MYELOMA TODAY

FALL 2008

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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

David Siegel, MD, PhD, discusses the role of Zolinza® (vorinostat) in multiple myeloma. Vorinostat is the first drug in a novel class of anticancer agents known as histone deacetylase (HDAC) inhibitors. By giving patients HDAC inhibitors, researchers are attempting to increase the level of expression of tumor suppressor genes. Vorinostat has been shown to have significant single-agent efficacy in cutaneous T-cell lymphoma. In myeloma, vorinostat has already been tested in several single-agent clinical trials and as part of combination therapy. ***PAGE 7***

Sundar Jagannath, MD, talks about the upcoming large international clinical trials of Zolinza® (vorinostat) and Velcade® (bortezomib), as well as two smaller myeloma clinical studies of the combination that have already been completed. In his randomized Phase III study, Dr. Jagannath is investigating the vorinostat and bortezomib combination therapy in previously treated myeloma patients. It is hoped that vorinostat will be proven to be effective at making bortezomib work better, as well as for bortezomib-refractory myeloma patients. ***PAGE 8***

Angela Dispenzieri, MD, explains how the serum immunoglobulin free light chain (FLC) assay, known as the FREELITE™ test, works and its role in multiple myeloma. Dr. Dispenzieri shares her advice about the three major indications for the FLC assay to measure circulating monoclonal immunoglobulins in myeloma – diagnosis, prognosis, and management. Studies have demonstrated excellent sensitivity of the serum FLC assay in detecting FLC in patients with oligosecretory myeloma and in patients with light chain multiple myeloma (LCMM). ***PAGE 9***

Supportive Care

Patricia A. Mangan, MSN, AOCN, CRNP, answers questions about the role of steroids in multiple myeloma therapy and the potential steroid-associated side effects that may result. While steroids are very active in the treatment of myeloma, such therapy can cause side events that may affect many body systems and have an impact on patients' physical, social, and psychological functioning. When managed carefully, the severity of side effects can be reduced, helping patients adhere to their therapeutic regimen and to have a better treatment outcome. ***PAGE 13***

IMF Hotline Coordinators answer an important question about whether it is necessary or beneficial to start treatment for myeloma immediately upon diagnosis. Both asymptomatic and symptomatic myeloma are discussed, as well as a benign condition known as monoclonal gammopathy of undetermined significance (MGUS). The CRAB Criteria is also explained. ***PAGE 14***

Profiles in the News

Edith Peterson Mitchell, MD, FACP, member of the IMF Board of Directors and Clinical Professor of Medicine and Medical Oncology, Program Leader in Gastrointestinal Oncology, and Associate Director of Diversity for the Kimmel Cancer Center at Thomas Jefferson University talks about her medical career and military service. Dr. Mitchell is the recipient of numerous military medals and ribbons, and cancer research and principal investigator awards, and serves on the NCI Review Panel and the Cancer Investigations Review Committee. ***PAGE 5***

John M. Ricco, myeloma patient and author of The Ride of Your Life: Fighting Cancer With Attitude, writes about his experience of coping with fear and cancer recurrence. Mr. Ricco, an eight-year myeloma survivor who is currently in his second remission, shares his lingering concerns about the possibility of disease recurrence and self-doubt about the choice of cancer treatment, as well as the tools he employs to deal with these anxieties. ***PAGE 18***

Leslie Byrnes, who has made a substantial investment in the myeloma community and the search for a cure, is profiled in the "Investing in the Future" feature. She shares the story of why she has chosen to contribute so significantly to the fight against myeloma and the sense of purpose she has found through making a commitment to an improved future for the myeloma community by supporting myeloma research and acting as an advocate for the patient and caregiver community. ***PAGE 19***

Also in this issue...

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).

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A Message from the President

Dear Reader,

In our annual year-end issue, I generally use this column to recap our achievements of the past year, to let you know the progress we've made and what the New Year may hold.

But this year, I need to devote this column to something very important – I need to ask you for your help.

I don't need to tell you what shape the economy is in. We're all affected by it, and the uncertainty of not knowing what's going to happen next is very stressful for us all.

But the IMF needs your help now more than ever. We're dependent on people like you to make a donation to ensure that the services and programs we provide continue to be the lifeline so many people have come to rely on – maybe even you.

I'm asking you to please give – give whatever you can – every dollar counts.

The IMF means many things to many people. We're often described as "the light at the end of the tunnel." And many people tell us that they "don't know what they'd do without us."

Over the past 19 years, we've become many things to many people. And we need your help to continue.

You're helped by the IMF when you -

Call the hotline and speak to one of our coordinators and find them to be a wealth of information, or just a buddy on the other end of the line when you really need someone to just listen.

Attend one of our Patient & Family Seminars or Community Workshops and feel empowered and hopeful from the incredible information and one-on-one attention you receive from the myeloma experts who participate as faculty. You feel such a sense of relief knowing you're not in this alone when you meet others and share experiences with them.

Open the complimentary information package and find the amazing array of brochures and booklets that pour out, and you have the latest and most up-to-date information at your fingertips. And you are relieved that the informational is available in multiple languages, because the IMF speaks your language!

Visit our multilingual website and find everything you need to know to help you in your fight against myeloma, and you're encouraged when you read an article about someone like you who has myeloma and is beating the odds.

Attend a support group meeting, and you see the love, dedication, and hard work that Kelly, Robin, Arin, and Andy put into it to make sure you and your group have what you need.

That's the hands-on stuff we do…

The IMF also does so much more, for so many people, such as developing the new Myeloma Manager – your very own "personal assistant," so you can keep track of your numbers and much more.

The IMF has changed the paradigm of treatment, through the IMF's International Myeloma Working Group, the International Myeloma Forum, and the Nurse Leadership Board.

We make advances in research through our grant program – and our signature research program Bank On A Cure®.

And of course we bring you the publication you're reading now, Myeloma Today. The first edition was published in 1992, and since then has been a resource for people around the world, with diverse articles of importance to all of our members, patients, doctors, nurses, and health care professionals.

Maybe you've always meant to give but haven't – well, now is the time! If you always give – thank you, don't stop!

The IMF team truly feels honored and humbled that we're able to reach out and help others. We do what we do because we care about you and your family. We never want to you to have to worry that you'd have to fight this disease alone. No one ever should.

So please give what you can, and help us continue to provide you with these outstanding services you've come to rely on. The IMF is a lifeline for so many.

Give what you can – but please give.

Thank you,

Susie Novis

"Until There is a Cure… There is the IMF."

Support Group Leaders' Retreat

My husband and I attended the IMF Support Group Leaders' Retreat in April. We try to help as many myeloma patients as we can. We want to give others hope that life will become normal again, even if that means a new normal.

Our myeloma support group has received wonderful support and materials from the IMF, and the Support Group Leaders' Retreat was AWESOME. We learned so much from the presentations, and we were thrilled to meet the people representing the IMF. We were particularly struck by Dr. Durie's and Susie Novis' extreme devotion to helping others. The hotline staff is wonderful, friendly, and so knowledgeable – they helped us so much in the days after diagnosis – and Kelly Cox was instrumental as well. Andy Lebkuecher is so kind, and is a real pleasure to know. And we can't say enough about Robin Tuohy – she is the sweetest, most patient-oriented person. You are all so dedicated to the cause of educating patients and fighting myeloma. Without the IMF, I don't know where we would be. We believe that the IMF is the ONE organization truly devoted to meeting the needs of the myeloma patient FIRST.

Sue & Rob Enright

IMF Hotline

Thank you so much for helping me on the phone – the information you gave me was invaluable! I went online and downloaded the patient information. Then the pamphlets you sent arrived and they were also a big help.

I wanted to let you know that my husband is now feeling much better. We got the notice about the one day conference in Phoenix in late November. It would be great if we could go but that is not looking too hopeful. But I would love to hear the information and think it would help us as we approach the stem cell transplant in December.

Thanks again. We couldn't get through this without people like you.

Christine Lawrence

IMF Website

I appreciate the up-to-date information on the IMF website that otherwise I would not learn about. It is much more specific info than other sites.

Brian Denyer

Patient & Family Seminar

What a great time we had at the IMF Patient & Family Seminar. We have approached myeloma with as positive an attitude as possible. Last weekend filled our fuel tanks with even more resolve and hope for the future. The knowledge shared, the spirit of hope, and the love felt among everyone that attended was fantastic. The IMF staff and the seminar faculty were so giving. Your sincere approach to the work you all seem to love showed all weekend. I will pray for all of us and the continued success of IMF.

Sandy & Nick Menedis

Eighteen members of the Rhode Island Multiple Myeloma Support Group (RIMMSG) attended the IMF Patient & Family Seminar in Boston. Twelve of us were passengers in a rental van, and six drove cars or took the train. The seminar was inspirational and educational, and we thank all who made this event so amazing. And, thanks to RIMMSG fundraising efforts, we didn't have to spend any personal money on the seminar fees, hotel rooms, train tickets, van rental, gas expenses, and parking fees. Fundraisers DO benefit patients & families in so many ways!

Members of the RIMMSG

We want to tell you how much we appreciate your efforts. My wife is a 14-year survivor of multiple myeloma (Igg). We have attended four of your educational seminars over the years and the knowledge that we have gained has greatly improved her, no our quality of life, contributed to her survival, and has given us both extra peace of mind. Thank Dr. Brian Durie for all of the questions he has answered over the years, and thanks also to Kelly Cox for the Denver support group meetings. You all have had a wonderful impact on us! In short, "Thanks for Tomorrow!"

Perry & Anita Willson

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

- ***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
- ***Access to Experts***
  Get one-on-one access to the experts with time to ask questions about your treatment options.
- ***Camaraderie***
  Share your experiences and gain strength from hearing other people's stories, as you become part of the IMF family.

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**.

MYELOMA TODAY IN CONVERSATION WITH EDITH PETERSON MITCHELL, MD, FACP

How did you become interested in the field of medicine?

When I was little, my great-grandparents lived in our home. When I was three years old, my great-grandfather became ill, and I would sit and read to him for hours. Before he succumbed, I would watch as a doctor would check on him during house calls. It was then that I decided I was going to be a doctor. I have loved medicine for as long as I can remember.

