and perspectives that led him to make profound investments in the myeloma community's search for a cure. Mr. Brown is an IMF benefactor who helped provide seed funding for the Bank On A Cure[®] research initiative. We hope that his story will inspire you as much as it does us. **PAGE 21**

Supportive Care

IMF Hotline Coordinators, who help you address the various aspects of myeloma in a more informed way, respond to a patient inquiry about the potential for blood clots resulting from therapy with Revlimid[®] (lenalido-mide) plus dexamethasone. **PAGE 13**

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The IMF is pleased to announce that **Mrs. Loraine Boyle** has joined its Board of Directors.

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Martin M. Oken, USA Headquarters

12650 Riverside Drive, Suite 206, North Hollywood, CA 91607-3421 U.S.A. Tel: 818-487-7455 or 800-452-CURE (2873) Fax: 818-487-7454 E-mail: TheIMF@myeloma.org Website: www.myeloma.org

IMF Staff

Executive Director	Senior Vice President, Strategic Planning	Vice President, Development
David Smith (dsmith@myeloma.org)	Diane Moran (dmoran@myeloma.org)	Heather Cooper Ortner (hortner@myeloma.org)
Special Outreach Coordinator	Hotline Coordinator	Development Associate
Arin Assero (aassero@myeloma.org)	Paul Hewitt (phewitt@myeloma.org)	Randi Liberman (rliberman@myeloma.org)
Director of Member Events	Meeting & Event Services	Data Specialist
anne Battaglia (sbattaglia@myeloma.org)	Spencer Howard (showard@myeloma.org)	Colleen McGonigle (cmcgonigle@myeloma.org)
Hotline Coordinator	Publications Editor	Publication Design
Nancy Baxter (nbaxter@myeloma.org)	Marya Kazakova (mkazakova@myeloma.org)	Jim Needham (jneedham@myeloma.org)
Hotline Coordinator	Development Assistant	Director, Medical Meetings & CME Programs
Debbie Birns (dbirns@myeloma.org)	Missy Klepetar (mklepetar@myeloma.org)	Lisa Paik (lpaik@myeloma.org)
Director, IMF Europe	Regional Director, Support Groups Southeast	Webmaster
egor Brozeit (greg.brozeit@sbcglobal.net)	Andrew Lebkuecher (imfsupport@charter.net)	Abbie Rich (arich@myeloma.org)
Administrative Assistant	Specialty Member Services Coordinator	Comptroller

Rachael Coffey (rcoffey@myeloma.org)

Director, Support Groups Outreach Kelly Cox (kcox@myeloma.org)

Kemo Lee (klee@myeloma.org)

Database & Inventory Control Macky Lee (mlee@myeloma.org) Jennifer Scarne (jscarne@myeloma.org)

Regional Director, Support Groups Northeast Robin Tuohy (tuohy@snet.net)

www.myeloma.org

D

Suza

N

Greg

Benson Klein

Dr. Robert A. Kyle

Isabelle Lousada

Y.C. Chen, REPUBLIC OF CHINA

Ian Franklin, SCOTLAND

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International Myeloma Foundation

Dear Reader,

We generally don't write about individuals when they pass away. However, I feel it is appropriate to make an exception with Rich Saletan, and to publicly acknowledge the outstanding contributions he made to the IMF, and to the entire myeloma community.

Rich Saletan was a driving force within the IMF. He was passionate about the mission and about helping other patients. The impact of his efforts and expertise positively changed the landscape for myeloma patients around the world, and his legacy will continue to benefit patients for years to come.

I met Rich in 2001 after Dr. Robert Kyle, a member of the IMF's Board of Directors, who is also considered to be the "grandfather" of myeloma, contacted me. He told me about a patient of his, Rich Saletan, who had expressed interest in getting involved with a myeloma organization. Rich had been diagnosed with myeloma in 1990, was doing great, and felt it was time to give something back. Dr. Kyle suggested he contact us.

Thankfully, Rich did call us. He immediately got involved. He dramatically and positively changed not only me, but also the Board of Directors,

the IMF as an organization, and consequently the lives of myeloma patients and their families.

The first time I met him in person was just after September 11th. We were holding a seminar in Stamford, CT. He came to meet me and I was really excited and thrilled to meet him. We had spoken a lot on the phone, and I had my fingers crossed that he had the skill set we needed to help this wonderful organization reach its full potential. He did. With over 35 years in business management,

strategic planning, and marketing, he had the experience and expertise we needed. He also had a great sense of humor, he was calm and patient – and over the years I'm sure I tried all of those good qualities to the max.

He became my mentor and my very, very good friend. He began the task of taking a "mom and pop" foundation and turning it into a grown up, wellrun, successful organization. But thankfully he left our heart and soul alone because he knew that's what makes us special.

One of the first things he did was put together a business plan for us, and Rich worked on every one thereafter. He improved our infrastructure, and we now have an amazing staff that is able to move the foundation forward. He improved the way we did business with our partners, which increased funding for more patient programs. He helped build our Board, and we now have a Board that's involved in all the right ways.



Rich and Sue Saletan with Dr. Brian Durie

The list goes on and on, but here is just a sampling of what he did to help the IMF help others:

Joining the IMF's Board of Directors in 2001, Rich Saletan was responsible for the growth of the foundation, not only in revenue but also in the innovative programs he developed. His guidance and expertise helped the foundation realize a 200% increase in revenue from 2001 through 2007.



His interest in developing programs to help myeloma patients led him to develop the Myeloma Matrix - a comprehensive listing of drugs making their way through clinical trials for myeloma patients. He also was responsible for the concept that led to the design of the Myeloma Manager a computer-based program where patients can track their lab results.

The IMF's cornerstone research project, Bank On A Cure[®], the world's first Myeloma specific DNA databank, was also the brainchild of Rich Saletan, from the initial concept in 2003, to the full establishment of the "Bank." The Bank will lead to untold progress in how myeloma patients are treated and

new drugs are developed.

Rich was instrumental in developing and advancing the many programs of the IMF, including Patient & Family Seminars, publications, website, hotline, and support groups to name a few. He was also directly responsible for putting in place an infrastructure that has allowed the IMF to grow and prosper, meeting the needs of myeloma patients and their families around the world. He came up with the positioning statement "Until There is a Cure... There is the IMF," which is

recognized around the world.

Rich and his wife Sue and Dr. Brian Durie and I became very good friends. It didn't take long – we just clicked. And whenever we could get together we basked in the glow of friendship – it was something very special – something Brian and I cherish.

One day when I called Rich, Sue answered. I called Rich a lot – just about every day – and sometimes several times a day. So Sue called out to him and said, "It's the Pest from the West!" And I think it was I who said, "Well if I'm the Pest from the West, then he's the Beast from the East!" And that's what we called each other from that moment on. He'd say, "Hey Pesty," and I'd say, "Hello Beast..."

I miss the Beast -

Susie Novis

Letters to the IMF

Myeloma Today

Thank you for publishing the excellent article by Dr. Jagannath on the benefits of serum free light chain testing in your last issue of *Myeloma Today*. I am a person with myeloma – kappa free light chain only – and the free light chain test has been extremely helpful for me for the last five years to monitor my response to treatment. I am very grateful for the FreeliteTM serum free light chain test and for the excellent care by my doctors. And I am forever grateful to everyone at the IMF for all the work and research you have done to help us deal with MM. You guys are wonderful!

Joyce Wells

The Hotline

You have done such a splendid job of explaining the light chain, heavy chain, urinary chain, and serum chain picture for me! When I am trying to grasp something complex, I spend a long time with bits and pieces of "aspects" (as I call them) of the entire scene cluttering my mind, and it takes a while to get the whole mosaic glued together. You've helped tremendously. Thanks for doing such a great job. My mental chain mosaic is much closer to completion.

Rita Kautz

Board of Directors

MYELOMA TODAY IN CONVERSATION WITH MARK DI CICILIA

How did you become a part of the IMF?

Susie and I have been good friends for many years. I remember her telling me about Brian Novis just a couple of days after they met. I met him shortly thereafter, and we became fast friends. Brian's multiple myeloma diagnosis was the result of a routine physical in preparation for their marriage. The diagnosis was a shock to everyone. I remember his bewilderment and frustration at being told there was nothing that could be done to help him. Brian was determined not to take his diagnosis lying down. He got on the phone and started making calls, insisting that people pay attention to him and his disease. Eventually, he found his way to the Arizona Cancer Center in Tucson, which is where he first met Dr. Brian Durie. As their doctor/patient relationship developed into a friendship, the idea of what later became the International Myeloma Foundation was born. Through Dr. Durie and Dr. Robert Kyle, Brian Novis began to connect with other patients, and a myeloma community began to emerge.



Mark Di Cicilia

to establish ourselves in the field of myeloma. Our third task, which continues to this day, is to create and implement innovative programs and services to benefit the myeloma community. It may be difficult for today's patients to relate to this, but the first IMF Patient & Family Seminar was considered audacious by many members of the medical community. Before the IMF, there were no myeloma patient education programs available. There was no myeloma hotline to call. There were no myeloma support groups to attend. There was no entity in existence dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure. At the time, these were all very radical ideas.

How would you compare that to where we are today?

At the early IMF seminars I attended, I remember spending a lot of time bringing pillows to people and assisting them when they needed to move. Today, as I look at the attendees of IMF seminars, I often find myself needing to

As the IMF took shape, Susie and Brian Novis decided that he would devote himself full-time to the Foundation while she kept the family going. He worked out of the basement of their home, an area we called "the hold." You had to practically crawl through a hole to enter the basement and, once you did, there was no room to even stand up straight. There was no phone down there, and I remember crawling under the house to run the telephone line to Brian's new "office." Once we had the phone and the fax installed, I remember us looking around "the hold" and saying, "Yeah, this is the International Myeloma Foundation."

Almost from the beginning of the IMF, my attitude was, "What can I do to help?" I worked with my hands when needed, offered emotional support and technical assistance, and got the IMF's first phone and voicemail system donated by the corporation I worked for. Then myeloma took the life of my dear friend and significantly altered the life of another dear friend. That's when I got really angry at this disease, and reaffirmed my commitment to participate in the fight against it in any way I could. A couple of months later, Susie invited me to join the IMF Board of Directors.

How did your background contribute to the early days of the IMF Board?

My background is predominantly in technology marketing, and my early contributions to the IMF were focused in the program areas that we wanted to develop. It was during this time that Susie transitioned from the corporate world into the presidency of the IMF. From the early days to the present, she has done and continues to do a phenomenal job, and I see my role with the IMF as doing whatever I can to assist all her efforts. And I am both humbled and honored to do this.

What challenges did the IMF face at that time?

In the beginning, our biggest challenge was raising enough funds for the IMF to simply survive from month to month. Our second challenge was

look at the identifying marks on their nametags to figure out who the patients are. There is a dramatic overall improvement in the physical condition of today's patients as compared to those I met 10 or 15 years ago, and the ranks of long-term survivors have grown impressively. That's a tangible testament to how much myeloma treatment has advanced, and the IMF is a big part of that advancement.

Has your relationship to the IMF changed over the years?

The most significant change took place in 2005 when I became a cancer patient myself. Through my work with the IMF in the preceding years, I had thought that I understood the challenges that cancer patients face. The day I became a patient, my entire outlook on what it means to have cancer changed. My commitment to the IMF has remained the same over all these years, but it is one thing to be compassionate about a disease and it's another thing entirely to experience it yourself. My diagnosis has helped me find a new way to identify with what the people the IMF serves have to go through.

In your opinion, what are the IMF's most significant accomplishments?

From day one to the present day, we have never lost sight of the fact that the patient is #1. It's all about the patient. That's our focus, and it is central to absolutely everything that the IMF does. Our programs and services have grown and changed, but our focus has never wavered.

How do you see the future direction of IMF efforts?

The IMF is instrumental in innovative myeloma research that could not have even been conceived of 10 years ago. We now have the ability to significantly impact the field of myeloma by directly contributing to the most promising research. In addition, the IMF is the strongest voice for a better future for the myeloma patient community, and we are doing this internationally. **MT**

Scientific Advisory Board

MYELOMA TODAY IN CONVERSATION WITH DR. ALAN SOLOMON

Please tell us a little about your background.