Edith Peterson Mitchell, MD, FACP
Jefferson Medical College
Thomas Jefferson University
Philadelphia, PA

I grew up on a farm in an agricultural community so, while I felt a calling to enter medicine, I really had no idea what it would entail. Neither of my parents got beyond the seventh grade in school, but they firmly believed that education was a requirement for their seven children. We were expected to go to college, and they made sure that I had access to opportunities that would help me realize my career aspirations. After the 10th grade, I spent the summer doing research at St. Jude Hospital, which was 50 miles from my home. It was then I fell in love with research. After my junior year in high school, I did research at Tennessee State University. The next year, I was valedictorian of my high school graduating class and entered Tennessee State University on full scholarship.

I pursued my interest in research while still an undergraduate college student. My mentor, biochemist Andrew Vaughn, who later became dean, really helped me to understand and to appreciate the various aspects of research. In 1974, I earned my medical degree from the Medical College of Virginia. I completed my internal medicine residency at Meharry Medical College in 1977, and my medical oncology fellowship at Georgetown University in 1981.

Currently, I am Clinical Professor of Medicine and Medical Oncology, Program Leader in Gastrointestinal Oncology, and Associate Director of Diversity for the Kimmel Cancer Center at Thomas Jefferson University.

In addition to your medical career, you have been awarded over 15 military service medals and ribbons, including the Legion of Merit, Meritorious Service Medal, Air Force Achievement and Commendation Medals, National Defense Service Medal, and Humanitarian Service Medal. How did you embark on your military career?

My husband was in the US Air Force, so joining the Air Force merged my medical career and my home life. In 1973, I received an Air Force commission through the Health Professions Scholarship Program and, from 1978 to 1984, I served as an Air Force Active Duty physician. From 1984 to 1987, I was a physician in the Air Force Reserve. I went to flight medicine school, and got my medical flying wings in the Air Force.

In 1987, when my children were young, I joined the Missouri Air National Guard, where I served as the senior medical Air National Guard Advisor to the Command Surgeon (Air Mobility Command), the medical liaison between the active Air Force and the Air National Guard, and Assistant Adjutant General and Assistant Commander (Joint Forces Command). My responsibilities in this role included ensuring maximum wartime readiness and combat support capability of the worldwide patient movement and aero medical evacuation system, the Global Patient Movement Requirements Center, and AMC's 52 Air National Guard medical squadrons.

Medical service in the military is not only about providing care to sick patients but also about providing care to well patients. We provide for military maneuvers and for care of the injured. We provide care to personnel deployed to unusual situations, such as to extreme climates. I also worked on developing the first cancer research programs at military hospitals, and these programs were very successful. I served as Assistant to the Command Surgeon for U.S. Transportation command and headquarters Air Mobility Command based at the Scott Air Force Base in Illinois.

I have graduated from military schools not attended by most military doctors, including the Air War College, a part of Air University and a component of the United States Air Force's Air Education and Training Command. I was able to couple my knowledge of medicine with knowledge of military procedures and strategy. I developed expertise in disaster preparedness, bioterrorism, and Air Space Medicine.

I led the medical team during the Great Flood of 1993, when the Missouri and the Mississippi rivers overflowed and hundreds of levees failed in nine states, resulting in record flooding of the Midwest and one of the worst American natural disasters to date. We provided disaster response and urgent care to individuals, dealt with the hepatitis outbreak, and offered both medical care and education to the public. Since then, we have also provided assistance following the attacks of 9/11 and during the war in Iraq.

In the course of my military service, I became the first woman to command a medical unit in the Missouri Air National Guard and the first woman to become state air surgeon for Missouri. I became the first African-American to achieve the rank of Brigadier General in the Missouri Air National Guard, and I am the first female physician to be promoted to this rank in the entire United States Air Force. I retired from the Air National Guard as Brigadier General, after 34 years of military service. I really loved the military, and I still do.

Please tell us how your career in cancer research began.

Dr. Philip Schein, my mentor at Georgetown, was a tremendously successful clinician. He has since served as President of the American Society of Clinical Oncology (ASCO), has chaired the Food and Drug Administration (FDA) Oncology Drugs Advisory Committee, and was appointed to the National Cancer Advisory Board by President Clinton. Dr. Schein understands medicine and he understands patients, and he taught me that an oncologist should never be satisfied with an existing treatment -- we should always be searching for something better to help the people we care for. He instilled in me the true understanding of the need for cancer research and, during my fellowship at Georgetown, introduced me to the

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EDITH PETERSON MITCHELL — continued from page 5

National Cancer Institute (NCI). Shortly thereafter, I received my first NCI research grant. My quest for research continued and, after completion of my fellowship, I was nominated to a research committee at the NCI. I have worked closely with the NCI ever since.

I was recently nominated to chair the inaugural NCI committee evaluating patient complexity in clinical trials. For each clinical trial, understanding the patients who enter the trial is very important. The term "patient complexity" was recently coined to attempt to understand and define differences in the patient populations. For example, complex patients may have multiple medical conditions in addition to cancer. Patients who are members of some ethnic group may be considered complex in the context of cancer research due to social, cultural, or socio-economic factors. If we are to successfully insure that all patients have access to clinical trials, and that outcome measures can be correctly and accurately evaluated, these differences must be taken into consideration.

In addition to your clinical responsibilities and serving on the board of directors for the IMF and the Colorectal Cancer Coalition, you are also co-leader of Guardcare, a program that provides free physical examinations to inner city individuals. Please tell us about your experiences working with underserved populations.

As I conducted research in gastrointestinal and hematologic malignancies, I was amazed by how well certain patient groups fared while others did not. For example, it has been observed that socio-economic factors can play a significant role in access to medical care, contributing to a higher mortality among African-Americans. But I knew from experiences in my clinical practice that there was more at play than access to care.

We have found some biological features of the differences we've observed in patients with colon cancer and with breast cancer. In breast cancer, there are some specific receptors plus an aggressive marker that are more frequently present or over-expressed in African-American patients. In colorectal cancer, biological factors have an impact on increased incidence and increased mortality in the African-American population. We are evaluating these biological factors and exploring how they influence the incidence of cancer as well as patient survival.

I have been Director of Special Populations for the Eastern Oncology Group since 1997, serve on the board of directors for the Colorectal Cancer Coalition, and am also co-leader of Guardcare, a program that provides free physical examinations to inner city residents. My work has expanded from the specific malignancies I have conducted research on for many years to researching cancer in specific ethnic group and populations.

Is that how you came to be part of the IMF?

Yes. Multiple myeloma occurs more frequently in African-Americans than in other ethnic groups, and African-American patients tend to have less favorable prognoses. I have worked with the IMF to influence research in myeloma because it is one of the cancers with significant disparity in both incidence and mortality between different ethnic groups.

What is the major challenge facing African-American myeloma patients?

It is not possible to assign one reason for such disparity between ethnic groups. There are multiple reasons that are all aspects of patient complexity. For example, earlier diagnosis of the disease is associated with better prognosis, but African-American patients are more likely to be diagnosed with myeloma at a more advanced stage. Access to appropriate therapies, such as clinical trial participation, is very important but African-American patients are less likely to be treated at major myeloma centers. In colorectal cancers, research has found that treating physicians are less likely to be up-to-date on the latest research and treatments while being more reluctant to refer African-American patients to major centers, and this is likely to extend to other cancers, including myeloma. Insurance coverage is another issue. Even in systems that are supposed to work for everybody, such as Medicare, research has shown that white patients have a higher rate of payment for their medical care. When we look at public education in this country, we see that more African-Americans have less than a high school education. African-Americans are also more likely to seek medical care through the emergency room than through a primary care provider. Cultural issues also play a role – bone marrow registries have fewer volunteers of African-American descent, so African-American patients who do not have a suitable donor are less likely to find a match. There are numerous disparities that might seem trivial at first glance but, when compounded and added to biological differences in cancer, make a significant difference in the prognosis of an African-American myeloma patient.

What can be done to improve this situation?

The IMF has taken measures to get myeloma educational information into African-American communities. We have disseminated IMF information to providers by working with the National Medical Association (NMA), which promotes the interests of physicians and patients of African descent. The NMA was formed in 1895, when blacks could not become members of the American Medical Association (AMA), and it remains an essential part of providing care to the underserved population in the United States. I have spoken about the IMF at NMA meetings around the country. The IMF's advocacy and educational programs, such as the Patient & Family seminars, have seen a significant increase in participation by African-American patients. The IMF has also developed materials for the African-American community, including a video presentation.

Apart from cultural issues, the IMF also recognizes that there are biological differences between myeloma patients, and the Foundation is pursuing relevant scientific research through Bank On A Cure® and other initiatives. This research is likely to help us answer questions about molecular aspects of myeloma that also contribute to disparities between patients. The IMF has truly been, and continues to be, beneficial and crucial to the African-American community. **MT**

Editor's Note: Dr. Mitchell is a Fellow of the American College of Physicians and a member of the American Medical Association, the National Medical Association, Aerospace Medical Association, Association of Military Surgeons, and the Medical Society of Eastern Pennsylvania. She also belongs to the Eastern Cooperative Oncology Group (ECOG), Radiation Therapy Oncology Group, National Surgical Adjuvant Breast and Bowel Project, and the Philadelphia Society of Medicine. Dr. Mitchell has authored and co-authored more than 100 articles, book chapters, and abstracts on cancer treatment, prevention, and cancer control. As a distinguished researcher, she has received 21 Cancer Research and Principal Investigator Awards, and serves on the NCI Review Panel and the Cancer Investigations Review Committee.

THE ROLE OF ZOLINZA® IN MULTIPLE MYELOMA

Myeloma Today in conversation with Dr. David Siegel

What is vorinostat?

Most traditional chemotherapy drugs attack the DNA, causing damage to the DNA in the hope that this will kill the cancer cells. Some of the newer anti-myeloma agents attack very specific biochemical pathways, such as protein metabolism for example, causing the myeloma cells to die. Vorinostat (Zolinza®) is the first drug in a novel class of anticancer agents called histone deacetylase (HDAC) inhibitors. This class of agents does not attack the DNA directly but rather modifies how the genes are expressed.

How does vorinostat work?

Histones are primary proteins that act as a sort of "scaffolding" for chromosomes. The chromosomes (or strands of DNA) are wrapped around a protein superstructure. There are enzymes that attach molecules to the histones, and these regulate how the DNA unfolds from the histones. By regulating the histones, we can regulate the expression of certain kinds of genes. Vorinostat is actually changing the expression of genes. In some sense, this can be called gene therapy. By giving patients HDAC inhibitors, we are not changing the genes themselves, but we are attempting to modulate the level of expression of certain kinds of genes. In particular, we hope to increase the level of expression of tumor suppressor genes. This is a completely new and different area of investigation, and vorinostat is the first drug that actually addresses the cellular process. This is a very exciting compound.

David Siegel, MD, PhD
Division Chief, Myeloma
Hackensack University Medical Center
Hackensack, NJ

How was the compound developed?

The compound was made by chemists at Columbia University, but the drug was developed in the laboratory of Dr. Paul Marks, president emeritus of Memorial Sloan-Kettering Cancer Center. One of the scientists who worked with this compound in Dr. Marks' lab was Dr. Joseph Michaeli, who was my mentor when I was a fellow at Memorial Sloan-Kettering Cancer Center and he was the head of the myeloma service at the hospital. I worked with him both in the lab and clinically, and he was the person who got me interested in the field of myeloma. And now, many years after Dr. Michaeli's death, the drug that resulted from the technology he was trying to develop has finally come to life as a myeloma drug.

To what extent has vorinostat been tested as a cancer therapy in general, and for multiple myeloma in particular?

Vorinostat has been shown to have significant single-agent efficacy in cutaneous T-cell lymphoma, which is much more rare than multiple myeloma, and the FDA has approved it for the treatment of that disease. In multiple myeloma, vorinostat has already been tested in several single-agent clinical trials, and it was concluded that there was modest anti-myeloma activity. The preliminary data suggested that more clinical trials were warranted.

Has vorinostat been tested as part of combination therapy in myeloma?

Yes, it has been tested in combination with other agents that are known to have activity in myeloma, including lenalidomide (Revlimid®) and bortezomib (Velcade®). Patients who had been shown to be lenalidomide-refractory were proven to be sensitive to the combination of lenalidomide and vorinostat. And patients who had been shown to be bortezomib-refractory were proven to be sensitive to the combination of bortezomib and vorinostat. Both combinations seem to show a significant degree of synergy between vorinostat and these well-established anti-myeloma agents.

What can you tell us about current investigations into the role of vorinostat in myeloma?

Underway are large, international, multi-center trials, with large numbers of myeloma patients participating. Ongoing is a randomized phase III, double blind clinical trial of bortezomib plus/minus vorinostat, with Dr. Sundar Jagannath as the principal investigator. And I am the principal investigator for the relapsed/refractory phase II-b open label clinical trial of bortezomib plus vorinostat. If we are able to confirm the efficacy of the vorinostat combinations, we hope that the drug will be approved for use in myeloma.

Who is most likely to benefit from vorinostat as part of their anti-myeloma regimen?

As reported by Weber et al and Badros et al at the 2007 annual meeting of the American Society of Hematology (ASH), activity of the combination of vorinostat plus bortezomib was observed in relapsed/refractory patients who had had few prior therapies as well as in patients who were heavily pre-treated, and response rates of >40% were reported. In addition, a sub-set of patients who were refractory to prior bortezomib therapy showed clinical activity when bortezomib was combined with vorinostat, and a response rate of >30% was reported. As bortezomib is widely used in myeloma, this refractory population is expanding and has an unmet medical need. The two new large trials of vorinostat I just mentioned will cover both these patient populations and will hopefully provide answers.

Has the safety and tolerability profile of vorinostat been established?

Data from all cancer patients who participated in the vorinostat clinical trial program, as monotherapy or in combination with other systemic therapies, demonstrate that vorinostat has an acceptable safety and tolerability profile. Vorinostat seems to be extremely well tolerated at the doses and schedules we are using currently. In the bortezomib trial, we are using the standard dose of bortezomib (1.3 mg/m^2 administered on days 1, 4, 8, and 11) plus vorinostat at 400mg/day for 14 days in each 21-day cycle. In the lenalidomide trial, the lenalidomide dose is being escalated and has not yet been determined, but the vorinostat dose is 400mg/day one week on and one week off in each 28-day cycle. Vorinostat is administered orally.

Any closing comments for our readers?

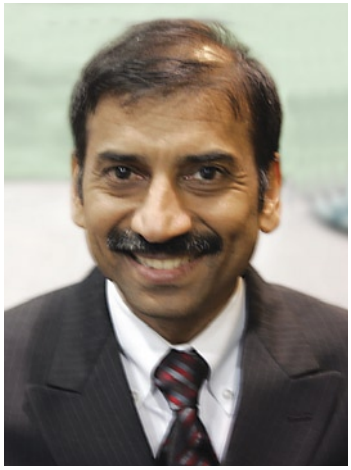
Vorinostat is a good drug, and we should be talking about it. Vorinostat is the first FDA approved HDAC in Non-Hodgkin's lymphoma (NHL), and this drug clearly has preliminary activity in myeloma. With HDAC inhibitors, we have arrived at a whole new level of compounds with a very promising future in the treatment of myeloma. HDAC inhibitors are a very interesting family of compounds because these drugs attack a whole new system than has been addressed by any anti-myeloma drugs we have used previously. This is a new and exciting approach to treating multiple myeloma. **MT**

PHASE III ZOLINZA®/VELCADE® TRIAL OPENING SOON

Myeloma Today in conversation with Dr. Sundar Jagannath

At present, what is known about the activity of Zolinza® in combination with Velcade® in myeloma?

Two myeloma clinical studies have been completed that have explored the combination of Velcade® (bortezomib) and Zolinza® (vorinostat), a histone deacetylase (HDAC) inhibitor that affects cell growth by modifying the transcription of cellular proteins. HDAC is able to unravel the DNA strand so that some of the anti-tumor genes become more active and some of the treatment-resistant cancer cells become more vulnerable to anti-cancer therapy. Vorinostat had already demonstrated anti-myeloma activity, alone and in combination with bortezomib, in preclinical models.



Sundar Jagannath, MD
Chief, Multiple Myeloma Program,
Bone Marrow and Blood
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At the 13th congress of the European Hematology Association (EHA), which was held in June of 2008, Dr. Donna Weber et al (MD Anderson Cancer Center) reported the results of her phase I dose-escalation clinical trial of vorinostat plus bortezomib in advanced myeloma. This was an open-label study, so all patients knew what they were taking. All patients accrued into the study had active relapsed/refractory disease and had previously received bortezomib, although they had not received it for at least three months preceding the study. The 21-patient trial was conducted to determine the maximum tolerated dose (MTD) and assess activity and safety of the combination regimen. The investigators concluded that MTD was bortezomib at the standard dose (1.3 mg/m^2 on days 1, 4, 8 and 11) plus vorinostat at 400mg once daily on days 1–14 of a 21-day cycle. Cycles were repeated a maximum of 8 times. All evaluable patients achieved a measurable response or stable disease (SD), and 4 had exhibited a partial response (PR, defined as ≥ 50% reduction in monoclonal protein). The duration of response ranged from 99 to 203 days. The adverse effects, including thrombocytopenia, were mild to moderate. The combination of vorinostat and bortezomib appeared to be both effective and reasonably well tolerated in the heavily pretreated myeloma patient population.

At the 2008 annual meeting of the American Society of Clinical Oncology (ASCO) earlier this year, Dr. Ashraf Badros et al (University of Maryland) presented a phase I trial of vorinostat plus bortezomib in relapsed/refractory myeloma patients. This was also an open-label study that aimed to determine MTD of vorinostat plus bortezomib in myeloma patients. It was based upon research that demonstrated that, *in vitro*, vorinostat has synergistic cytotoxicity with proteasome inhibitors in myeloma cells. The 23 participating myeloma patients had received between 3 and 13 prior regimens, including autologous transplant and novel agents. Of the participating patients, 4 had never received bortezomib and 9 were bortezomib-refractory. The study determined MTD to be bortezomib at the standard dose (1.3 mg/m^2 on days 1, 4, 8 and 11) and vorinostat, which was escalated 100-400mg on days 4–11 in 5 patient cohorts. Of the bortezomib-refractory patients, 3 achieved a PR and 4 had SD, which was quite impressive. Of the bortezomib-naïve patients, 1 achieved a very good partial remission (VGPR, or ≥ 90% reduction in monoclonal protein), 2 had PR, and 1 had SD. Of the remaining 10 patients, 1 achieved VGPR, 2 had PR, 5 had SD, 1 had progressive disease, and 1 was not evaluable. The regimen was well tolerated and has promising activity in myeloma patients who had been heavily exposed to prior therapies.

What is the next step in exploring the vorinostat and bortezomib combination in myeloma?

The clinical studies I just mentioned are both quite small. So the next step is to explore the combination of vorinostat and bortezomib in a more formal way in large international trials. There are two multi-center trials that should bring answers to at least some of our questions: Dr. David Siegel's phase II b open-label clinical trial of bortezomib plus vorinostat in bortezomib-refractory patients, and my multi-center randomized phase III double-blind clinical trial of vorinostat or placebo in combination with bortezomib.

In my study, the patients will have had at least 1 but no more than 3 prior anti-myeloma therapies. In other words, participants will have experienced 1, 2, or 3 relapses. Approximately 750 myeloma patients will be randomized. The bortezomib will be given at the standard dose of 1.3 mg/m^2 on days 1, 4, 8 and 11.

Are there other HDAC inhibitors currently in development for myeloma?

Yes, other HDAC inhibitors are currently in development for myeloma, but the advantage of vorinostat is that it is already approved by the FDA for another hematologic cancer. Drug approval is a lengthy process, and vorinostat is currently on the market, which is one huge advantage for this compound. Patients who have already been treated with bortezomib and lenalidomide (Revlimid®) and have become drug-resistant do not currently have another anti-myeloma drug awaiting them. If vorinostat is proven to make bortezomib work better, and if it is proven effective for bortezomib-refractory myeloma patients, it can become available to them rather quickly. Even before it gets to the point of approval for myeloma, vorinostat may receive an "indication" for use in this disease. So it makes a lot of sense to investigate this compound in large phase II and phase III myeloma clinical trials, so we arrive at an answer rather quickly.