Born in New York City and educated in its public school system, I attended Bucknell University and Duke University School of Medicine. After completing an internship at Mount Sinai Hospital in New York, I chose to undergo an additional eight years of clinical and research training at the National Institutes of Health's (NIH) National Cancer Institute (NCI) and at the Rockefeller University Institute for Medical Research. My career at the University of Tennessee began in 1966. It is here that I developed an integrative basic and clinical research program involving, respectively, the elucidation of human antibody and structure/function and care of patients with monoclonal immunoproliferative disorders. For the past 40 years, I have served as professor of medicine and head of the Human Immunology and Cancer Program at the University of Tennessee Graduate School of Medicine.

What is your current professional focus?

To translate discoveries made in the laboratory into clinical practice. This has been especially relevant during the past 10 years as my work has become

focused on amyloid-associated illnesses, particularly primary (AL) amyloidosis, and the development of new methods for the diagnosis and treatment of this disorder. My most recent efforts involve the utilization of amyloid-reactive monoclonal antibodies that we have discovered. In animal models, we have shown that these antibodies incite the body's immune reaction to destroy amyloid. Additionally, we have shown experimentally that when a radioisotope is attached to these antibodies, they can be used to visualize amyloid deposits in the body by PET/CT scans, which would help both to diagnose amyloidosis and to document response to treatment. In the next phase, we hope to test this agent in patients with AL amyloidosis. If the imaging agent works, it will provide an invaluable diagnostic tool for doctors caring for patients with this disease and will move us closer toward using the antibody for treatment. We have received Investigational New Drug (IND) authorization from the Food and Drug Administration (FDA) to use this agent in a Phase I exploratory study of up to 33 patients, and we are very excited about starting this work.

How is primary (AL) amyloidosis related to multiple myeloma?

In both illnesses there is a proliferation or growth of plasma cells in the bone marrow. These plasma cells, which normally make antibodies, continue to produce a single (monoclonal) antibody species. In myeloma, there are generally more plasma cells present in the bone marrow. Typically, there is bone destruction and the resulting consequences of that destruction. Myeloma is also characterized by the production of a fragment of an antibody molecule called the "light chain" or "Bence Jones" protein. This protein can clog the kidneys. This clogging causes kidney damage in myeloma patients with this particular protein abnormality.

Primary (AL) amyloidosis is a disease process where there is abnormal deposition of fragments of the light chain portion of the antibody molecule into various tissues and organs of the body, such as the heart, liver, spleen, kidneys, brain, etc. As these proteins are deposited, organ



Alan Solomon, MD University of Tennessee Graduate School of Medicine Knoxville, TN function diminishes. For example, as proteins are deposited into the muscles of the heart, it cannot pump as effectively, and this may lead to heart failure. If amyloid is deposited into a kidney, you will have the progressive impairment of kidney function. This may necessitate dialysis in order to avoid renal failure. There is typically less bone destruction in amyloidosis than in myeloma because amyloidosis does not involve the same level of proliferation of plasma cells in the bone marrow.

Is primary (AL) amyloidosis reversible or treatable?

Because, like myeloma, amyloidosis starts in the bone marrow, the treatments for amyloidosis include all the same drugs used in myeloma. These include high-dose chemotherapy followed by stem cell transplantation, as well as therapy with the novel agents thalidomide, Revlimid[®] (lenalidomide), and VELCADE[®] (bortezomib). As in myeloma, the goal of treatment is to prevent formation of the abnormal protein. If treatment results in reduction or

elimination of the protein that is causing the problem, it is possible to achieve improvement in organ function, which may be referred to as 'reversing' the disease. Without treatment, the prognosis for amyloidosis patients is not very good.

How frequently or infrequently do both disorders occur in the same patient?

It is commonly held that between 10% and 15% of myeloma patients will develop amyloid but, in all my experience over the years, I have only seen one or two such cases. In my opinion, this is an unusual and rare occurrence. The protein being formed by the abnormal plasma cells must have the potential to form amyloid, and in many cases, the abnormal protein does not have this ability. Also, with the newer and more effective treatments for myeloma currently available, there is less production of the abnormal plasma cells and, therefore, less opportunity for the development of amyloid.

What about the reverse order? Can someone with amyloidosis develop myeloma?

I don't think I've ever seen anyone with amyloid develop myeloma.

How did you become interested in working in this field?

Many years ago, when I was an intern, I had under my care a patient with Waldenström's macroglobulinemia, another disease related to myeloma. Subsequently, when I was a clinical associate at the NIH, we had a number of myeloma patients with Bence Jones. The treatment we developed for our patients was plasmapheresis, a process where we take the blood and discard the plasma cells before returning it to the patient. This was the foundation for the work I have done in the years that followed, trying to elucidate factors that make antibody proteins behave in an abnormal way; learning more about the human immune system from studying these

News & Notes

Major New Intergroup SWOG/ECOG/CALGB Study

Dr. Brian G.M. Durie is the principal investigator of a new clinical trial set to open May 1, 2008. This intergroup effort by the Southwest Oncology Group (SWOG), the Eastern Cooperative Oncology Group (ECOG), and the Cancer and Leukemia Group B (CALGB) will study Revlimid[®] (lenalidomide) plus low-dose dexamethasone versus VELCADE[®] (bortezomib), Revlimid, and low-dose dexamethasone as frontline treatment of multiple myeloma, with stem cell transplant optional. Accrual is planned to include approximately 600 patients. For more information, please visit the IMF website at www.myeloma.org or call the Hotline at 800-452-CURE (2873).

FDA "Priority Review" of VELCADE®

The decision of the Food and Drug Administration (FDA) to grant "priority review" for VELCADE[®] (bortezomib) in newly-diagnosed myeloma recognizes the benefits of powerful new therapies and the need to get them to more patients sooner. VELCADE is already approved for myeloma patients who have received at least one prior therapy. Priority review status accelerates official FDA review for newly diagnosed patients from ten months to six months, which means VELCADE could be approved for expanded use this June. So far, more than 85,000 patients have been treated with VELCADE worldwide.

Thalidomide Regimen in Europe

The positive opinion from the European Medicines Agency (EMEA) could clear the way for a new treatment regimen in Europe. The decision recommends approval of thalidomide in combination with melphalan and prednisone (MP) for newly diagnosed myeloma patients over age 65. "Thalidomide is available in the United States, Australia, New Zealand and elsewhere now, and we would like all patients to have safe access to its demonstrated benefits," said Susie Novis, president and co-founder of the IMF. This positive opinion from EMEA for thalidomide with MP is based on a multi-center clinical trial showing average survival of more than 4 years, a year and a half more than MP without thalidomide. Studies have also shown improved response by adding VELCADE[®] (bortezomib) or REVLIMID[®] (lenalidomide) to MP. The EMEA recommendation sets the

ALAN SOLOMON — continued from page 5

proteins; and trying to develop treatments to either eliminate these proteins or to make them less toxic to the body.

What is your outlook for the future?

With improvements in diagnostic modalities and new treatments on the horizon, I am quite optimistic. Our hope is that if these illnesses cannot be cured at present, they will at least become chronic in the near future, which will improve the quality of live and the longevity of patients with these diseases. **MT**

Editor's Note: Dr. Solomon has been a recipient of the United States Public Health Service (USPHS) Career Development Award, an American Cancer Society Clinical Research Professorship, and research grants from the NIH, National Science Foundation, and American Cancer Society, as well as grants from biopharma industrial sources and private foundations. He is the author of over 190 scientific publications and is a former member of the NCI's Clinical Cancer Program Review Committee and the Board of Scientific Counselors. He was recently awarded a five-year renewal on a grant from the NCI, originally awarded to Dr. Solomon in 1965, making it the longest active grant in NIH history. stage for the return of thalidomide to Europe with safe distribution for an important indication. Although historically linked to an epidemic of birth defects when prescribed for pregnant women, a proprietary risk management system in the United States has seen more than 100,000 prescriptions without a single incidence of birth defects, demonstrating that the drug can be used safely. Hematologist Ralph Naumann (University Clinic, Dresden, Germany) prescribes thalidomide for his patients even though he personally has experienced the effects of thalidomide since his own mother took it when she was pregnant with him. He has stated: "Thalidomide is not a bad drug, it's just a drug that was badly used, and for the many myeloma patients today who are benefiting from thalidomide, that's a crucial distinction."

90% Overall Response to New Combination

Data from the Phase II BiRD study provide a new option for newly diagnosed patients with multiple myeloma, whether or not they subsequently proceed to stem cell transplant. The findings show a superb overall response rate of 90.3%. Using European Group for Blood and Marrow Transplantation (EBMT) criteria, 38.9% of the patients achieved a complete response and 73.6% achieved a 90% or greater decrease in M-protein levels. Using the new International Myeloma Working Group (IMWG) criteria - recently developed to better define the magnitude of a complete response -30.6% of the patients achieved the new stringent complete response (sCR). sCR requires the complete absence of M-protein by immunofixation, normal free light chain ratio, and a negative marrow biopsy by immunohistochemistry. The findings have been published in the online version of the journal Blood. The BiRD regimen is made up of Biaxin® (clarithromycin), REVLIMID® (lenalidomide), and a low dose of the steroid dexamethasone. The BiRD treatment did not impede stem cell transplantation, and demonstrated a two-year event-free survival rate of 85.2% for patients who underwent stem cell transplant and 75.2% for those who continued on therapy without transplant. In addition to the response criteria, the findings from the BiRD study, like a previous study of REVLIMID with low-dose dexamethasone, show response deepening over time: the average time to partial response was just over six weeks, but average time to complete response was 22 weeks, and stringent complete response was reached at 38 weeks. "This is an exciting time for the treatment of myeloma," said Susie Novis, president and co-founder of the IMF. "We now have multiple studies showing improved response and survival with various regimens including REVLIMID/dexamethasone in previously treated and newly diagnosed patients, DOXIL®/VELCADE® for previouslytreated patients who want a steroid-free regimen, and thalidomide/melphalan/prednisone in older patients not eligible for transplant."

Obesity Increases Cancer Risk

British researchers led by Dr. Andrew Renehan analyzed 144 published studies and more than 200 sets of data involving more than 282,000 people. This study, which has been published in *The Lancet* medical journal, reveals that obesity can lead to common and less common forms of cancer. "We showed an association with less common cancers that had not been shown before," says Dr. Renehan. According to the study, these forms of cancer include leukemia, multiple myeloma, esophageal cancer, gallbladder cancer, and non-Hodgkin's lymphoma. "Being able to quantify cancer risk in relation to body weight should help public health officials estimate the impact of both the aging of the population and the obesity epidemic on cancer rates over the next decade and beyond." Obesity is one of the main health problems in the world, with 400 million people currently classified as obese by the World Health Organization, the public health arm of the United Nations. **MT**

EUROPE UPDATE: FRONTLINE MYELOMA THERAPY

Myeloma Today in conversation with Dr. Jesus San Miguel

Prof. San Miguel, please share with our readers the current state of frontline therapies available to myeloma patients in Spain, outside the clinical trial setting.

In Spain, outside of clinical trials, we can only use the following therapies: For transplant candidates, what is available is either conventional chemotherapy like the VAD (vincristine, Adriamycin[®], dexamethasone) regimen or the more commonly used PETHEMA (Programa para el Tratamiento de Hemopatías Malignas) induction chemotherapy regimenVBMCP/ VBAD, followed by an autologous stem cell transplant. For elderly patients or others not proceeding to transplant, the only approved treatment is the conventional chemotherapy of melphalan and prednisone. These are the only approved options for upfront therapy. None of the three major novel agents - thalidomide, Revlimid[®] (lenalidomide), or VELCADE[®] (bortezomib) - have been approved yet in the upfront setting.



Jesus San Miguel, MD, PhD University Clinic Hospital Salamanca, Spain

How is this circumstance likely to change?

In Spain, we have a very active comparative group, known as PETHEMA-GEM (Grupo Español de Mieloma), which includes more than 80 medical centers across the country. Within this group, we currently have two ongoing clinical trials for newly diagnosed patients: one clinical trial for transplant candidates under age 65 and one clinical trial for patients over 65 who are not transplant candidates.

Please tell us about the study of newly diagnosed patients who are candidates for a transplant.

The GEM randomized study of transplant candidates is comparing three induction regimens. The first one is based on four cycles of chemotherapy followed by two cycles of VELCADE. The second arm is thalidomide and intermediate-dose dexamethasone (thal/dex). The third group is receiving thal/dex plus VELCADE. All patients are receiving six courses of induction therapy and subsequently an autologous transplant with melphalan 200 mg/m². Three months after the transplant, we proceed with a second randomization comparing three maintenance regimens. In the first arm, patients receive interferon, in the second they receive low-dose thalidomide, and in the third arm patients receive thalidomide plus VELCADE.

What about the newly diagnosed patients who are not transplant candidates?