Does the combination of vorinostat and lenalidomide hold equal promise?

Besides the activity that vorinostat has on its own, it is synergistic with bortezomib because of protein biosynthesis. Lenalidomide works in a different way, and we do not know if it will have synergy with vorinostat. Also, both vorinostat and lenalidomide can cause thrombocytopenia , so it is unlikely that both drugs can be used at full doses in combination. In contrast, vorinostat and bortezomib can be used in combination at full doses. Clinical trials will bring us more information.

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SERUM IMMUNOGLOBULIN FREE LIGHT CHAIN ASSAY IN MYELOMA

Myeloma Today in conversation with Dr. Angela Dispenzieri

What is the purpose of the serum immunoglobulin free light chain assay?

In multiple myeloma, the marker used to help diagnose and follow patients is known as monoclonal protein, which also goes by the names, M-protein, M-spike, and immunoglobulin. Until the 1990s, the repertoire of tests to document and measure this marker included electrophoresis (PEL), immunoelectrophoresis, and immunofixation electrophoresis (IFE). For most myeloma patients, as well as for individuals with the often benign condition known as monoclonal gammopathy of undetermined significance (MGUS), these measurements appeared to be sufficient. However, they were inadequate for patients with minimal production of the monoclonal proteins, including the majority of patients with amyloidosis and more than 3% of patients with "non-secretory" or "oligosecretory" myeloma.

Angela Dispenzieri, MD
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A normal immunoglobulin is made up of two heavy chains and two light chains. In healthy individuals and in the majority of myeloma patients, most of the circulating light chain is bound to heavy chains. When there is a disconnect in the proportion, this results in some people having excess (or "free") light chains in their blood stream. The serum immunoglobulin free light chain (FLC) assay, known as the FREELITE™ test developed by The Binding Site Ltd in the United Kingdom, measures levels of the two types of free immunoglobulin light chains: κ (kappa) and λ (lambda). The measurements are reported in three values: the "absolute κ value," the "absolute λ value," and the ratio of κ to λ values. A "kappa patient" is someone who has more κ than λ, and a "lambda patient" is someone who has more λ than κ. Several studies that have demonstrated excellent sensitivity of the serum FLC assay in detecting FLC in patients with oligosecretory myeloma and in patients with light chain multiple myeloma (LCMM).

In myeloma, what are the indications for the FLC assay?

In myeloma, there are three major indications for the FLC assay to measure circulating monoclonal immunoglobulins -- diagnosis, prognosis, and management.

Diagnosis

Having excess FLC is common to most plasma cell disorders, and the ease of performing the FLC measurement could lead to earlier diagnosis of these disorders. In the context of screening for myeloma or related disorders (except for AL amyloidosis), the serum FLC assay in combination with serum protein electrophoresis (SPEP) and immunofixation negates the need for 24-hour urine protein electrophoresis and immunofixation (which measures and detects FLC, respectively). Both patients and physicians are often reluctant to do 24-hour urine collections because of the inconvenience posed. However, if a diagnosis of a plasma cell disorder is established, 24-hour urine studies are required for all patients.

Prognosis

In addition to the increased diagnostic sensitivity for the FLC diseases and the ability to eliminate urine from the diagnostic process, it was discovered that baseline values of serum FLC can be used for prognostication. It is recommended for the serum FLC assay to be measured at diagnosis for all patients with plasma cell disorders. Several studies have shown that baseline FLC measurement is prognostic for survival in patients with newly diagnosed active myeloma. It is of major prognostic value in virtually every plasma cell disorder, including active and smoldering (asymptomatic) myeloma, MGUS, AL amyloidosis, and solitary plasmacytoma.

Approximately 97% of patients with active myeloma will have an abnormal FLC ratio. In smoldering myeloma, it has been found that an abnormal FLC measurement predicts for higher rate of progression to active disease that requires treatment. In our study, patients with smoldering myeloma who do not have an abnormal FLC ratio had 5-year progression rates of 25%. Patients with smoldering myeloma who have an abnormal FLC ratio, and the most risk factors, were found to have a 5-year progression rate as high as 76%. The frequency of visits by smoldering myeloma patients I follow in my practice is based on the number of risk factors an individual patient has. The higher the number of risk factors, the more closely the patient is followed.

There is a lesser likelihood that a patient with MGUS will be found to have an abnormal FLC ratio than a patient with smoldering myeloma, and MGUS patients are far less likely to progress to active myeloma. Based on our investigation, MGUS patients who do not have an abnormal FLC ratio and have a small IgG monoclonal protein have a low risk of progression to myeloma -- 5% in 20 years. Breaking with the traditional approach, patients in this group who are seen at Mayo Clinic are told that they do not necessarily require follow-up on their condition because their risk of progression is so low. This is not the case for the approximately one third of MGUS patients who have abnormal FLC ratios and have a higher rate of progression to myeloma. Depending on the number of risk factors present, a patient with MGUS may have as high a rate of progression to myeloma as 58% in 20 years, and may require follow-up as frequently as every six months.

In a study of patients with solitary plasmacytoma, an abnormal serum FLC ratio was present in 47% of patients and was associated with a higher risk of progression to myeloma. The 5-year risk of progression was 44% in patients with an abnormal FLC ratio at diagnosis, compared with 26% in those with a normal FLC ratio.

There are many more questions in this arena that are yet to be answered by research. For example, while an abnormal FLC ratio is certainly not a perfect marker, there seems to be an association between higher abnormal measurements and patients with more of the cytogenetic abnormalities, although this is an observation that is yet to be confirmed.

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FREE LIGHT CHAIN ASSAY — continued from page 9

Management

The FLC assay allows for essential quantitative monitoring of the majority of patients with oligosecretory (low-secreting) myeloma. In oligosecretory myeloma, although not formally validated, serial FLC measurements reduce the need for patients to be subjected to frequent bone marrow biopsies. It is important to emphasize that routine serial use of the FLC assay is only recommended for oligosecretory diseases.

The FLC assay cannot replace the 24-hour urine protein electrophoresis for monitoring patients with measurable urinary M-proteins. We have yet to determine what role the FLÇ assay should play in following patients with myeloma that is measurable using serum and urine electrophoresis, but it seems that serial FLC measurements are not indicated for patients who have M-proteins measurable by electrophoresis.

Monitoring of serum FLC may eventually prove to be appropriate in myeloma patients with intact immunoglobulin, since approximately 97% also produce excess serum FLC, but there are few data to support this recommendation presently. For myeloma patients with intact immunoglobulin, 24-hour collection is typically done infrequently.

It has been noted that measurements of serum FLC may be more sensitive for early response (or lack thereof) and early relapse of disease than are standard measurements of the involved heavy chain. However, no one has shown that early detection of lack of response predicts for ultimate treatment failure, or that the 3-4 week time delay that may occur when using measurements of heavy chains actually affects the ultimate outcome for the myeloma patient. Serial measurement of serum FLC may detect relapse sooner than do the protein electrophoresis studies, but there is an absence of data to support that knowledge of disease reactivation or drug failure a few months early has any impact on overall patient outcome.

It must be noted that myeloma patients with advanced disease can develop light chain escape with or without extramedullary (outside the bone marrow) disease and, if periodic urinary evaluations or serum FLC measurements are not done, this phenomenon can be missed.

Some patients become concerned by the inconsistencies of their measurements. Should they worry?

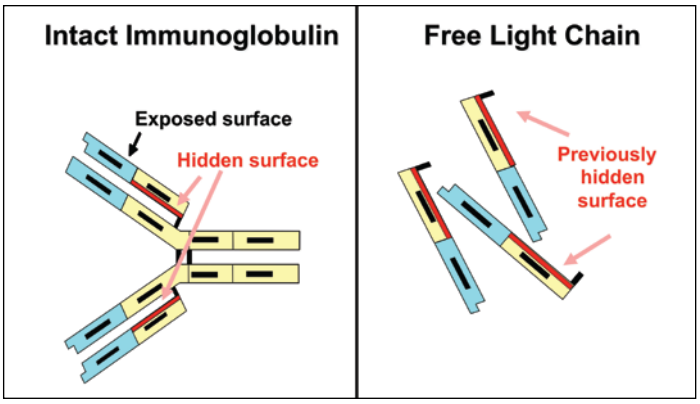
Myeloma patients who closely track their test results might see their FLC measurements and ratios jump around a bit. This does happen, and this is not necessarily cause for worry. For the sake of consistency, I would advise that patients have their serial FLC tests done at the same lab, as this should reduce the measurement fluctuations from test to test. However, if a particular test brings dramatically outlandish measurements, I would suggest having the test repeated.

Are there questions pending regarding the use of the FLC assay?

The most important area for future investigation includes defining the clinical relevance of early FLC "response" or "relapse" in patients with measurable intact serum immunoglobulins or measurable urinary M-proteins. At present, apart from initial diagnosis and documentation of stringent complete response, its use is not advocated in these patients.

Any closing comments?

In conclusion, baseline measurement of FLC is helpful for prognostication in virtually all patients with plasma cell disorders. Serial FLC ascertainment



should be routinely performed in myeloma patients with oligosecretory disease. Finally, it should also be done in all patients who have achieved a CR to determine whether they have attained a stringent CR as defined by the International Myeloma Working Group (IMWG).

Editor's Note: Dr. Dispenzieri has authored over two hundred manuscripts and book chapters in the field of plasma cell disorders, including multiple myeloma, immunoglobulin light chain amyloidosis, and POEMS syndrome. She is the principal investigator of a National Cancer Institute supported clinical trial using a genetically modified measles virus (MV-NIS) to treat patients with relapsed or refractory multiple myeloma. Dr. Dispenzieri serves as the Clinical Trials Research Chair for the Mayo Clinic Division of Hematology. She serves on the Editorial Boards of *Amyloid, The International Journal of Experimental and Clinical Investigation*, and *The American Journal of Hematology.*

PHASE III ZOLINZA®/VELCADE® TRIAL — continued from page 8

What would you want myeloma patients to know?