In this group, we are comparing melphalan and prednisone plus VELCADE (MPV) versus thalidomide, prednisone, and VELCADE. All patients are receiving six cycles of therapy before being randomized to a maintenance therapy of either thalidomide plus VELCADE or prednisone plus VELCADE.

What other clinical studies of frontline therapies are ongoing in Spain?

The third clinical trial studying frontline therapy is focusing on high-risk smoldering myeloma. High-risk smoldering myeloma patients have both more than 10% plasma cells in the bone marrow and more than 3 grams/dL of paraprotein. These patients are randomized to receive no treatment, which is the conventional approach, versus Revlimid plus low-dose dexamethasone.

You are the principal investigator of the VISTA clinical trial of VELCADE. What can you tell us about this study?

The VISTA trial is a randomized controlled study that has been conducted in 22 countries with the participation of 151 institutions and 682 patients over approximately a year and a half. It was designed in order to compare nine 6-week cycles of melphalan and prednisone (MP) versus the same schedule of MP plus VELCADE (MPV). The primary end point of the study was time to progression (TTP). The secondary end points

were: complete response rate, overall response rate, duration of response, time to next therapy, and progression-free survival (PFS). The VISTA trial was stopped early based on the recommendation of an independent monitoring committee due to the superiority of the MPV arm in all the efficacy end points. The results of this trial showed high efficacy in terms of response with an overall response rate of 82% (including CR of 30% by EBMT criteria), which is significantly superior to the 50% response rate (including CR, of 4% by EBMT criteria) in the MP arm. There was also significant prolongation in TTP with an approximate 52% reduction in risk of progression in the MPV arm, and a median TTP of 24 months in the MPV arm versus 16.6 months in the MP arm. The improved TTP was observed in all study subgroups, including elderly patients, those with poor cytogenetics, those with impaired renal function, and patients with advanced clinical stage of myeloma. In addition, this trial showed a significant benefit in overall survival (with approximately 40% reduction in risk of death for patients treated with MPV) and a projected overall survival (measured at two years as 82.6% with MPV versus 69.5% with MP). The EBMT (European Group for Blood and Marrow Transplant) criteria were used to evaluate response and TTP.

What is the toxicity profile associated with MPV?

The frequency of serious adverse events was higher in the MPV arm (46%) as compared with the MP arm (36%). There was no major difference in hematological toxicity, but there were more Grade 3 adverse gastrointestinal events, 19% in the MPV arm versus 5% in the MP arm. There was a higher incidence of Grade 3 peripheral neuropathy (PN) (13%) but, in 75% of the cases, the PN was resolved or improved in a median of 64 days. In both study arms 14% of patients discontinued therapy due to adverse events.

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CLINICAL TRIALS UPDATE

Myeloma Today in conversation with Dr. Keith Stewart

Dr. Stewart, please help our readers make better sense of the rather large number of current clinical trials in the field of myeloma.

For the purposes of this overview, perhaps it would be helpful to divide clinical trials into several categories. One category is trials employing drugs already approved by the Federal Drug Administration (FDA) in the frontline setting for newly diagnosed patients. This first category is divided into two sub-categories: patients who are proceeding to transplant and those who are not. The second category is trials employing drugs not yet approved by the FDA in the relapse setting for refractory patients.

A quick side question: Is the use of transplantation in myeloma declining?

Some think that the percentage of patients proceeding to transplant is on the decline. This impression may arise from the news about novel agents that are producing

good results, or from patients who are "voting with their feet" in opting out of transplant. But transplantation still has a place in myeloma treatment, especially with younger patients, and remains the option that is recommended by many academic centers. Certainly, all patients who are candidates should discuss this option with their physicians and give it serious consideration. We hope that in the near future, some of the clinical trials currently underway will help us better answer the question about the potential added value of transplantation for patients who are able to achieve a complete remission (CR) prior to transplantation.

Which current clinical trials are relevant to newly diagnosed patients who are planning to have a transplant?

There are a number of large Phase III clinical trials going on across the US that look at combinations of newer drugs to try to determine which combinations are more successful in producing a response, particularly CR. These trials usually accrue between 300 and 700 patients and offer the most state of the art therapy available. The combinations being studied usually include Velcade[®] (bortezomib) or Revlimid[®] (lenalidomide) combined with older drugs or combined together. Trials are asking whether combinations of three drugs are better than two or whether four drugs are better than three and, if so, are the side-effects profiles of such combinations acceptable? Are combinations improved (or not) by the addition of steroids during induction? The impetus for these trials is to find answers to these urgent questions.

Are the clinical trials you are referring to close to producing meaningful data?

Some of these trials for newly diagnosed patients are still accruing patients, others are ongoing. The only trials in this category that recently closed and will soon be publishing data are the Eastern Cooperative Oncology Group (ECOG) and the South West Oncology Group (SWOG) trials that looked at Revlimid and dexamethasone (dex) versus dex alone (in the SWOG trial) and Revlimid with low-dose dex and high-dose dex

A. Keith Stewart, MD Mayo Clinic Scottsdale, AZ

(in the ECOG trial). The results have been reported, but not yet published, that the combination of Revlimid and low-dose dex is the preferred combination. The cooperative group in France has reported that Velcade plus dex works better than VAD chemotherapy, which is still used in many parts of the world. Another trial demonstrated that the Velcade, thalidomide, and dex combination showed improved time to response over thalidomide and dex alone. In other words, several trials have demonstrated that Velcade and Revlimid are worthwhile additions to upfront therapy. In the newer generation of trials, we are looking to see if combining these two novel agents together or with other drugs such as cyclophosphamide, doxil or steroids might be better than using either one of them alone.

Has the availability of Revlimid caused a decline in the use of thalidomide?

Our impression is that thalidomide is possibly less potent and slightly more toxic for patients than Revlimid. For these two reasons, Revlimid is gaining dominance over thalidomide in the US. Outside the US, thalidomide remains more accessible for myeloma patients than Revlimid, and it is still a very useful standard. It is also important to note that there is a set of clinical trials that have been published recently with low-dose thalidomide as maintenance after transplant, and three out of three trials have shown that thalidomide as maintenance is beneficial to patients who have not achieved CR after transplant. So there is definitely a continuing role for thalidomide in myeloma.

Now let's talk about the clinical trials for newly diagnosed patients who plan to proceed to transplant.

SWOG has a trial of VELCADE, Revlimid, and dex versus VELCADE and dex. ECOG has a similar trial that allows one to two months of any non-VELCADE therapy prior to the same regimens as the SWOG trial. One Millennium-sponsored Phase III trial (known as EVOLUTION) is comparing a three-drug cocktail of VELCADE, Revlimid, and dex, with a four-drug cocktail of the same combination plus cyclophosphamide.

What studies are looking at treatment for relapsed patients?

There are around 40 new drugs being studied in relapsed myeloma, so there are many clinical trials in this category and most large cancer centers are participating in at least some of these. Many of these trials include existing agents. Some of the new drugs that are currently showing promise are carfilzomib (a proteasome inhibitor), LBH589 (a histone deacetylase inhibitor), and CC4047 (a next generation version of thalidomide and Revlimid). These are mostly Phase I and Phase II trials, but there is also one large international Phase III trial currently underway that is comparing VELCADE plus tanespimycin, (KOS-953) that blocks Heat Shock Protein 90 (Hsp90) to VELCADE alone. This trial will show whether tanespimycin improves VELCADE response. Other similar trials are underway adding new drugs to Velcade.

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BANK ON A CURE® RESEARCH INITIATIVE UPDATE

Myeloma Today in conversation with Dr. Brian Durie

In the Winter 2007/2008 issue of *Myeloma Today*, we announced that your abstract presentation on results from Bank On A Cure[®] research was singled out as part of 2007's "Best of ASH" session. Please tell us about this project.

For several years now, we have been conducting DNA testing as part of the IMF's Bank On A Cure® research initiative. We have been looking at different types of correlations, such as the risk of deep vein thrombosis (DVT) with the use of thalidomide and/or Revlimid[®], the potential risk of peripheral neuropathy (PN) with the use of VELCADE® (bortezomib), and a variety of other issues. One important issue in myeloma is bone disease. Some myeloma patients have little or no bone involvement, while others experience severe bone destruction. Myeloma cells depend upon the bone marrow microenvironment for growth and survival. Bone disease in myeloma occurs as a result of the complex interactions between myeloma cells and the bone marrow osteoclasts, osteoblasts, and other accessory cells and microenvironmental components. Until now,

no studies have evaluated the potential impact of genetic polymorphisms upon the functioning of the bone marrow microenvironment and the development of bone disease. So I realized that we could study DNA single nucleotide polymorphisms (SNPs) that would either predispose patients to get myeloma bone disease or not.

How did you select the patient population to study?

For this project, we selected the data set from the myeloma center at the University of Arkansas in Little Rock, as their patient population has extremely good documentation of bone disease. Our analyses included 282 patients with previously untreated myeloma who were enrolled in the Little Rock "Total Therapy 2" (TT2) protocol. These patients had full skeletal x-ray, MRI, and PET scanning as a baseline. This was the most complete and detailed data set to document myeloma bone disease of any center in the world. These patients were then classified based upon the number of lytic lesions: patients with limited or no bone disease (x-rays and/or MRI negative or with 0-7 focal lesions), patients whose x-rays and/or MRI were positive with 7-20 lesions, and those who had more than 20 lesions.

There was an added advantage to using the Little Rock data set. Dr. John Shaughnessy had studied the bone marrow samples from all these patients to see what they were producing that was causing the bone disease, and then published a paper about DKK1, a protein produced by the myeloma. DKK1 shuts down the osteoblasts, which normally heal bone, while increasing destructive osteoclast activity, which is a characteristic feature of myeloma. Expression of DKK1 is regulated by a combination of intrinsic genomic factors, specific stimuli, and interactions with the bone marrow microenvironment. An important mechanism for DKK1 activation is through a pathway that is in turn activated by microenvironmental oxidative stress, which is caused by a system's ability to detoxify or easily repair the damage resulting from reactive oxygen. In our project, we looked for the DNA pattern that would either allow patients to resist the myeloma bone disease or would predispose them to it.



Brian G.M. Durie, MD Aptium Oncology Cedars-Sinai Comprehensive Cancer Center Los Angeles, CA

How did you identify and analyze the DNA patterns?

A big part of this was the design of the experiment. Once this was accomplished, we were able to proceed with the analysis. The patient DNA was genotyped and studied using the Affymetrix[®] custom SNP chip, which was designed and developed by teams at the University of Minnesota and the Royal Marsden in the UK as part of the Bank On A Cure project. This chip was used to assess presence or absence of relevant genetic polymorphisms. Testing revealed several SNPs that are significantly correlated with the statistical likelihood of bone disease in patients with myeloma. The direct biologic significance is supported by the strong correlations with the number of focal lesions and the direct amount of DKK1 RNA (ribonucleic acid) measured in gene expression studies with bone marrow myeloma cells from the same patients. This is the first time that the potential role of microenvironmental SNP patterns has been substantiated in a fashion which reveals a complementary role linking SNP pattern with

myeloma cell DKK1 gene expression patterns in reflecting the predisposition to myeloma bone disease.

This first evaluation of SNPs linked to bone disease in myeloma has revealed several important correlations which now deserve more detailed investigation. An important adjunct to these initial SNP correlations is the formal evaluation of the correlated SNPs in large epidemiologic studies. Such studies are currently underway in collaboration with the NCI epidemiology branch. In addition, the results with the customized targeted SNP chip are being compared and contrasted with wider genome screening to identify unknown SNPs which are potentially relevant. Studies are already planned in this regard to evaluate both the Affymetrix 6.0 SNP chip and the Illumina 500 chip.

Has the study produced any surprising results?

Interestingly, one separate unexpected finding was the strong correlations with SNPs linked to drug and/or toxin metabolism. One of the "top" SNPs that showed up in the statistics was the SNP that influenced the activation of the DKK1 pathway and indicated a predisposition to bone disease that relates to DKK1. In other words, patients with bone disease were more likely to have a DNA pattern where DKK1 could be activated. We called our statistical analysis "recursive partitioning," which is like a branching tree. We found that there were four dominant SNPs: rs 3766934 Epoxide hydrolase (EPHX1); sr 3783408 MAP4K5 kinase; sr 1062637 RNA helicase DDX18; and sr 3181366 TNF5F8-TNF-α. These SNPs influenced DKK1 production, osteoclast activation, and the ability to metabolize environmental toxins, specifically dioxins. The predisposition to bone disease seems to be related to the ability to detoxify dioxins and polycyclic aromatic hydrocarbons (PAHs). Further studies are required to understand the significance of these correlations.

How do you see the future of this direction of myeloma research?

The focus of further studies is likely to include a transition from target SNP to genome-wide screening, working towards personalized molecular

SAN MIGUEL / EUROPE UPDATE — continued from page 7

What conclusions have you drawn based on your experience with MPV?

I think these data are very important for patients over age 65. I would summarize the results in four relevant findings. The first is the high response rate achieved with MPV. The second is the early detection of the survival benefit. The third is the prolonged time to subsequent therapy, otherwise known as the treatment-free interval. The fourth is that the efficacy of MPV treatment is consistent across all patient groups, including those with poor prognostic characteristics, such as age greater than 75 years, impaired renal function, and high-risk cytogenetics. My experience with the VISTA trial and MPV is just one example of how participation in a clinical trial is often the best way to secure the best treatment a patient can receive. **MT**

Editor's Note: Prof. San Miguel is a Scientific Advisor to the IMF, a board member of the Spanish Hematology and Genome Foundations, the National Councillor at the International Society of Hematology, and the Board Councilor of the European Hematology Association. He is the recipient of the 2007 Waldentröm Award and a seven-time prize recipient of the Spanish Society of Haematology and Spanish Cancer Association. Prof. San Miguel has published more than 450 articles, 80 book chapters, and 340 abstracts.

DURIE / BANK ON A CURE UPDATE - continued from page 9

classification for treatment and prevention.

What other research is being done under the Bank On A Cure umbrella?

With cooperation from the Intergroupe Francophone du Myélome (IFM) we are studying the patient DNA from a recent IFM clinical trial of VELCADE[®] (bortezomib) plus dexamethasone versus VAD (vincristine, Adriamycin[®], dexamethasone) as frontline therapy before a double transplant. We set up a very detailed protocol for peripheral neuropathy (PN) testing at baseline, then a protocol to document PN with treatment. The aim of this project will be to look at the predisposition to PN with the use of VELCADE. If we are able to identify people who are likely to develop PN, this would have significant implications. Another related study will be done in cooperation with Prof. Sonneveld in the Netherlands. Please stay tuned for further reports. **MT**

Editor's Note: Dr. Durie is a co-founder of the IMF and serves as its Chairman, as well as member of its Scientific Advisory Board. He is the National Director for Hematologic Malignancies for Aptium Oncology Inc. and is the Specialist in Multiple Myeloma and Related Disorders at the Cedars-Sinai Outpatient Cancer Center in Los Angeles. He co-chairs the Southwest Oncology Group myeloma committee. Dr. Durie is the recipient of many professional honors, including the Robert A. Kyle Lifetime Achievement Award, which honors the physician who most exemplifies a singular dedication to and compassion for myeloma patients and treatment of their disease. He is a Leukemia Society of America Scholar, a U.S. Hematologic Research Foundation Annual Áwardee, and a Marquis Member "Who's Who in America" and "The Best Doctors in America." Among Dr. Durie's many appointments and research accomplishments, he co-created the Durie/Salmon Myeloma Staging System, the first system ever developed to classify myeloma in a standard, universal fashion, and the vital building block for the International Staging System, also co-developed by Dr. Durie with the International Working Group. Dr. Durie has written over 400 research papers, 30 book chapters, and five books, work which has impacted myeloma treatment around the world.

STEWART / CLINICAL TRIALS UPDATE — continued from page 8

What about trials for newly diagnosed patients who are not planning to have a transplant?

For newly diagnosed patients who are not going on to transplant, there are several large Phase III clinical trials opening. One example is Ea106, an inter-group trial (ECOG, CALGB, and the National Cancer Institute of Canada) that is accruing 560 patients to compare melphalan, prednisone, and thalidomide (MPT) with melphalan, prednisone, and Revlimid (MPR). MPT is now considered by many in the field to be the treatment of choice for patients who are not proceeding to transplant. But studies have shown that Revlimid may be slightly better than thalidomide, so the intent of this head-to-head comparison is to show whether MPT or MPR results in better survival. Toxicity of the regimens will also be evaluated. In addition, monthly questionnaires will track each participant's quality of life, as this is a very important end point of our study. If one of the arms of the study is shown to be better, we need to know whether or not this is associated with reduced quality of life in the patient population.

There are also industry-sponsored trials. Millennium Pharmaceuticals recently reported the results of a trial of VELCADE, melphalan, and prednisone (MPV) versus melphalan and prednisone and showed the MPV arm to be superior. They are now going to study MPV versus VELCADE, thalidomide, and dex versus VELCADE and dexamethasone alone. Celgene is studying MPR versus melphalan and prednisone in Europe and will study Revlimid low dose dexamethasone versus MPT in the US.

Would you tell us about studies looking at bone and kidney disease, etc.?

There are studies looking at complications of Zometa[®] and trials of new drugs for bone disease, such as denosumab. There is also a study of VELCADE and bone formation in patients with relapsed/refractory myeloma. There are no new trials looking at kidney disease, but there will be a study of how to properly dose Revlimid, which is excreted by the kidneys. A study looking at infection and the role of antibiotics during chemotherapy was completed recently, and we expect to know results within six months to a year. There are also some studies that are looking at the side effects of drugs.

Why should patients consider participation in clinical trials?

In the US, participating in a clinical trial is one way for patients to gain access to drugs that may not be covered by their insurance company. Outside the US, participating in certain clinical trials gives patients access to novel agents that are otherwise unavailable to them. Often the treatment being given during clinical trial participation will be more effective than some of the therapies available outside the study setting. There is a lot of exciting clinical trial activity worldwide – hundreds of studies across the spectrum – and I would like to encourage patients to participate in the process of the development of the best, most modern, and most effective therapies. **MT**

Editor's Note: Dr. Stewart graduated from medical school at the University of Aberdeen in Scotland, and trained in internal medicine at Queen's University in Canada. He has also completed an MBA from Richard Ivey Business School at the University of Western Ontario. Currently, Dr. Stewart is Professor of Medicine at Mayo Clinic, with specialized interests in biology and treatment of multiple myeloma, Waldenstrom's macroglobulinemia, amyloidosis, drug development, clinical trials, correlative biology, and genomics.

CURCUMIN IN MULTIPLE MYELOMA

Myeloma Today in conversation with Dr. Bharat Aggarwal

Please tell us about the use of natural products in cancer therapy.

The use of natural products in cancer therapy is nothing new. Between the years 1981 and 2002 almost 74% of all drugs approved by the US Food and Drug Administration (FDA) were either natural products, were based thereon, or mimicked them in one form or another. Many of the active chemical entities in these natural products have already been identified. So it is a matter of course for our research group at the MD Anderson Cancer Center to look for the treatment for multiple myeloma in natural sources.

How are your studies related to myeloma?

We are studying the potential of natural products in prevention and treatment of myeloma. The natural product that my research group chose to focus on is curcumin, which is the main biologically active phytochemical derived from a plant called turmeric. In the Western world, curcumin is sometimes referred to as curry powder.



Bharat B. Aggarwal, PhD University of Texas MD Anderson Cancer Center Houston, TX

black pepper or long pepper) at 10 mg in two divided doses for 12 weeks. Blood was collected before and after treatment with curcumin and examined for expression of NF- κ B, cyclooxygenase (COX)-2 (an enzyme that is regulated by NF- κ B and controls inflammation and proliferation), and phospho-STAT3 (signal transducer and activator of transcription) as surrogate biomarkers.

What results did you obtain?

The results were quite interesting. We showed that treatment with curcumin in combination with a fixed dose of Bioperine was well tolerated. There were no significant adverse events. Of the 29 evaluable myeloma patients treated so far, no objective responses were noted.* However, 12 patients have continued treatment for more than 12 weeks and five of them have completed a full one year of treatment with stable disease. Peripheral Blood Mononuclear Cell (PBMC) examination of 28 of the evaluable 29 patients showed that oral administration of curcumin significantly downregulated the constitutive activation

What does curcumin do in myeloma?

Curcumin has been described as an anti-inflammatory agent. Inflammation is an ideal target to discover therapeutics for prevention and treatment of cancer. Numerous genes that control tumorigenesis, the formation of tumors in the body, also control inflammation. Curcumin is a very

potent blocker of a pro-inflammatory transcription factor called NF- κ B (nuclear factor-kappa B). Several laboratories, including ours, have shown that NF- κ B plays a very important role in cancer. In myeloma, it has been shown that NF- κ B is active in promot-



ing myeloma cell proliferation. Curcumin suppresses the activation of NF- κ B. Our lab demonstrated in vitro that curcumin downregulates the activation of NF- κ B, which leads to inhibition of proliferation of myeloma cell lines.

How did you proceed from that discovery?

We isolated myeloma cells that had been collected from patients and exposed them to curcumin ex vivo, and this was very effective. Our next step was a Phase I/II clinical trial in patients with myeloma, using 500 mg capsules of curcumin. The objective of the trial was to evaluate the safety, clinical tolerance, and biological effects of curcimin in myeloma patients with asymptomatic, relapsed, or plateau-phase disease. Curcumin was administered either alone orally at 2, 4, 6, 8, or 12 gms/day in two divided doses, or in combination with Bioperine[®] (a standardized extract from

of NF- κ B and STAT3, and suppressed COX2 expression. This study successfully demonstrated, for the first time ever, that curcumin is a highly safe agent that is bioavailable and can downregulate NF- κ B, STAT3, and COX2 in myeloma patients. This suggests a potential therapeutic role for curcumin in myeloma that should be further investigated.



How do you view the disconnect between the encouraging data on curcumin in the lab with its lesser effectiveness in the patient? Overall, cancer treatment requires

treatment requires suppression of multiple cell-sig-

naling or survival pathways. Inhibition of single pathways is not adequate. Curcumin is an ideal agent to investigate for the treatment and prevention of myeloma, as it adapts multiple cell-signaling pathways, and is safe to administer.

What about further investigations of curcumin for myeloma?

Our lab has already used curcumin in vivo and in vitro with Revlimid[®] and with VELCADE[®], and we have demonstrated that Revlimid and VELCADE work better when combined with curcumin.

*No complete or partial responses were seen.

Editor's Note: Dr. Aggarwal is Professor of Cancer Research and Experimental Therapeutics, Division of Cancer Medicine, and Chief of Cytokine Research Laboratory at the University of Texas MD Anderson Cancer Center.

Special Event

PROF. MARIO BOCCADORO RECEIVES THE ROBERT A. KYLE LIFETIME ACHIEVEMENT AWARD



Prof. Mario Boccadoro

he sixth annual Robert A. Kyle Lifetime Achievement Award was presented to Professor Mario Boccadoro. The event was held in the town of Nichelino, just outside Torino, Italy, on February 6th, 2008, at the historic and beautiful Palazzinadi Caccia Stupinigi. A residence of the Royal House of Savoy, it is one of the UNESCO World Heritage Sites, and was originally built as a royal hunting lodge in the early eighteenth century. It was the perfect setting for a very special event.

Prof. Boccadoro is the head of

the hematology section of the oncology division at the University of Torino. Prof. Boccadoro created the Italian Myeloma Study Group, the first research consortium in Italy and one of the first in Europe. He began his



career in myeloma research and treatment in 1978 as a post-doctoral fellow in Brussels, Belgium, working with Prof. Benjamin Van Camp, one of the earliest researchers in the field of myeloma. Following this, Prof. Boccadoro was appointed assistant professor in the Department of Medicine and Experimental Oncology under Prof. Alessandro Pileri, a noted researcher in the area of multiple myeloma.

able collective contribution to the

myeloma community, and have been

published in all the major journals,

including The New England Journal

of Medicine, Blood, and the Journal

of Clinical Oncology. Prof. Boccadoro

is a member of numerous profes-

sional societies both in Europe and

Dr. Robert A. Kyle

In the early 1980s, Prof. Boccadoro spent two sab-

baticals as a visiting investigator at the Arizona Cancer Center in Tucson, where he worked with Prof. Brian Durie and Prof. Sydney Salmon, codevelopers of the Durie/Salmon Staging System for myeloma. Under Prof. Boccadoro's direction, the Italian Myeloma Study Group has conducted a series of pivotal clinical trials, initially involving chemotherapy, then transplantation, both autologous and allogeneic, and most recently the range of exciting novel agents: thalidomide, VELCADE[®], and Revlimid[®]. These clinical trials, spanning over two decades, represent a remark-



Prof. Boccadoro, his sister Milena, and his mother Sara

has held the title of Professor and Head of the Hematology Section of the Oncology Division at the University of Torino.