I want patients to know that new drugs, and new drug combinations, are being developed to help fight myeloma. Even patients who are failing treatment from among the currently available options should have hope of new approaches to their disease. Our phase III study is just one of the valid investigations either currently ongoing or soon to initiate clinical trials. Our accrual starts early next year. The anticipated duration of the phase III study is approximately 33 months, as there is a lot of work to be done – we need to determine if the vorinostat and bortezomib combination results in increased response, if the response is durable, and if the time to progression (TTP) is longer. Even while our trial is still ongoing, if the combination looks as promising as we think it is, patients will have access to vorinostat because it is already commercially available. We must have patience but the possibilities are quite exciting. **MT**

Editor's Note: Dr. Sundar Jagannath is the chief of multiple myeloma service at St. Vincent's Comprehensive Cancer Center in New York City. In addition, he holds the position of professor of medicine at New York Medical College since 1999. Dr. Jagannath has published extensively on topics concerning multiple myeloma and bone marrow transplantation. He is a reviewer for several journals, including *American Journal of Hematology, Blood, Bone Marrow Transplantation,* and *Journal of Clinical Oncology*. He is an active member of the American College of Physicians, the American Society of Clinical Oncology, the American Society of Hematology, and the American Society for Bone and Marrow Transplantation.

Dr. Luc Montagnier Awarded the 2008 Nobel Prize

The IMF congratulated renowned French researcher Dr. Luc Montagnier as co-recipient of the 2008 Nobel Prize in medicine. Dr. Montagnier, who is best known for his role in discovering the virus that causes AIDS, has also contributed to new lines of research related to multiple myeloma – he attended the very first IMF scientific advisors retreat, and participated in an IMF round table at the VII International Myeloma Workshop in Stockholm.

"Dr. Montagnier has helped advance our research into the role of viruses in multiple myeloma," said Brian G.M. Durie, M.D., chairman and co-founder of the IMF. "We thank him for his time and insights, and for his advanced equipment and expertise that have led to new discoveries that help us understand the root causes and improve early detection of myeloma."

Specifically, Dr. Montagnier has helped Dr. Durie and his research partner, Howard Urnovitz PhD, CEO of Chronix Biomedical, advance efforts to develop molecular diagnosis of myeloma. They were looking specifically at the intriguing role played by segments of RNA, a chemical relative of the genetic molecule DNA, that circulate in the blood of myeloma patients. Dr. Montagnier named their discovery "voyager RNA."

"We continue to thank Dr. Montagnier for his thoughts and vision on this important project that could lead to 21st century personalized medicine for myeloma patients," said Dr. Urnovitz. "We also whole-heartedly support this worldwide endorsement of his contributions to science and medicine." Dr. Montagnier currently serves as director for the World Foundation for AIDS Research and Prevention in Paris.

Ellen Stovall Steps Down as President and CEO of NCCS

Long-time cancer survivor and advocate Ellen Stovall stepped down as President and CEO of the National Coalition for Cancer Survivorship (NCCS), a position she has held for the last 16 years. Fortunately for the cancer community, Ellen will continue at NCCS in her new role as Senior Health Policy Advisor. Her work has benefited many in the cancer community, and has included the establishment of both the Office of Cancer Survivorship at the National Cancer Institute (NCI) and THE MARCH…Coming Together to Conquer Cancer™.

REVLIMID® Recognized by Prix Galien Award

Lenalidomide (REVLIMID®), oral cancer drug for the treatment of multiple myeloma, has been granted the Prix Galien USA 2008 Award for Special Therapeutic Development. The Prix Galien Award, considered to be the highest accolade for pharmaceutical research and development, was presented during a ceremony in New York City on September 24.

The IMF congratulated Celgene and all of the researchers, patients, and physicians who helped in the development of REVLIMID. Susie Novis, president and co-founder of the IMF said, "REVLIMID, along with the other novel therapies, signals an era where incurable cancers will be transformed into chronic, manageable diseases. Myeloma patients are well aware of the contributions this drug has made to improving outcomes, and we are pleased that the esteemed Prix Galien awards committee has recognized that same value."

The Prix Galien Award recognizes the technical, scientific, and clinical research skills necessary to develop innovative medicines. Prix Galien is considered by many to be the pharmaceutical industry's equivalent of the Nobel Prize. The recognition of REVLIMID was one of six pharmaceutical awards presented by Prix Galien this year and is the only one in the field of multiple myeloma.

David Girard, IMF Executive Director, added, "As the award criteria state, REVLIMID is a prime example of 'pharmaceutical science that improves the human condition,' and offers life-changing benefits to myeloma patients and the medical community."

Prix Galien was first established in 1970 by French pharmacist Roland Mehl and was inaugurated in the United States in September 2007. The Prix Galien USA awards committee comprises 11 individuals including Nobel laureates, founders of major biotech companies, and editors of world-renowned biology journals.

Susie Novis Receives Wellsphere Health Impact Award

The IMF is proud to announce that Susie Novis, president and co-founder of the Foundation, has received the Wellsphere Health Impact Award for providing outstanding support and education to myeloma patients and caregivers, and driving innovation in the field of myeloma treatment.

The Wellsphere health network is an extensive internet community that includes expert medical writers and patients who write on a variety of health and medical topics. Wellsphere's mission is to help millions of people live healthier, happier lives by connecting them with the knowledge, people, and tools they need to manage and improve their health. The Wellsphere Health Impact Award honors individuals and organizations making the greatest impact in the lives of patients.

"We are very proud of Susie's receipt of the Health Impact Award," said David Girard, executive director of the IMF. "Susie's commitment to myeloma patients and her dedication to supporting the entire myeloma community inspire the work of the IMF, and we are pleased that her efforts and the efforts of the IMF have been recognized by the Wellsphere health community."

Criteria for determining recipients of the Health Impact Award include: providing support for patients; conducting or supporting basic and applied research; improving accessibility and affordability of care; raising awareness of significant health issues; promoting prevention and proactive care; providing and supporting education; and driving and inspiring innovation.

"I am pleased to accept the Health Impact Award on behalf of all of the dedicated IMF staff who tirelessly serve myeloma patients and their families," said Ms. Novis. "The IMF works hard to achieve its mission of promoting patient and family support, education and advocacy, as well as supporting myeloma research, and I am pleased that this award recognizes the IMF's important role as a resource for the myeloma community." **MT**

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NLB ACTIVITIES UPDATE

Myeloma Today in conversation with Elizabeth Bilotti and Beth Faiman

Please bring us up to date on the prior activities of the IMF Nurse Leadership Board (NLB).

Beth Faiman,
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Elizabeth Bilotti, RN, MSN, APN
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Beth Faiman: The vision of the Nurse Leadership Board (NLB) is to partner with nurses providing care to multiple myeloma patients, to gain insights into their needs, and to help them address a variety of disease management issues. The manuscript produced by NLB members – Consensus on Care: New Insights on Novel Therapies in Multiple Myeloma – was published in the June 2008 issue of Clinical Journal of Oncology Nursing and has been very well received around the country.

At the March 2008 NLB meeting, we discussed additional tools and materials to be developed both for nurse education and for patient education. We started developing a speakers' bureau and created two separate slide decks for educational presentations about myeloma side effects. One set of slides is designed for oncology nurses and the other for myeloma patients. The two sets of slides will be used by NLB members to educate patients and nursing professionals around the country.

What was the focus of the November 2008 NLB gathering?

Elizabeth Bilotti: Beth and I served as faculty for the meeting, which aimed to take the collaborative work of NLB another step forward. First, the NLB welcomed two new participants, Ann McNeil (Hackensack University Medical Center, Hackensack, NJ) and Charise Gleason (Emory University Hospital, Atlanta, GA). Then we addressed our current project, the NLB Survivorship Care Plan, which focuses on the many body systems that may be affected by dealing with myeloma over the stretch of many years. Now that myeloma patients are living longer, the patients and the medical professionals tending to their care must address long-term consequences of the disease.

In preparing the NLB Survivorship Care Plan for publication, subgroups of members are drafting our recommendations on various issues. At the meeting, subgroup leaders presented the work of their groups to date. Tiffany Richards (MD Anderson Cancer Center, Houston, TX) is the leader of the Sexuality & Sexual Dysfunction work group. The Bone Health & Bone Disease work group is being led by Teresa Miceli (Mayo Clinic, Rochester, MN). The Functional Mobility & Safety group is led by Sandra Rome (Cedars-Sinai Medical Center, Los Angeles, CA). Beth is the leader of the Renal Complications group and I am leading the Health Maintenance group. These are the major issues that have an impact on patients coping with myeloma long-term. In addition, chronic pain and pain management is a part of each of the above subcategories. After presentations to the general assembly, each group held its own breakout session to continue developing its part of the NLB Survivorship Care Plan.

What is next on the NLB agenda?

Elizabeth Bilotti: Once the final draft of the Survivorship Care Plan is completed, it will be submitted for publication. We have already submitted an abstract of the plan to the 12th International Myeloma Workshop that will take place in India in February, and will likely present the plan at the 2009 annual congress of the Oncology Nursing Society (ONS) this coming April.

Beth Faiman: Once the plan is published, the NLB will focus on disseminating the information and helping patients and clinicians put it into practice. Then we will move on to other areas of interest to the myeloma community, an important one of which is insurance coverage. We are also planning a qualitative study that will poll myeloma patients about health maintenance issues, then follow up with the participants to assess the impact our recommendations have had. And we are exploring a user-friendly, interactive program for both patients and clinicians that would help track the various health issues faced by myeloma survivors. **MT**

STEROID-ASSOCIATED SIDE EFFECTS IN PATIENTS WITH MYELOMA

Myeloma Today in conversation with Patricia A. Mangan, MSN, AOCN, CRNP

What exactly are steroids and what is their role in multiple myeloma therapy?

There are several different kinds of steroids, but the types that are used in therapy for multiple myeloma are corticosteroids (also known as glucocorticosteroids). These powerful chemicals are very different from the anabolic steroids that are associated with increasing muscle strength. Corticosteroids are effective in reducing swelling and inflammation in many kinds of tissue. They are the foundation for therapeutic regimens for patients with myeloma.