Guests arriving at the event honoring Prof. Boccadoro entered through the former stables, where coat racks were cleverly located in



Carlotta & Simone Boccadoro

the horse stalls. They then proceeded into a long, impressive hall, where cocktails and hors d'oeuvres were served and lively conversation took place. After cocktails, they proceeded into a truly grand "salon," whose original function was that of a winter nursery for



Prof. Mario Boccadoro, Susie Novis, Dr. Robert Kyle, and Dr. Brian G.M. Durie

the lodge's lemon trees. The impressive room with a huge vaulted ceiling was devoid of any furnishings except for large, red-trimmed drapes and elegantly set tables. It made a perfect setting for this festive occasion.



Susie Novis and Dr. Brian Durie welcomed the guests and acknowledged the event's presenting sponsor, Celgene, the platinum sponsor, Pharmion, the gold

and how their relationship grew into a close

and personal friendship. Dr. Durie then had

the honor of introducing Prof. Alessandro

Pileri, Prof. Boccadoro's long-term mentor.

Prof. Pileri gave an eloquent speech about

his protégé and the importance of hav-

ing such an outstanding myeloma team in

Torino, which grew out of their many col-

sponsor, Janssen-Cilag SpA, the silver sponsor, The Binding Site, and the bronze sponsor, Genentech BioOncology.

Susie Novis noted what an honor it was to be able to recognize and celebrate Prof. Boccadoro's many achievements in the presence of his loving family, his many friends, and numerous colleagues. Dr. Durie spoke about what a privilege it has been to work with Prof. Boccadoro over the years



Prof. Mario Boccadoro & Prof. Allessandro Pileri

Setting the stage for the climax of the evening was a video presentation that showed the many faces of Mario Boccadoro: doctor, researcher, col-

laborations together.

laborator, loving father and devoted husband, dog and cat lover, motorcycle enthusiast, and definitely a person with a lust for life.The highlight of the evening was Dr. Kyle's presentation of the award to Prof. Boccadoro. Prof. Boccadoro gave an impassioned speech about the Torino myeloma team and the importance of the contributions made by each member that had enabled the team to be so successful. He ended the



Susie Novis & Rosella Boccadoro

evening by showing his own presentation, an homage to his "family" at work and his loving family at home.

Coffee and dessert were served as the evening drew to a close. The guests left the event knowing that they had honored a wonderful and deserving person, and experienced an authentic notte italiana! MT



Supportive Care

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.

My doctor has just prescribed Revlimid[®] (lenalidomide) and dexamethasone and I've read that blood clots can be caused by this regimen. What can I do to guard against this?

As always, it is best to discuss this question with your own doctor. For example, prior blood clot issues or heart/ lung/vascular problems may mean that Revlimid/dexamethasone is not a good choice for you. If you go ahead with Revlimid/dexamethasone, your doctor is in the best position to decide what medications you might need to help



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

individual risk factors are: increased age, obesity, history of blood clots, having a central-venous catheter, prolonged inactivity (such as during a long airplane flight), varicose veins, other diseases (diabetes, infections, sickle cell disease, cardiac diseases), surgical procedures (including vertebroplasy and kyphoplasty) and inheritied thrombophilia (genetic mutations that can increase the likelihood of forming a blood clot). In addition, myeloma itself is a risk factor, as is hyperviscosity (thickening of the blood).

Aspirin alone is recommended for

prevent blood clots based upon the drugs and dosages you are receiving and whether or not you are at a higher risk than average for blood clots. We can provide some general background that you can use as a basis for a discussion with your doctor. The IMF's International Myeloma Working Group has just had an article published in *Leukemia* (2008, vol. 22, pp. 414-423) on the prevention of blood clots in thalidomide- and Revlimid- based therapies. You can access the full article on our website www.myeloma.org. The IMF's Nurse Leadership Board has also created the Consensus Statement for the Prevention of Thromboembolic Events Associated with Novel Therapies in Patients with Multiple Myeloma, which will shortly be published in the *Clinical Journal of Oncology Nursing*, and will appear on our website at that time.

While the addition of both thalidomide and Revlimid to the arsenal of anti-myeloma treatments has extended survival for patients, there are some potential serious side effects of these treatments. Myeloma patients treated with thalidomide or Revlimid in combination with steroids or chemotherapy have an increased risk of blood clots: venous thromboembolisms (VTEs) or deep vein thrombosis (DVIs). Blood clots or DVIs are a serious condition and are potentially life threatening. DVT is a blood clot in a deep vein of the lower extremities (usually occurring in the leg or thigh, and very occasionally in the neck or upper arm). A blood clot from a DVT can break loose (embolize) and travel to the lung, causing a pulmonary embolism (PE), which is very dangerous. The symptoms of DVT are warmth, swelling, redness and/or pain in an extremity, or difficulty breathing. Any of these symptoms should be reported immediately to your doctor.

All patients on a regimen of thalidomide or Revlimid in combination with a steroid or chemotherapy should receive routine prophylaxis (medications taken to prevent something) in the form of a blood thinner to prevent blood clots. The choices of prophylaxis are several: aspirin (81–325 mg once daily), LMWH (low molecular-weight heparin) or full-dose warfarin.

Which drug is best for you depends upon both the regimen you are on and whether you have any additional risk factors for blood clots. The primary patients who have either no risk factor or only one individual/myelomarelated risk factor. Thus, for a majority of patients receiving Revlimid combined with low-dose dexamethasone (i.e. dexamethasone taken only one day each week), aspirin alone is sufficient prophylaxis.Patients who have at least two individual/myeloma-related or therapy-related risk factors (highdose dexamethasone, doxorubicin, or multi-agent chemotherapy) should receive LMWH or full-dose warfarin. The International Myeloma Working Group has stated that ongoing randomized trials comparing aspirin, warfarin, and LMWH will soon determine the optimal prophylaxis strategy.

The patient (and his or her doctor) must also keep in mind that there are side effects and risks associated with prophylaxis. Thus the doctor must weigh your entire situation when making a decision about what type of prophylaxis is best for you.

Again, we caution that this is a complicated issue and that the above information is designed to provide a basis for discussing this issue with your doctor. We encourage you to share the *Leukemia* article from the International Myeloma Working Group with your doctor, as well as the IMF Nurse Leadership Board consensus statement on this issue. **MT**

What do you get at an IMF Patient & Family Seminar?

Access to Experts

• Camaraderie

Get one-on-one access to the

about your treatment options.

strength from hearing other

part of the IMF family.

experts with time to ask questions

Share your experiences and gain

people's stories, as you become

Education

- Get vital, up-to-date information, including:
- Options for front-line therapy
- What to do at relapse
- What is the current role of transplantation
- Which emerging therapies look promising

See the calendar on the back page for dates and locations of upcoming seminars. To register for a seminar, please call (800) 452-CURE (2873) or email TheIMF@myeloma.org.



Page Bertolotti, RN, BSN, OCN

Cedars-Sinai Medical Center Samuel Oschin Comprehensive Cancer Institute Los Angeles, CA

Elizabeth Bilotti, RN, MSN, APRN, BC, OCN St. Vincent's Comprehensive Cancer Center New York, NY

> Jacy Boesiger, RN, BSN, OCN Mayo Clinic Scottsdale Scottsdale, AZ

Kathleen Colson, RN, BSN, BS Dana-Farber Cancer Institute Boston, MA

Kathy Daily, RN, TSN H. Lee Moffitt Cancer Center and Research Tampa, FL

> Deborah Doss, RN, OCN Dana-Farber Cancer Institute Boston, MA

Beth Faiman, RN, MSN, CNP, AOCN Cleveland Clinic Taussig Cancer Center Cleveland, OH

Bonnie Jenkins, RN, OCN University of Arkansas Medical Sciences Little Rock, AR

Kathy Lilleby, RN Fred Hutchinson Cancer Research Center Seattle, WA

Ginger Love, RN, OCN University of Cincinnati Hem/Onc Care Cincinnati, OH

Patricia A. Mangan, MSN, AOCN, CRNP University of Pennsylvania Philadelphia, PA

> Emily McCullagh, RN, NP-C, OCN Memorial Sloan-Kettering Cancer Center New York, NY

> > Teresa Miceli, RN, BSN Mayo Medical Center Rochester, MN

Kena Miller, RN, MSN, FNP Roswell Park Cancer Institute Buffalo, NY

Tiffany Richards, MS, ANP, AOCNP MD Anderson Cancer Center Houston, TX

> Sandra Rome, RN, MN, AOCN Cedars-Sinai Medical Center Los Angeles, CA

Stacey Sandifer, RN, BSN Cancer Centers of the Carolinas Greenville, SC

Lisa Smith, MSN, FNP, AOCN Cancer Centers of the Carolinas Greenville, SC

Joseph Tariman, RN, MN, ARNP-BC, OCN University of Washington Seattle, WA

> Jeanne Westphal, RN Meeker County Memorial Hospital Litchfield, MN

REPORT FROM 2008 NLB MEETING

The 2008 meeting of the IMF's Nurse Leadership Board (NLB) took place on March 8th and 9th in Las Vegas, NV. This was the third general meeting of the NLB membership. Spearheaded by IMF Senior Vice President Diane Moran, the NLB is comprised of 20 nursing leaders in clinical practice, and provides an excellent forum for addressing the needs of the nursing and patient communities. The nurses exchange information about multiple myeloma nursing care, identify and implement key nurse education programs, and facilitate information flow between the IMF, oncology nursing organizations, and patients. As a result of the previous NLB2 meeting in 2007, four taskforce teams were created to focus on nursing education, patient education, publications, and long-term care.

The key targets for NLB3 included identifying opportunities to disseminate the NLB consensus statements, development of new educational materials and tools for nurses and patients, advancing the development of the NLB's Long-Term Care Plans for myeloma patients, and moving forward with a new publication.

The update on NLB's side effects management consensus statements was presented to the group by Patricia Mangan. The NLB has developed five consensus statements on the management of side effects associated with the novel therapeutic agents used in treating multiple myeloma patients: myelosuppression, deep vein thrombosis and pulmonary embolism, gastrointestinal effects, peripheral neuropathy, and steroid-related side effects. The NLB's side effects management consensus statements will be published in June 2008 in the prestigious *Clinical Journal of Oncology Nursing* (CJON). The continuing education (CE) accredited supplement will be disseminated at IMF's 2008 Oncology Nursing Society (ONS) satellite symposium in May.

Kena Miller presented the Nursing Education Taskforce activity update. The NLB Speakers' Bureau will initially focus on the NLB Consensus Statements. An updated slide presentation on the Consensus Statements will be used by the Speakers' Bureau, and portions will be incorporated into the IMF-ONS satellite symposium meeting in Philadelphia. The group is also devising a plan for effectively disseminating the consensus statements within NLB institutions and the nursing community at large.

Ginger Love presented the Patient Education Taskforce activity update. Their aim is to create educational material based on the NLB consensus statements that are user friendly educational tools for patients and caregivers. The taskforce works cooperatively with the Nurse Education Taskforce to help nurses educate patients. Patient Education Taskforce members are participating in the IMF's Support Group Leaders Retreat in April. This will help taskforce members to do a needs assessment in order to see how NLB can best help the patient community. A joint working group will be established between patient education taskforce members and several support group leaders.

The activity update for the NLB Publications Taskforce was presented by Jeanne Westphal. The taskforce will support editing, reviewing, and publishing of relevant myeloma-related documents. The current focus is on an article on new myeloma drugs in clinical trials. The IMF's Myeloma Matrix was used as a starting point to evaluate promising new agents under development that will be addressed in the publication.

The Long-Term Care Plan Taskforce activity update was presented by Elizabeth Bilotti. With the advent of novel therapeutics, the myeloma treatment paradigm has evolved dramatically over the last decade and, as a result, patients with myeloma are living longer with their disease. There is a greater need for managing long-term consequences of the disease and its treatments. The taskforce is focused on educating patients by developing statements on bone health and bone disease, functional mobility and safety, health maintenance, renal complications, sexuality and sexual dysfunction, and chronic pain and pain management.

Dr. Brian Durie provided a scientific update and his "Best of ASH 2007" webcast. The new IMF-NLB web portal, an initiative to enhance communication among NLB members, was introduced by Teresa Miceli. IMF Board of Directors member Mike Katz then presented the IMF Myeloma Manager, a new patient and caregiver tool. IMF Board of Directors member Dr. Tom Bay, who is an experienced and inspiring public speaker, offered speaker coaching for effective dissemination of NLB consensus statements. A very full first day at NLB3 closed with remarks by Patricia Mangan.

Day two included a recap by Teresa Miceli, then progressed to the Long-Term Care Plan session lead by Elizabeth Bilotti. The taskforce divided into subgroups for breakout sessions to define outlines and deliverables, then gathered again for group reports facilitated by the faculty.

Before closing, NLB3 participants discussed the NLB key targets for 2008. We recognize and applaud the tremendous effort and involvement of the NLB members. Their commitment is invaluable to the nursing community involved in myeloma care and to the patients they are dedicated to serving. **MT**

Education & Awareness

CANCER AWARENESS DAY

By Ian MacDonald

I am 15 years old and am a Life Scout from Troop 28 in New Windsor, NY. To complete my Eagle rank, the highest rank in scouting, I organized a Blood Drive, Bone Marrow Donor Registration, and Cancer Awareness Day. The event took place on January 26 at the Salisbury Mills firehouse in Orange County, NY.

The choice of my Eagle project was a direct result of some very personal circumstances. When I was 4 years old, my mother was diagnosed with Hodgkin's disease. In the Summer of 2007, at age 69, my grandfather was diagnosed with terminal liver cancer. Less than six weeks later, at age 50, my father, Edward MacDonald, was diagnosed with multiple myeloma, Stage III with meta-

static lytic disease. My dad's cancer diagnosis has been a complete shock to everyone.

I contacted the IMF and requested the Foundation's participation in the Cancer Awareness Day. In addition to providing information and educational materials for distribution to patrons who attended the event, the Foundation also arranged for Robin Tuohy (IMF Regional Director Support Groups - Northeast) to attend in person to answer questions about myeloma and IMF programs and services.



Ian MacDonald and Robin Tuohy

My dad is a volunteer firefighter with the Salisbury Mills firehouse, so the event received broad cooperation from every firehouse in the area. In addition, I received support from my extended network community of Boy Scouts, Girl Scouts, Cornwall High School, St. Thomas of Canterbury Church and youth group, and numerous local businesses.

The turnout was awesome. My original goal for the blood drive was 150 pints, but we collected 276 pints of blood! In addition, over 100 people registered for the national Bone Marrow Donor Program. And many more people were exposed to myeloma education. I feel very strongly that if people receive information about their disease early enough, it could make a significant difference in their life. Education is key. Both my dad's and my

grandfather's cancers were diagnosed at advanced stages, and I can't help thinking what a huge difference a proper early diagnosis might have made for them and for my entire family. **MT**

"Ian did an outstanding job! His family and the entire community have a lot to be proud of. As a member of the cancer community myself, I am so thankful for all he has done and continues to do to help others."

- Robin Tuohy, IMF Regional Director Support Groups - Northeast

SPOTLIGHT ON ADVOCACY

President Bush Includes Slight Increase for Cancer Research Funding

By Christine Murphy, MA

On February 4th, President Bush released the last budget of his Administration. Included in the President's fiscal year (FY) 2009 Budget is \$29.5 billion for the National Institutes of Health (NIH). This is the same funding level NIH received in FY 2008. The President's funding level is estimated to support a total of 38,257 research project grants, including 9,757 new and competing awards – approximately the same levels as FY 2008. The National Cancer Institute (NCI) received a \$5 million increase to \$4.810 billion in the President's FY 2009 budget. The IMF supports \$30.926 billion for the NIH and \$5.260 billion for the NCI in FY 2009.

The Geraldine Ferraro Blood Cancer Program at the Centers for Disease Control and Prevention (CDC) received a slight decrease to \$4.313 million in the President's budget. IMF supports \$5.5 million for the blood cancer program in FY 2009.

Additionally, the President's budget proposed a \$200 billion reduction in spending for Medicare and Medicaid over five years. In the proposal, hospitals will bear the brunt of the Medicare cuts.

With the release of the President's budget, Congress officially begins the FY 2009 appropriations process. Currently, Congress is combing over the

Christine K. Murphy, MA Murphy Consulting LLC Arlington, VA

President's budget and hearing testimony from federal agencies including NIH, NCI, and CDC. Congress is predicted to put more funding into important social programs, including health programs. With the upcoming elections in November, the FY 2009 budget and appropriations process is expected to be contentious, as the President has vowed to veto any appropriations bill that includes funding levels higher than those contained in his budget.

The IMF continues to monitor these issues to keep you informed. Please visit www.myeloma.org for updates. **MT**



800-452-CURE (2873)

Education & Awareness

DID YOU KNOW?

An Important Milestone for the Myeloma Community

By E. Michael D. Scott

In late 1982 the US Congress passed the *Orphan Drug Act*, which was signed into law by President Ronald Reagan on January 4, 1983. This Act has been of critical importance to the global myeloma community for a variety of reasons.



As some readers will know, the Act provides a mecha-

nism whereby organizations (commercial and non-profit) can apply for certain exclusive rights in developing and bringing to market products that may be used to treat groups of patients with disorders that each affect fewer than 200,000 individuals in the United States. Multiple myeloma is one such disorder. Developers of so-called "orphan drugs" gain the exclusive right to market a designated drug for an orphan indication for 7 years from the date of FDA approval. During that timeframe, no other manufacturer may market the same chemical or biological product for the same clinical indication. This exclusivity provides manufacturers with an economic "safe haven" through which they may reasonably expect to recover their investment in drug development and earn a profit.

In the 10 years preceding the approval of the *Orphan Drug Act*, only 10 new drugs had been developed by the pharmaceutical industry for rare disorders. In the 25 years since the approval of the Act, more than 300 new drugs have been approved for treatment of orphan diseases — averaging more than 11 new drugs every year. Importantly for the myeloma community, these drugs have included:

INTRON A[®] (interferon alfa), Thalomid[®] (thalidomide), Revlimid[®] (lenalidomide), VELCADE[®] (bortezimib), Aredia[®] (pamidronate), Zometa[®] (zoledronate), Procrit[®] (epoietin alfa), Doxil[®] (doxorubicin liposomal), Trisenox[®] (arsenic trioxide).

First St. Louis Regional Community Workshop a Great Success!

By Kathy Cartwright

The IMF held a Regional Community Workshop in downtown St. Louis on December 15, 2007. The venue was the Grande Dame of St. Louis hotels – the Adams Mark –



and it was just wonderful. Even the six inches of snow that fell the night before didn't stop the more than 70 attendees from learning more about their disease, new treatments, side effects, and, thanks to Kelly Cox, a little about the IMF. The warm atmosphere, the food, and most importantly, the participating patient community and physicians and nurse practitioner made the day memorable. Very special thanks to Drs. Keith Stockerl-Goldstein and Ravi Vij from Washington University, as well as to George Bryant, NP, from Siteman Cancer Center, for their presentations and answers to the many questions directed their way.

At the end of the day, besides taking home the information and IMF publications being disseminated, those who were there took home the most important thing possible – HOPE. We ended the day having made new friends, so huge kudos to everyone involved. The event was such a success that there is talk of organizing another St. Louis Regional Community Workshop in 2008. **MT**

In other words, most of the drugs that have had significant impact on the treatment of myeloma over the past 20 years have been developed through the use of the *Orphan Drug Act*. At least some of them might never have been developed if this Act hadn't been approved.

Passage of the *Orphan Drug Act* in the USA also led to passage of similar laws in the European Union, in Australia, in Japan, and in other countries around the world, making it possible for the same drugs to be used in the treatment of myeloma patients in a multitude of other countries too.

Even more importantly, many companies are still using the *Orphan Drug Act* to develop additional new agents that have significant potential in the treatment of myeloma. There are currently over 1700 drugs designated as orphan drugs by the USA in clinical development for specific orphan disorders. Of course most of these drugs aren't in development for treatment of myeloma, but many are, and so we can continue to look forward to the impact the *Orphan Drug Act* will be having on the management of myeloma for several years to come.

It is worth noting that the National Organization for Rare Disorders (NORD) was also established in 1983. NORD is dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is also committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. Just as Brian Novis had a vision that led to the founding of the IMF, so NORD's founding president, Abbey Meyers, a housewife from Connecticut whose son needed treatment for a rare disorder, envisioned the steps that led to the passage of the *Orphan Drug Act*. Abbey, the primary consumer advocate responsible for the Act, will be retiring as president of NORD this year.

In collaboration with others, NORD has planned multiple events during 2008 to celebrate the 25th anniversary of the signature of the *Orphan Drug Act.* **MT**

BlueVoice.org Conducting Toxins Testing Program

IMFer and myeloma patient Hardy Jones, who is the Executive Director of BlueVoice.org, an oceanic conservation group he co-founded with actor and ocean activist Ted Danson, is continuing work on a comprehensive study of the links between ocean contamination and cancers in marine mammals and humans. He will present his report at the International Whaling Commission in



June 2008 in Santiago, Chile. The report is an overwhelming indictment of eating whales and dolphins, not only for moral reasons, but because their meat is contaminated with heavy metals and organochlorines. "We are conducting tests of dolphin meat and the hair of people who eat dolphins in Japan," says Hardy. "Our most recent test on the meat of a bottlenose dolphin killed at Taiji showed levels of mercury 18 times higher than the maximum allowed by Japanese health officials. Our test of the hair of a Taiji man who eats dolphin meat showed he had 33 parts-per-million, 30 times the level considered safe. A Japanese doctor recommended that this man be hospitalized immediately. These two facts clearly point out the danger that eating dolphin meat poses to human consumers. While direct action in the Antarctic is running the Japanese fleet ragged, the real end to the slaughter of whales and dolphins will come when it is fully exposed how contaminated the meat is." Ongoing studies are evaluating the correlations between polution in aquatic mammals and humans and links to the onset of cancers including myeloma. For more information, please visit www.bluevoice.org. MT

International Affiliates

UPDATES FROM JAPAN & LATIN AMERICA

IMF Japan

IMF Japan experienced one of its busiest years ever in 2007. Perhaps this is fitting, since 2007 is also the year that IMF Japan celebrated its 10th anniversary of service. The Foundation held an impressive roster of eight well-attended patient and family seminars throughout Japan, including meet-



ings in some of the most remote regions of the country. The main 2007 annual event, which featured a faculty of the most highly regarded myeloma specialists in Japan, attracted more than 300 attend-

IMF Japan hosts its 10th anniversary meeting panel discussion on living with myeloma

ees! In 2008, IMF Japan has already held one patient and family seminar, and will hold five more, visiting some locations for the first time ever.

The past year also marked the submission of four formal requests to Japan's Ministry of Health, Labor, and Welfare for early approval of key myeloma drugs and a general improvement in the availability of myeloma therapies. Japan has universal health insurance, which means that everyone has low-cost access to all drugs, treatments, and tests approved by the authorities. However, for many and varied reasons, all new authorizations take a very long time. This gap is known as the "drug lag" problem.

When it comes to new myeloma therapies, Japan's patients have access to VELCADE[®] (bortezomib) as second-line treatment in combination with dexamethasone, but there are no other novel therapies in the arsenal. No thalidomide. Revlimid[®] (lenalidomide) has only recently started Phase I investigation. Even VELCADE cannot be used in combination with any agent except dex, or in newly diagnosed patients. It is such circumstances that made the 2007 appeals to the Ministry so essential.

In 2008, IMF Japan will continue to focus on lobbying for approval of the novel therapies that are already available in the US and elsewhere. They will join forces with other patient organizations in a call for action addressed to the national government and to entities involved in drug development and authorization. IMF Japan's Daisuke Nakao has already been interviewed by a major Japanese daily newspaper and a US-based newswire, and has received several requests for manuscripts on this topic. Another issue that IMF Japan is tackling is the serious shortage of doctors with myeloma experience, so staffers are identifying and cultivating hematologists willing to take on myeloma patients and to participate in patient seminars.

IMF Japan is run by a small core of dedicated volunteers. "We recognize that at this time we cannot physically reach everyone who can benefit from the help we can offer," says Daisuke Nakao. "So, we are putting extra effort into upgrading our publication base. We recently updated our translation of the IMF Patient Handbook, and we are keeping our translation team very busy with other projects. Kyoko Joko has written a chapter on patient self-help and the role of patient support organizations such as the IMF for an upcoming book on the latest treatment options for myeloma, and she has several other publications in the works. We are also continuing with our semi-annual publication *Ganbarimassyoi*. Research by the Japanese medical community on myeloma pathogenesis and treatment is gathering steam and is keeping Dr. Hiroyuki Hata busy with his Aki Memorial Award project. And, as always, our boss, Midori Horinouchi, is making sure that everything is moving along smoothly."