Patricia A. Mangan, MSN, AOCN, CRNP
Coordinator/Bone Marrow
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Among the many types of corticosteroids, the ones most commonly used to treat myeloma include dexamethasone, prednisone, and prednisolone. Prednisone has been used to improve the response rate of melphalan therapy for myeloma since the late 1960s. Dexamethasone has been used in myeloma since the 1980s, both in combination with other therapeutic approaches and as a single agent. Each works through a different mechanism. Dexamethasone and prednisone kill myeloma cells by inhibiting the activity of cytokines, which are proteins in the body that encourage the growth of myeloma cells, and by reducing the action of nuclear factor-kappa B (NF-κB), a molecule responsible for increasing inflammation associated with myeloma.

Both dexamethasone and prednisone are prescribed for patients with myeloma as single agents and in combination with other anti-myeloma agents, including novel anti-myeloma drugs thalidomide (Thalomid®), lenalidomide (Revlimid®), and bortezomib (Velcade®).

What side effects may be experienced by myeloma patients receiving corticosteroid therapy?

Steroids are powerful medications and may be accompanied by significant side effects. The severity and nature of these side effects vary. They are related to the dose and duration of therapy. These side effects may have an impact on patients' physical, social, and psychological functioning. Side effects fall into several categories, which include:

- Constitutional (flushing, sweating, insomnia)
- Psychiatric (personality changes, mood alterations, hyperactivity)
- Immune (elevated white cell count, infection)
- Musculoskeletal (osteopenia/osteoporosis, muscle cramping)
- Ophthalmic (blurred vision, cataracts)
- Gastrointestinal (heartburn, flatulence, taste alteration, hiccoughs)
- Endocrine (high blood sugar, adrenal insufficiency)
- Cardiovascular (fluid retention)
- Dermatologic (rash, acne, skin tears)
- Sexual dysfunction

Can these side effects be managed?

The most important element in managing and reducing side effects associated with corticosteroids is clear communication between patients and their healthcare providers. Toxicities associated with corticosteroid therapy may be managed by altering the type of steroid and the dose and schedule used in order to achieve a balance between treatment effectiveness and quality of life. The success of corticosteroid therapy in treating myeloma relies on educating patients and encouraging communication with their medical team. This requires that patients be educated about possible side effects and encouraged to report any adverse effects. Patients who are aware of side effects and report them promptly are more likely to adhere to their therapeutic regimen and to have a better treatment outcome.

How does one assess the severity of side effects?

The National Cancer Institute (NCI) has developed a scale for assessing side effects – or adverse events. It is known as the CTCAE (Common Terminology Criteria for Adverse Events). For each side effect a patient may experience, a grade is assigned from 1 to 5. A grade of 1 means the experience of a side effect is mild. Grade 2 means it is moderate in its impact; Grade 3 is severe; Grade 4 is life-threatening or disabling; and Grade 5 refers to a death related to the adverse effect. For the CTCAE to be effective in monitoring corticosteroid therapies and useful in determining whether dosing changes must be made, doctors and patients must communicate openly and regularly about adverse events.

The information gathered through use of the CTCAE plays an important role in evaluating new cancer therapies. It is also valuable as a consistent, reliable method for comparing the severity of side effects across different healthcare providers – an important factor when patients see different specialists or when treatments are compared across clinical trials.

Once identified and assessed, how can side effects be managed?

A great deal of research and experimentation has gone into finding effective approaches to reduce the severity of adverse events associated with corticosteroid therapy. They fall into three categories: pharmacologic (medication), non-pharmacologic (non-medication remedies), and patient education. Most side effects may be treated using one or more of these approaches.

When flushing or sweating occurs, it is important first to rule out such conditions as thyroid dysfunction or perimenopause. If neither is the cause, then non-pharmacologic interventions such as using cold cloths or ice packs, along with drinking fluids to maintain hydration, are effective.

If patients experience edema (swelling), this may be treated non-pharmacologically by reducing salt intake, elevating limbs, using elastic compression stockings, and increasing physical activity. The most common pharmacologic approach is the use of diuretics.

Bone loss is a side effect of corticosteroids that is of particular concern if there are other risk factors for osteoporosis (older age, post-menopause, history of smoking, or presence of lytic lesions). If these factors are present, a baseline bone density scan should be obtained. Myeloma patients who have bone lesions should consider treatment with bisphosphonates. Use of calcium is controversial for patients on steroid therapy because it may interfere with drug absorption.

If personality changes occur, in addition to support groups and psychological counseling, there are pharmacologic interventions such as dose reduction (or discontinuation) or alteration of schedule of steroids along with the use of psychoactive medications.

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IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

The IMF Hotline 800-452-CURE (2873) is staffed by Debbie Birns, Paul Hewitt, Nancy Baxter, Missy Klepetar.
The phone lines are open Monday through Friday, 9am to 4pm (Pacific Time).
To submit your question online, please email TheIMF@myeloma.org.

My father was just diagnosed with what the doctor says is early stage asymptomatic multiple myeloma. The doctor doesn't want to start treatment yet and just wants to follow him. I thought that once you were diagnosed with cancer, the best thing was to treat it as quickly as possible. Why would they just follow my father's myeloma and not get started with treatment since they found it early?

Debbie Birns, Paul Hewitt, Nancy Baxter, and Missy Klepetar

You raise a common and important question, especially as myeloma patients are beginning to be diagnosed earlier in their disease. It is also a complicated question and one that your father must discuss openly and carefully with his doctor.

Unlike most so-called solid tumors (e.g. breast cancer, lung cancer, colon cancer), blood-related cancers such as multiple myeloma do not always require immediate treatment. There are two main categories of multiple myeloma: **asymptomatic myeloma** (also called smoldering or indolent myeloma) and **symptomatic myeloma**. Any patient diagnosed with myeloma should be followed carefully by a doctor who is a hematologist/oncologist with significant myeloma experience.

In addition, there is also a condition called **MGUS** (monoclonal gammopathy of undetermined significance), which is actually a benign condition where the patient has a low level of monoclonal protein (less than 10% plasma cells in the bone marrow) and no myeloma organ damage. We won't discuss this condition here, but MGUS does not require treatment. For more information about MGUS, please see the *IMF Patient Handbook* or the *IMF Concise Review*.

Asymptomatic myeloma has a higher level of monoclonal protein and bone marrow plasma cells than MGUS, but is still not associated with symptoms or organ damage. The definition of organ damage uses a simple acronym to help remember the specific organ damage most commonly considered: the "CRAB Criteria." This is what the acronym represents:

- **C – c**alcium elevation (serum calcium of greater than 10 mg/L)
- **R – r**enal (or kidney) dysfunction (serum creatinine of greater than 2 mg/dL)
- **A – a**nemia (hemoglobin of less than 10 g/dL)
- **B – b**one disease (lytic lesions or osteoporosis)

The monoclonal protein must be monitored closely along with other tests that might show CRAB symptoms. If a patient does not have one of these abnormal findings, the general practice is not to treat the myeloma. However, as with all things myeloma, this is not a hard and fast rule. For example, if a patient no CRAB symptoms but has repeated infections, a doctor may decide to institute anti-myeloma treatment. And, if the patient experiences any new symptoms (such as bone pain), these must be reported to the doctor immediately.

Another important and complicated question is what to do when the patient's monoclonal protein (aka M-spike, paraprotein, M protein) is rising. Again, this must be considered on a case by case basis. If the rise is not great, then the doctor may continue to watch and very carefully monitor the patient. However, if the rise in the monoclonal protein is great (e.g. doubling each time), the doctor may decide to treat before the patient develops symptoms. This is just one example of why it is very important to have a doctor who is quite familiar with myeloma and can make an informed decision.

Thus, in your father's case, the important information to know is whether or not your father has any of the CRAB symptoms or a lot of repeated infections. And, he must make sure than his monoclonal protein is followed carefully. If your father has any of the CRAB criteria, then obviously the doctor should probably institute anti-myeloma therapy. If he does not, then observation is most likely appropriate. As always, your father can certainly consider a second opinion with a myeloma specialist.

With the increased attention on the very issue you have addresses, and with the advent of the Freelite assay, there have been articles published that are helping doctors evaluate which patients are more or less likely to progress from asymptomatic myeloma to symptomatic myeloma. For more information, please see Dr. Angela Dispensieri's interview on page 9 of this issue of *Myeloma Today*. **MT**

STEROID-ASSOCIATED SIDE EFFECTS — continued from page 13

To manage insomnia, a patient may benefit from taking steroids in the morning so they wear off by evening, or taking steroids just before bedtime so the patient is asleep during the highest blood concentration of the drug. Pharmacologic interventions include the used of hypnotics or sedatives. Non-pharmacologic interventions may include taking a warm bath before bed and not watching television or reading in bed.

If the white blood cell count becomes elevated (leukocytosis), it is important to watch for any signs of infection. If indicated, pharmacologic interventions may include prophylaxis and treatment with antibacterial, antiviral, or antifungal agents.

An often overlooked side effect of corticosteroid therapy is fatigue and myalgia (muscle pain) in patients who discontinue a regimen of high-dose steroids. Interventions may include having patients take low-dose steroids for a few days following high-dose steroid administration, then tapering their dosage over time. Muscle weakness, especially the proximal muscles (which are the muscles needed to raise yourself out of a chair or climb stairs), can occur and also requires dose adjustment or discontinuation.

What is the safest and most effective way to taper dexamethasone?

Tapering, or slowly reducing the dosage of a medication, is particularly

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SPOTLIGHT ON ADVOCACY

Congress Focuses on Cancer Related Legislation

By Christine Murphy, MA

With less than 30 legislative days left before the Presidential election, Congress concentrated their work on legislation that must be completed before the end of the year. This legislation included the fiscal year (FY) 2009 appropriations bills as well as legislation that halted cuts to Medicare. Below is a summary of cancer-related legislation Congress completed before the August recess.

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

NIH Receives Additional $150 Million in FY 2008

Congress approved and the President signed into law on June 30, 2008, the FY 2008 war funding Supplemental Appropriations bill. In addition to providing funding for the war in Iraq, the measure also included supplemental funding for a number of domestic programs. The National Institutes of Health (NIH) received an increase of $150 million above the FY 2008 level. The increase in funding for NIH will be distributed to the individual Institutes in a manner consistent with FY 2008 funding allocations, which means that the National Cancer Institute (NCI) will receive approximately $25 million.