We hope that you will join us in wishing IMF Japan a very successful year in 2008.

IMF Latin America

In 2007, IMF Latin America celebrated its third anniversary. The auspicious occasion was celebrated by holding IMF Latin America's first ever Gala. The event took place on November 13th and was called Doctors in Concert. Physicians from many specialty areas – oncology, hematology, neurology,



Ana Maria Braga (television host and member of IMF Latin America's Board of Honorables), Christine Battistini, and Roberto Civita (president of Brazil's largest publishing company and member of IMF Latin America's Board of Honorables)

surgery, orthopedics, pediatrics, etc. – who also have musical talent, performed for the IMF. Over 400 guests attended, making the event a smashing success. The evening also garnered significant media coverage, including primetime television and major print magazines. Doctors in Concert was hosted by a well-known

Brazilian prime-time Evening News reporter. IMF Latin America is already looking forward to marking its fouth anniversary in 2008 with another Gala, and plans to make this an annual event.

IMF Latin America's 2007 Symposium for Nurses was held during the Brazilian Society of Hematology Annual Meeting. More than 200 nurses attended this important symposium, and there is clear demand to make this educational forum available on an annual basis. As part of its education programs, IMF Latin America has hosted 11 patient and family semi-

nars in its first three years. For 2008, five patient and family seminars are planned in Brazil, one in Argentina, and one in Mexico, bringing the total number of IMF Latin America patient and family seminars to 18 by year's end. In addition, IMF Latin America has sent out approximately 15,000 educational InfoKits.

We would like to extend our thanks and congratulations to Christine Jerez Telles Battistini (President, IMF Latin America), Abílio Gunutzmann Filho (Director, IMF Latin America), the members of the IMF Latin America Scientific Advisory Board, the Board of Honorables, and the dedicated staff for all their impressive accomplishments. **MT**



Christine Battistini being interview by TV program Estilo Ramy

Support Group Profiles

EAST TEXAS MYELOMA SUPPORT GROUP

Donna LaRocque's husband, Roger, was diagnosed with multiple myeloma in the spring of 2005. Like many other couples facing

this diagnosis, they felt alone. "There were other types of support groups in the East Texas area, but nothing for multiple myeloma patients or their families," says Donna. "People dealing with many other types of cancer can't relate to us. There are cures for



can't relate to us. There are cures for Donna and Roger LaRocque some other hematological malignancies, but not for multiple myeloma. Myeloma is uniquely challenging."

The East Texas Myeloma Support Group invites you not to take the myeloma journey by yourself, but to come join them for mutual support and education. The group's logo is an open book with the motto, "Learning Together," which is an accurate description of its mission and activities.

On October 20, 2007, the East Texas Myeloma Support Group co-sponsored the "Understanding Myeloma" symposium with the IMF. Designed





for patients, family members, and health-care professionals interested in learning more about myeloma, the event featured presentations from medical professionals and from people living with the disease. One-onone access to myeloma experts gave many community members an opportunity to ask questions about their treatment options, and a welcoming environment created a comfortable space to share personal experiences.

Doctors on the faculty addressed the topics of myeloma therapies, kyphoplasty and vertebroplasty, opiate pain management for compression fractures, and the ever-popular "Myeloma 101," which was of particular interest to the newly diagnosed and their caregivers. Other presenters included IMF's Andy Lebkuecher, representatives from the North Texas Myeloma Support Group, and Bonnie Jenkins, oncology nurse extraordinaire from the Myeloma Institute at the University of Arkansas at Little Rock.

The East Texas Myeloma Support Group always welcomes new members. This group meets in Gladewater on the second Saturday of each month from 11am to 1pm. For more information please contact Donna LaRocque at 903-845-6711, Joe and Millie Denton at 903-858-2332, or Ed and Carolyn Evans at 903-839-4653, or visit http://easttexas.myeloma.org.

Photos:

Top row, far left: Andy Lebkuecher and Loul Biru. Check-in table: Ed & Carolyn Evans with Georgia Herndon standing. Top row, far right: speaker Dr. Gary Gross. Lower row, far left: Jim & Nancy Ver Shaw, friends of the family, and Bonnie Jenkins from Little Rock. Lower row, second from left: speaker Dr. Lee Griffith.

Lower row, third from left: speaker Dr. Frank Ward. Lower row, far right: Yelak Biru, Dr. Frank Ward, Andy Lebkuecher, Dr. Carolyn Harvey, Dr. Gary Gross and Bonnie Jenkins.

TAMPA/ST. PETERSBURG MYELOMA SUPPORT GROUP

When Carolyn and Frank Kaiser attended the IMF Patient & Family Seminar in Tampa/St. Petersburg, Florida, in November 2007, they did not know what to expect. Newly faced with Carolyn's myeloma diagnosis, they sought out information, education, and support wherever they could find it. Frank had even attended a caregiver's meeting at a local facility but did not find it very helpful. "Myeloma is such an unusual and complex disease that generic cancer information just does not apply," said Frank. "The IMF meeting helped us to begin to answer some of our questions, and gave us a sense of community and camaraderie."

Carolyn and Frank volunteered to work on starting a support group in their area, along with Marti Hill and Jim Barth. Marti was diagnosed in January 2004, following a year of being misdiagnosed with a rheumatoid condition. After unsuccessful treatment with thalidomide and dexamethasone, she had an autologous transplant, which helped her achieve a twoand-a-half year remission before relapse. Jim was diagnosed with Stage 2 myeloma in 2006 in the course of an annual physical, and is currently not receiving treatment.

IMF's Andy Lebkuecher visited Florida to meet with the group as they planned their first meeting. The planning get-together was set up by Marti at a local restaurant. "The meeting was extremely productive," says Andy. "We discussed strategies on how to get a new group off the ground, the



Carolyn Kaiser, Jim Barth, Frank Kaiser, and Marti Hill

type of services that a support group can provide to the local community, meeting structure, booking guest speakers, and handling a variety of patient and caregiver needs."

In less than a month, the new Tampa/St. Petersburg Myeloma Support Group was actively moving towards its first public meeting. Carolyn had distributed hundreds of flyers publicizing the group and its inaugural meeting, and her fellow group leaders canvassed local physicians and nurses. The group's first meeting was held successfully on March 15th, and the second meeting has been scheduled for April 19th. Andy Lebkuecher plans to attend once again and invites you to do the same. For more information, please contact Marti Hill at m23rose@gmail.com or 727-953-6527, or contact Carolyn and Frank Kaiser at cskaiser@mac.com or 727-726-0066. MT

Patient & Caregiver Experience

MY MANY MIRACLES

By Christine McClay

My husband, Robert, and I were married in 1996. Two years later we arrived at the decision that we were ready to start a family. I got pregnant. And that's when all hell broke loose.

The 20-week ultrasound showed that our baby boy did not have a brain, and the pregnancy had to be terminated. Shortly thereafter I started having what we thought was severe sciatica pain. Our doctors thought that the pain was pregnancy-related, and they prescribed a lot of pain-killers and muscle-relaxants. But the pain did not get better. In fact, it got so excruciating that soon I could no longer sit or lie down in



The McClay Family

comfort. An MRI scan was performed. It revealed Stage 3 myeloma, with a lesion on my sacrum at the bottom of the spine impinging upon the sciatic nerve. It became clear that if I had carried my little boy to term, my myeloma would not have been discovered in time. So I like to think that he gave his life for mine.

I was 33, and suddenly facing coming to the end of my life within three to five years. My husband and I desperately needed to absorb and process what all of this meant. We were made aware that the radiation I was about to undergo – part of the chemotherapy, radiation, and transplant treatment plan – would destroy my fertility. We talked to the doctors about our options to have children, and got started towards an egg retrieval process the very next morning. The fertilized eggs were frozen to wait for a better day, and I moved on with my myeloma therapy.

During my first year of treatment, I felt like I was having an out-of-body experience. It was a very difficult time, but my husband would never let me get down or focus on the negative. Neither of us has any family living nearby, so we got through those early myeloma days thanks to the broad network of local support that began to emerge. We had to learn to rely on others. Our church came to our aid with meals and healing services, and our neighbors and coworkers offered their assistance when we needed it most.

Then somehow we got word that there was going to be a convention in our area for couples who are infertile. As I was still dealing with the aftereffects of a transplant, I was not able to attend, but my husband went. He met a lawyer who specializes in surrogacy and adoption, and told him about our situation. In the Spring of 2000, when I finally recovered from my transplant, we called the lawyer. By the end of the year, we had found our gestational carrier. We cashed in the stock options my husband had received as part of his company's compensation plan in order to finance the surrogacy. We like to think that no one has ever received a better return on any stock. Our son Aidan was born on his due date in 2001. He was perfect.

When Aidan was about a year and a half, we decided it was time to give him a brother or a sister. Aidans' gestational carrier was no longer available, so we had to start the search process all over again. In early 2004, we found another woman and did an embryo transfer in March. Nothing happened. We had one last shot and, in May, transferred the remaining three embryos. To everyone's amazement, eight weeks later, we had three strong heartbeats. It's got to be very hard to carry someone else's babies – and triplets at that! – but our carrier was able to get them to 29-and-ahalf weeks. Our girls spent 5-and-a-half weeks in the neonatal intensive care unit and came home while still significantly short of their original due date. Each of them had slight medical problems, but all of these were resolved over time. Our church family was here to hold, swaddle, and cuddle the girls from 9am to 9pm

every day, and the triplets thrived. Now Keely, Jenna, and Erin are healthy, happy, active three-year-olds. And Aidan is a wonderful big brother.

Currently, I am experiencing a myeloma relapse, but that is just part of the challenge of living with this disease. After my transplant, I went on interferon in hopes of prolonging the remission, which lasted about a year and a half. In 2002, I took thalidomide for about nine months before my IgG reached normal levels. In 2004, I had a pulmonary embolism that, thankfully, was caught in time. In 2005, I was back on thalidomide and, once again, achieved remission. In May 2006, while my IgG tested within normal range, I developed a lesion on my rib. It was then that we learned that I had become a non-secretor. Apparently, this can happen as a result of thalidomide therapy. After two weeks of radiation, I started Revlimid® (lenalidomide) therapy. In October of 2007, I relapsed once more. I am dealing with a series of broken ribs and am now on combination therapy consisting of VELCADE® (bortezomib) and DOXIL® (doxorubicin Hcl). Our goal is to shrink the tumor burden enough to do a mini-allo transplant using my brother's bone marrow, as he is an exact HLA match.

There have been times when this disease brought me to my knees, but my husband and our support network have always lifted me up. I am a paralegal for a pharmaceutical company. I had also been in the Army Reserves as a Russian linguist for 12-and-a-half years. But the chemo did such a number on me that I found I could no longer keep up mentally with the demands of military intelligence work, not to mention the physical rigors of training, so I got a medical discharge. Recently, I became a sales director for Mary Kay Cosmetics, and a new group of friends entered my life. Unbeknownst to me, when I was unable to work while dealing with the most recent relapse, they collected enough money to help us pay our mortgage this past December. Once more, friends came to our aid and, once again, it overwhelmed me to know that people wanted to help.

I marvel that here I am, almost nine years after my diagnosis. Some mornings, just getting out of bed is tough, but I work at remaining positive and optimistic. I operate on an attitude of gratitude, and am thankful for everything. Myeloma has given me a new window on life. It taught me to be humble, that I don't control everything, that it's okay to accept help from others, and that there is much goodness in people and much beauty in life. I have chosen to live with myeloma as if it is already just a chronic disease, and I intend to be here for my children and grandchildren. **MT**

Member Events

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

Jammin' For A Cause

The Twin Cities Myeloma Foundation was born out of the local Twin Cities Area Multiple Myeloma Support Group about five years ago. The sup-

port group was providing an essential service but wanted to figure out a way to finance their meeting expenses, sponsor projects designed to raise myeloma awareness, and contribute in a significant way to myeloma research. Three years ago, Donna Costello and Pat Harwood, who run the Twin Cities Myeloma Foundation, organized their



Donna Costello, Famous Dave, and Pat Harwood

first fundraiser, a sit-down dinner for patients and their network of supporters. The evening also featured presentations by myeloma experts, and the event was a huge success, attracting more than 300 people. The proceeds from that event enabled the funding of a research grant for a project being conducted by the Mayo Clinic in Rochester, MN. In April of 2007,



the Twin Cities Myeloma Foundation hosted their second fundraising event, which was also a big success.

In August of 2007, a local philanthropist, Tom Ryan, offered the group an opportunity to hold an event on November 20th

Pat Harwood and Donna Costello with event volunteers Laura & Jeff Schuerman

at Elko Speedway, a well-known local attraction. Donna and Pat are both myeloma patients and, having already organized one big fundraiser in 2007, they found the thought of a second large event in the same calendar year somewhat daunting. "But we decided to move forward with the Elko event anyway," says Donna. "We received support and sponsorship from two pharmaceutical companies, Celgene and Millennium, and a local restaurant, Famous Dave's of Linden Hills. The IMF was also very helpful in getting the project going, and Kelly Cox and Suzanne Battaglia both attended the evening to lend their support."

The event was called "Jammin' For A Cause," as the featured attraction was a performance by the Johnny Holm Band, very popular local musicians who draw big crowds to their concerts. Unlike previous Twin Cities Myeloma Foundation events, Jammin' For A Cause drew a wide audience composed of people already familiar with myeloma and also those not peviously aware of it. Thus, there was a significant opportunity to spread the word about myeloma to a larger community. The event was attended by 800 people and, besides the musical performance, it included a live auction, a raffle with some very nice offerings, a martini bar, and a dinner of ribs, corn, baked beans, and cornbread. Funds raised by Jammin' For A Cause will be used to support the IMF's Bank On A Cure[®] research initia-tive at the University of Minnesota.

Mailing For A Cure

Matt Jacobs has battled multiple myeloma for over three years. "If this were a boxing match, we would be in the sixth round of a 15-round fight. And so far, it is a draw," says Matt. "Over the past year, I have been knocked to the mat, but when it looked like I was not going to beat the 10-count, a new drug protocol became available that put me into an eight-month

remission. And, although I am back in treatment again, I'm convinced that I'll be OK."

In a December 2007 letter, Matt asked his friends and family to donate to the International Myeloma Foundation during the holiday season, and they responded with great enthusiasm. In addi-



Phyllis & Matt Jacobs

tion to raising funds for myeloma research and other IMF programs, this type of fundraising also allows its organizer to be proactive in creating public awareness about the disease while sending cards and letters, something most of us do anyway on many holiday occasions. Hats off to Matt for a job well done!

Join Us

We are 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 awareness and funding for myeloma education and research. 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. Please contact me, Suzanne Battaglia, at sbattaglia@ myeloma.org or 800-452-CURE (2873).

UPCOMING MEMBER EVENTS

April 15, 2008 "Spirit of 76" – Lewisville, TX Contact: Jim Conrad, 972-317-8798

April 24, 2008 "Music Against Myeloma" – New York, NY Contact: Slava Rubin, 312-804-3076 or slavarubin@gmail.com

April 27, 2008 "A Song For Ireland" – Philadelphia, PA Contact: Doug Farrell, 215-870-5189

May 4, 2008 "Afternoon Tea" – Washington DC Contact: Carol Klein, carol60klein@verizon.net, or Nancy Moses, nancykmoses@aol.com

May 17, 2008 "JC Golf Tournament" – St. Cloud, MN Contact: David Johnson, 952-546-6000 or Djohnson@borkonlaw.com

June 21, 2008 "Schirinzi Golf Tournament" – Prato, Italy Contact: Vittorio Schirinzi, vschirinzi@tin.it

July 13, 2008

"Multiple Musicians Against Multiple Myeloma" – Great Neck, NY Contact: Naomi-Margolin, 516-487-6712 or Nmargolin@aol.com

July 19, 2008 "Naperville Golf Tournament" – Naperville, IL Contact: Craig Czerkies, 630-721-0557 or czak16@aol.com

Investing in the Future

MYELOMA TODAY IN CONVERSATION WITH DAVID BROWN

"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.

When were you first diagnosed?

During a routine physical in 1998, blood tests revealed irregularities in my blood chemistry. The oncologist I was referred to diagnosed me with MGUS (monoclonal gammopathy of undetermined significance). There were no symptoms, but the doctor was pessimistic about my prognosis. That was what led me to do my own research, to connect with the IMF, and to seek a second opinion from Dr. Brian Durie, who had been highly recommended in the field of multiple myeloma. At the time I lived in San Jose, California. Dr. Durie agreed to accept me as a patient and monitor the disease. He is an excellent physician, a terrific person, and has since become a good friend.



David Brown

achieve remission. The next therapeutic approach involved several months of thalidomide and dexamethasone. Next came an autologous transplant, which was performed at Mayo Clinic in July 2003. I relapsed after an 18- month remission.

In late 2006 my oncologist at Mayo Clinic, Dr. Craig Reeder, started me on Revlimid[®] (lenalidomide) and dexamethasone. Unfortunately, in my case, Revlimid did not bring the disease into remission. In August 2007, also at Mayo Clinic, a second transplant was performed. The lambda light chain numbers remained normal until the end of February 2008, when they began to rise slightly.

The problem with this disease is not just the myeloma itself, but all the peripheral medical issues that have happened along the way. I have

had major sinus disease, which involved two surgeries. As a result of numerous cases of pneumonia, I developed infections in the pleura of my right lung, which required a thoracotomy. Recovery from the operation took almost a year.

Myeloma has had a profound impact on my life. Of the last seven years, I have probably had only about 18 months when I wasn't actively dealing with some aspect of this disease. Because of my chronic leg and back pain, I have had to cope with my inability to do physical things with my two young sons. Our experience with myeloma has been challenging, both physically and emotionally, but it is now part of our lives. We have adapted and are doing well. Every day is a new day and we are learning to take one day at a time and to be grateful for our many blessings.

What has been most helpful to you along the way?

Without the support of my family and my strong Christian faith, I do not know that I could have survived this experience. My faith has grown during this trying period. I am learning to trust in the Lord, to wait on the Lord, and to hope in the Lord. It is also very essential to have the support of others – friends, other myeloma patients, and doctors. I have sought out the best myeloma doctors I could find. I have become close friends with them. My relationship with Susie Novis and the IMF has also been very important. I certainly recommend that other members of the myeloma patient community reach out to the IMF and learn about all available support services. Myeloma can be a lonely and scary disease, and it helps to have others to talk with about it. As a result of my disease I am able to offer support by sharing my experiences.

Why have you chosen to support the IMF and myeloma research?

I am a benefactor both to the IMF and to the Mayo Clinic. The IMF is a wonderful organization that provides a key support system for myeloma patients and their families. I helped provide seed funding for the IMF's Bank On A Cure[®] research initiative. Being a visionary in my business

What were the circumstances in your life at that time?

I have three grown daughters and 11 grandchildren. By 1998, I was in a second marriage, with a two-year-old son. In June 1999 we moved fulltime from Silicon Valley to Pagosa Springs, Colorado. The initial diagnosis was an emotional blow to my entire family, but we learned to accept it over time. My March 2001 checkup confirmed that my condition still did not require treatment, as no symptoms had emerged. In June 2001, my wife and I had our second son.

When did you convert from MGUS to active myeloma?

The day before 9/11, I started to experience some pain in my right femur while I was exercising on the treadmill. The pain continued to get worse, and by Thanksgiving I was on crutches. During that same time I was experiencing significant chronic pain caused by degenerative disc disease that has subsequently required six different operative procedures. In the late fall of 2001 I went to Mayo Clinic in Scottsdale, Arizona, to obtain opinions on the leg and back pain. While at Mayo, scans revealed that I had an in-place fracture to my femur and that the MGUS had progressed to multiple myeloma, which was the cause of the fracture. During this time I was still under the care of Dr. Durie, who recommended immediate radiation of the right femur to kill off the myeloma. I returned to Colorado for the treatment.

Please tell us about your experience with myeloma.

While at home in December 2001, I had a fall that fractured my leg. After four hours I ended up in the emergency room in Durango, Colorado, an hour and a half drive from where we live. The leg was reset and a rod was implanted in the hip. After being released from the hospital, I received more radiation therapy. During the next nine months we waited for the bone to regraft, which did not occur. In January 2003, I underwent surgery at Mayo to have a titanium prosthesis installed to replace the damaged bone. The prosthesis connects with my femur and goes over the knee into the tibia. The recovery from this surgery was quite lengthy. I started on chemotherapy (Cytoxan[®]). There was some improvement, but I did not

INVESTING IN THE FUTURE — continued from page 21

life, I decided to invest in what at the time was a novel idea. The decision was made largely from knowing Susie Novis and Dr. Brian Durie and the caliber of the people around them. My interest is in funding research that aims to mitigate this disease and to find a cure for it. I was confident from the beginning that Bank On A Cure would ultimately be successful.

The myeloma scientific community has come a long way since my initial 1998 diagnosis. After being given a prognosis of a 5-year survival, I am now in my 10th year. My current treatment options include novel agents that were simply not available a few years ago, and more new products are being developed every day. **MT**

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
- Annuity TrustsUnitrusts
- Gifts of Securities (Stocks)Gifts of Real Estate
 - /
- Charitable Lead or Remainder Trusts
- Term-of-year TrustsGifts of Life Insurance

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 Heather Cooper-Ortner at 800-452-CURE (2873) or hortner@myeloma.org. We also invite you to visit our website at www.myeloma.org for a more detailed explanation of these giving plans.



Put your old cell phone to good use!

Donate your old cell phone and become part of finding the cure. The IMF has partnered with a cell phone recycling organization that makes a donation for every cell phone we turn in. Current cell phone models are worth up to \$20 each. Many older models are worth \$1 to \$10.

You can help the IMF continue its research and programs. You can help our environment. You can provide cell phones to underserved communities. And it's as easy as sending us your old cell phones. For more information about how to turn your old cell phone into a contribution (or how to set up an IMF collection program at your business or school), call Kemo Lee at at 800-452-CURE (2873).

Or, you can mail your phones direct to the IMF:

International Myeloma Foundation c/o **Cell Phones for a Cure** 12650 Riverside Drive, Suite 206 North Hollywood, CA 91607-3421.

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2008 IMF Calendar of Events

April 17 – 19	IMF Scientific Advisory Board Retreat — BERMUDA	June 27 – 28	IMF Patient & Family Seminar — Seattle, WA	
April 25 – 26	IMF Patient & Family Seminar — Vienna, AUSTRIA	June 27 – 29	Eastern Cooperative Oncology Group (ECOG) meeting – Boston, MA	
April 30 – May 4	Southwest Oncology Group (SWOG) meeting – Atlanta, GA	July 25 – 26	IMF Patient & Family Seminar – Boston, MA	
May 15 — 18	Oncology Nursing Society (ONS) – Philadelphia, PA	August 8 – 9	IMF Patient & Family Seminar – Short Hills, NJ	
May 28	Regional Community Workshop for Physicians – Barcelona, SPAIN	August 22 – 23	IMF Patient & Family Seminar — San Diego, CA	
May 30 — June 3 May 31	American Society of Clinical Oncology (ASCO) meeting – Chicago, IL IMF Patient & Family Seminar – Valencia, SPAIN	Sept 18 – 19	Biennial — 5th Annual International Symposium on Clinical Applications of Serum Free Light Chain Analysis — Bath, UK	
June 2	Regional Community Workshop for Patients/Physicians – Pamplona, SPAIN	October 10 October 17	IMF Patient & Family Seminar – Paris, FRANCE IMF Patient & Family Seminar – Rome, Italy	
June 12 – 15	European Hematology Association (EHA) meeting — Copenhagen, DENMARK	Oct 29 — Nov 2 Nov 14 — 16	Southwest Oncology Group (SWOG) meeting – Chicago, IL Eastern Cooperative Oncology Group (ECOG) meeting –	
June 25	Regional Community Workshop — Ulm, GERMANY		Ft. Lauderdale, FL	
June 26	Regional Community Workshop — Stuttgard, GERMANY	Dec 6 – 9	American Society of Hematology (ASH) meeting – San Francisco, CA	
Other events/meetings will be posted in later editions of Mveloma Today as dates are finalized				

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.

We speak your language

The IMF publishes a comprehensive library of informative myeloma resources. Used by patients, caregivers, healthcare professionals, and anyone needing a reliable source of up-to-date information regarding the disease, these publications are critical to a better understanding of myeloma.



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International Myeloma Foundation 12650 Riverside Drive, Suite 206 North Hollywood, CA 91607-3421 U.S.A. www.myeloma.org (800) 452-CURE (2873) Change Service Requested

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 our website www.myeloma.org, or contact Suzanne Battaglia at SBattaglia@myeloma.org or 800-452-CURE (2873).



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