Outlook for Cancer Research Funding Remains Unclear

On June 26, 2008, the Senate Appropriations Committee approved the FY 2009 Labor, Health and Human Services, and Education Appropriations (LHHS) bill. The bill provides $30.2 billion for the NIH, an increase of $1.025 billion over FY 2008 levels. It also includes $4.959 billion, an increase of $154 million over FY 2008, for the National Cancer Institute (NCI), and level funding for the Geraldine Ferraro Blood Cancer Program at the Centers for Disease Control and Prevention (CDC), at $4.331 million.

The House Labor-HHS-Education Appropriations Committee approved its FY 2009 bill on June 19, 2008. The bill will boost NIH funding by $1.2 billion over the FY 2008 level, the largest increase for NIH in six years. This increase in NIH funding will support 1,000 new research grants. Final funding levels for NCI and the cancer programs at CDC will not be released until the House Appropriations Committee marks up the LHHS Appropriations bill, which has been postponed due to political posturing.

Due to the election year and the short number of legislative days left, it is likely that all of the unfinished Appropriation bills will be considered as a continuing resolution. Even if the FY 2009 Appropriations bills are packaged as a continuing resolution, the timing of consideration is still unclear. A continuing resolution could be considered in September and extend until early 2009. This would leave the responsibility for finishing spending bills to a new Congress and new Administration. Congress could also draft a continuing resolution for a shorter period and return for a lame duck session to finalize unfinished Appropriations bills.

Congress Overrides Veto of Medicare Bill

On July 15, 2008, President Bush vetoed HR 6331, the Medicare Improvements for Patients and Providers Act of 2008. The House of Representatives and Senate moved immediately to override the veto. The House overrode the veto by a vote of 383 to 41 and the Senate overrode the veto by a vote of 70 to 26. This legislation eliminated the 10.6 percent cut in the Medicare physician payment that went into effect on July 1, 2008 and boosted physician payments by 1.1 percent beginning on January 1, 2009.

CMS Announces Three Compendia That Will be Utilized in Medicare Part B

CMS has recently announced the three compendia that may be used to determine off-label uses of cancer drugs that may be reimbursed through Medicare Part B. The National Comprehensive Cancer Network (NCCN) Drugs and Biologics Compendium, Thompson Micromedex DrugDex and Elsevier's Gold Standard Clinical Pharmacology will be the reference compendia for determining off-label uses of cancer drugs that may be reimbursed by Medicare Part B. When CMS announced the addition of Clinical Pharmacology to the list on July 2, 2008, it also indicated that it was considering changes that would clarify off-label coverage under Medicare Part D and Medicaid.

Congressional attention to cancer issues (other than funding for important cancer programs) will soon wane as the election draws closer. IMF will continue to monitor these issues and push for Congress to take action on myeloma-specific issues before adjournment of the 110th Congress. For more information on IMF's advocacy activities, please visit www.myeloma.org. **MT**

STEROID-ASSOCIATED SIDE EFFECTS — continued from page 14

important in corticosteroid treatment because sudden discontinuation of drugs like dexamethasone may cause severe side effects. It is very important to reduce dosing of dexamethasone only under supervision of the treating physician.

The IMF has produced a consensus statement by its Nurse Leadership Board regarding dexamethasone tapering. It lays out a clear methodology for reducing dosage based on three factors: current dosage, schedule of treatment, and severity of side effects. It includes contingencies, such as what to do if the side effects persist. As a standard of care, it is an effective strategy for reducing the adverse events associated with tapering dexamethasone.

Reducing the dose of dexamethasone may also reduce the risk of thromboembolic events (blood clots), particularly if administered in combination with other anti-myeloma agents such as lenalidomide and thalidomide.

Be sure to consult your treating physician for guidance and supervision. It is very important that patients not change or taper their dosage on their own.

An important addendum is that if steroids are taken for one day only, as with the one day per week low dose dexamethasone schedule, usually no taper is required and it is best to avoid a taper if possible. **MT**

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PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma.

Connecticut Support Group Stands Up To Cancer

On September 5, as part of the nationwide Stand Up To Cancer effort, members of the Connecticut Multiple Myeloma Fighters Information and Support Group hosted a community party. Support group founders Robin and Michael Tuohy organized the event, which was held at the Harold Leever Regional Cancer Center in Waterbury. More than 50 guests gathered by 8pm to watch the commercial-free prime time hour to raise awareness about cancer and research.

To promote the gathering, the support group put out flyers and sent out a mailing, and a local newspaper ran a story about the planned event. "The evening was planned around a good cause but it was also a way for us to get together and have some fun," said Michael. "We had a wonderful dinner and lively conversation, watched the television broadcast, and then talked about myeloma and how empowering it can be to be part of the search for a cure."

"This was an opportunity for our group members to do our share to promote cancer awareness and education, and to raise funds for myeloma research," said Robin. "Many of us in attendance had benefited greatly from the efforts of the IMF, so we were thrilled to be able to raise almost $1000 for the Foundation's research program through donations, auction items, and raffle prize giveaways. Unfortunately, funding for myeloma research is just not happening in a significant enough way at the government level so I feel that, in this economy, if I am going to donate my hard-earned dollars to cancer research, I want that money to go to myeloma. It may be selfish on my part, but I want my money to go towards research that is most likely to help my family and the other myeloma patients and caregivers we care about."

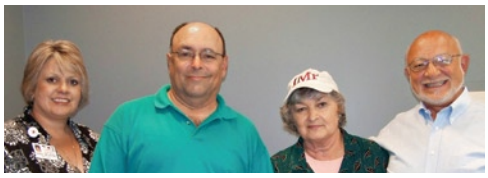
The North Florida Multiple Myeloma Support Group

n August, the North Florida Multiple Myeloma Support Group held its first annual summer picnic at the Sawgrass Beach Club Pavilion. Twenty-eight myeloma patients and caregivers attended the event. Andy Lebkuecher, the IMF Southeast Regional Director for Support Groups, made the trip from Georgia to join the local group members in their celebration. Also in attendance were representatives from Celgene Corporation, whose grant sponsored the picnic, and a nurse practitioner from Mayo Clinic in Jacksonville. Participants enjoyed pleasant views of the Atlantic Ocean, a colorful summer sunset, and a delightful buffet dinner. A good time was had by all.

The North Florida Multiple Myeloma Support Group meets from 6-8:30 PM on the second Wednesday of each month at the Courtyard Marriott on the Mayo Clinic campus in Jacksonville, FL. For more information about the group and its meetings, please contact Hunter and Dianna Chiles at 904-491-0007 or luvsuns@comcast.net.

New Support Group is formed in Louisiana

The IMF is pleased to welcome a new support group to the St. Tammany Parish Hospital (STPH) in Covington, LA. The hospital has partnered with the IMF and the Leukemia and Lymphoma Society (LLS) to offer a support group for members of the Northshore patient and caregiver community who are coping with multiple myeloma, myelodysplastic syndrome, leukemia, and lymphoma. The group meets the second Saturday of each month in the hospital's Abita Room. For more information, please call 985-898-4581. **MT**



(left to right) Debra Miller (STPH Cancer Resource Nurse), Glynn Brown and Barbara Nero (group co-facilitators and LLS representatives), and IMF's Andy Lebkuecher

STEROID-ASSOCIATED SIDE EFFECTS — continued from page 15

Do you have any closing comments for our readers?

Steroids are very active in the treatment of myeloma when give alone or in combination with other agents. A very important study recently conducted by the Eastern Cooperative Oncology Group (ECOG) looked at the effectiveness of high-dose dexamethasone vs low-dose dexamethasone when given in combination with lenalidomide in newly diagnosed patients. This study showed that the use of lower-dose dexamethasone provided better results over time than did the use of higher-dose dexamethasone. This has had significant impact on practice and patient care. We hope this will decrease or eliminate some of the potential side effects associated with steroids in patients taking lenalidomide.

Steroid therapy can cause side events that may affect many of our body systems. But when managed carefully, patients may reduce the severity of side effects and benefit from steroid therapy. This requires patients and their caregivers to be educated about what to expect during treatment. It is equally critical that healthcare providers be fully informed about anything that might affect corticosteroid treatment, including whether patients are taking any over-the-counter herbs, vitamins, or medicines, as these may interact with steroids and reduce treatment efficacy or increase the risk of side effects through drug interactions. The best way to promote adherence to therapy, improve quality of life, and lead to positive outcomes is through education and communication. **MT**

UPDATES FROM AROUND THE GLOBE

Dr. Robert A. Kyle Meets with European Patients and Doctors

This summer IMF Scientific Board Chairman Dr. Robert A. Kyle (Mayo Clinic, Rochester, MN) represented the IMF at a number of patient and doctor events in France, Germany, and the Czech Republic.

On September 7, 2009, Dr. Kyle spoke to more than 110 hematologists at the quadrennial meeting of the Czech and Slovak hematology societies. On the day prior to that, Dr. Roman Hajek hosted Dr. Kyle and IMF Europe Director Greg Brozeit at the annual meeting of the Czech Myeloma Group in Podebrady, Czech Republic. Dr. Kyle gave the keynote address before 100 patients and Brozeit gave a modified version of Michael Katz's "How to be a Better Patient" presentation.

Prior to the Czech meetings, IMF Scientific Advisor Orhan Sezer (Berlin Charité) hosted Dr. Kyle and 90 patients and family members. It was the third meeting in three years that Drs. Sezer and Kyle have done together in Berlin, Germany. Dr. Kyle also spoke to a number of other patient and doctor groups throughout Germany, focusing primarily on the latest research findings of novel therapies in myeloma.

Among the highlights was a patient meeting in Ulm, with Drs. Hartmut Döhner and Peter Liebisch (Ulm University Clinic), which was attended by more than 170 patients and family members. Prior to the meeting, Dr. Kyle gave the keynote address at the clinic's annual post-ASCO meeting for doctors in the region. Dr. Liebisch also joined Dr. Kyle and 80 patients in Bergisch Gladbach at a meeting co-sponsored by the North Rhine-Westphalia Myeloma Support Group, the oldest and largest in Germany. The group is chaired by myeloma patient Dr. Rolf Pelzing, has over 600 members, and hosts two comprehensive meetings a year for patients in the region.

Between those meetings, Dr. Kyle was hosted by Dr. Hans-Günther Mergenthaler at the Klinikum Stuttgart to present a myeloma overview and update. About 100 patients and family members were also given extensive time to pose questions to Dr. Kyle.

Additionally, Dr. Cyrille Hulin (University Hospital, Nancy, France) hosted Dr. Kyle, who presented an overview of the history and progress in myeloma research since the mid-1800s before 45 colleagues. Dr. Christian Straka of the Agirov Klinik outside of Munich, Germany, also hosted a roundtable discussion with local doctors and Dr. Kyle. **MT**

Expanded Approval of VELCADE® for Previously Untreated Patients

In Europe and Canada, the expanded approval of bortezomib for injection (VELCADE®) broadens options for previously untreated patients with multiple myeloma, giving them access to drugs similar to what is available to patients in the United States.

The announcement, made on September 8 by the European Commission, provides for the approval of VELCADE in combination with melphalan and prednisone for the treatment of patients with previously untreated multiple myeloma who are not eligible for high-dose chemotherapy with bone marrow transplant. VELCADE is already approved in Europe for myeloma patients who have received at least one prior therapy.

Also on September 8, VELCADE received Health Canada approval for previously untreated multiple myeloma, in the same indication as mentioned above. With these new approvals, patients with multiple myeloma may now receive VELCADE earlier following an initial disease diagnosis.

Says Greg Brozeit, Director IMF Europe, "These announcements underscore the consistent and important momentum we have observed in the last 15 months, where treatment options are expanding outside of the U.S. to give new hope for previously untreated patients with multiple myeloma."

VELCADE, along with what are called the other novel therapies - thalidomide (THALOMID® in the U.S.) and lenalidomide (REVLIMID®) – has changed the outlook for myeloma patients. However, until this year, only thalidomide had been approved for newly diagnosed patients in Europe and Canada. Unofficially, based on clinical data, many doctors are already using the novel therapies for the full range of patients.

Adds Carol Westberg of Myeloma Canada, "We are pleased to see that there is a worldwide continuum of approvals of important drug options. This is undoubtedly one of the most exciting and hope-filled times in the history of multiple myeloma patient treatment."

VELCADE is the first in a new class of medicines called proteasome inhibitors, which disrupt the life cycle of a cancer cell. More than 100,000 patients in 85 countries worldwide have been treated with VELCADE.

Editor's Note: The IMF continues to strive to find better ways to serve our community – wherever in the world it may be. If you have ideas to contribute to our continued growth and development, please feel free to contact us at TheIMF@myeloma.org or 800-452-CURE (2873).

COPING WITH FEAR AND CANCER RECURRENCE

By John M. Ricco

This story began for me on June 13, 2000, when my primary care physician told me I had multiple myeloma. The cancer was diagnosed through blood tests during my annual physical exam. The IgA protein was a tad high – it measured 4120, instead of falling within the normal range of 70 to 380!

I had never heard of myeloma, but soon was learning all I could about this disease and its treatments. Six months later, after three rounds of chemotherapy that contributed to an onset of diabetes and blood clots in the leg, I had a stem cell transplant. As a result, I was able to achieve a complete remission that lasted for nearly seven years. Life was good!

However, by the beginning of this year, my myeloma had relapsed. Once again, I went through three rounds of cancer therapy and, once again, experienced diabetes and blood clots. My second transplant, using a second batch of cells collected in 2000, took place on June 27, 2008. Currently, I am fortunate to be in my second remission.

Like the majority of other cancer patients, mortality has been my main concern and remission my main goal. But, even when remission is achieved, concern still lingers in the form of the possibility of disease recurrence, and self-doubt may raise questions about the choice of cancer treatment. My worry is not all-consuming, but it certainly remains in the back of my mind. For myeloma patients like me, relapse is likely to occur at some point, and this brings back the anxieties that came with the original cancer diagnosis.

It is not unreasonable for cancer survivors, who are already very sensitive to changes in our bodies, to notice every slight lump, faint change in skin color, and minute ache. And for those of us who monitor our test results and other pertinent markers, any change in the wrong direction may cause distress. In effect, we find ourselves reliving our original ordeal all over again. Fears are a natural part of life as cancer survivors, but we must learn coping techniques so that we do not undermine our own health and quality of life.

In coping with both the fear of recurrence and any actual recurrence, it is important to use the lessons learned during our initial experience with cancer. All the skills and support networks used the first time should be brought to bear, and all the tools used to create and to sustain a positive attitude should be employed. When we face adversity, we must acknowledge it. But we must also move forward beyond the bad news because we all have so much to live for. And, in the case of a cancer relapse, it is important to remember that we did get through it the first time.

My positive attitude has helped me through the recent relapse. After my 2000 diagnosis, I focused on the week-to-week tests, therapies, and procedures. After my 2008 relapse, I found that I was simply focused on getting done with necessary treatment so I could get back to just living my life. The road of life is full of bumps and hills -- fear of recurrence is just another bump, and any actual relapse is just another hill. To navigate the road on my journey with myeloma, I have found it essential to build and to reinforce positive attitudes with positive behaviors.

I try to keep healthy by eating right and by doing some doctor-approved exercise to keep both mind and body in reasonably good shape. I undergo regular oncology checkups and rely on close monitoring as a way to head off any potential problems early. I try to use my talents and abilities to contribute to making a better world. I try to let go of thoughts of cancer and to direct my thoughts to all that I want to accomplish in my life. I think of all the places my wife and I want to travel to, and I look forward to the day I will escort my three daughters down the aisle. And the list goes on!

My myeloma diagnosis was, and still is, the most traumatic thing to have happened in my life. But advances in cancer research are improving the outlook for patients like me, and the rate of progress in treating my disease has increased during each year of my survivorship. I have found a way to live my life to the fullest and to not let the fear of cancer recurrence consume my time or my energies. **MT**

Editor's Note: John Ricco is the author of *The Ride of Your Life: Fighting Cancer With Attitude*. The book is available at www.johnriccobooks.com, with a percentage of each purchase going to support IMF programs and services. Direct inquiries can be emailed to Mr. Ricco at JMRauthor@aol.com.

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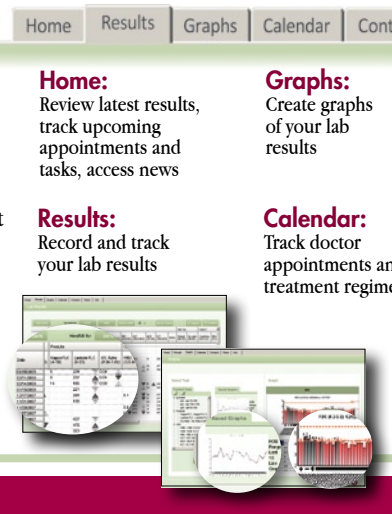

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MYELOMA TODAY IN CONVERSATION WITH LESLIE BYRNES

"Investing in the Future" features profiles of IMF members who are making substantial 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 they inspire us.

When did you become a part of the myeloma community?

My husband was diagnosed with multiple myeloma in 2003 at age 64. Peter had been suffering from back pain, but his orthopedic doctor thought he had simply hurt himself playing golf. Peter was in so much pain that he insisted on a magnetic resonance imaging (MRI) scan. That was how the diagnosis of myeloma was established. Seventy-seven lesions were visible on the MRI. Otherwise, Peter was in great physical shape.

How did you cope with the news?

Peter's first wife had died of breast cancer five years earlier, so he had a very pragmatic attitude towards myeloma. He was committed to doing whatever it took to deal with his disease. Peter had a brilliant mind, and studied myeloma the way a researcher might study it. Peter's oncologist referred us to three different cancer centers where myeloma is a primary focus and even made calls on Peter's behalf to facilitate scheduling appointments. We were grateful for this kind of approach. Peter's oncologist, who is also a hematologist, served an important role for us throughout Peter's illness. We sought and consulted the best scientists and clinicians in the field of myeloma, and even reached out to statisticians and other experts. Peter had an innate ability to absorb and process highly complex and sophisticated information, and this ability served him well as he educated himself about myeloma.

As for me, I did not feel that there was any time to waste by sinking into emotional despair. I admit I was scared and overwhelmed by all the new medical jargon, but there was so much that needed to be done. I was Peter's wife, his closest friend, his support, and his caregiver. We moved in parallel through the four years of treatment and were as close as two people could be. I was fortunate to be at Peter's side 24/7 so we could really fight the battle together.

Would you like to tell about that fight?

All the homework we did led us to decide on our course of action. Within ten days of Peter's diagnosis, he started chemotherapy, which was followed by an autologous transplant five months later. When the myeloma returned 18 months later, he had a second transplant. Nine months after that, Peter had his third transplant. After the end of his third remission, which lasted six months, he joked about proceeding to a fourth transplant. Of course, this was not an option. Peter had a difficult journey through a nasty disease, but he never gave up the fight or lost his spirit. That was the only way he knew to live his life.

In the course of Peter's illness, our local oncologist continued to confer with myeloma specialists across the nation, and we saw newer and better treatments become part of the anti-myeloma arsenal. It seemed like we were always chasing after that next most promising drug or treatment. Some of the novel agents were helpful to Peter for brief periods of time. Then, unfortunately, as the most recent agent became approved for use in myeloma, it was too late to be of benefit to Peter. My husband passed away four years after diagnosis, on June 14, 2007. But I can confidently say that he lived each day he had, fully and completely. And knowing this helps me cope with losing him.

Why did you remain active in myeloma causes?

Ever since his diagnosis, both Peter and I were very committed to the search for a cure for myeloma. Peter had arranged for contributions to be made that would ultimately fund research in the field of myeloma, including the IMF s Bank On A Cure® initiative, which is a project he believed in. Over the years, the more we got to know the IMF, the clearer it became that the most efficient path to a cure for this disease is through collaboration between the bests minds in the field. Like the IMF, we both saw the necessity for myeloma experts to work together, to share information, and to encourage progress in each other's research.

After Peter passed away, I initially wanted nothing to do with the disease that killed my husband. As time passed, I began healing and soon felt drawn to reconnect with the IMF. I was searching for purpose and also felt that getting directly involved could satisfy my desire to do what Peter could not finish. Peter's support of various institutions would be better served as a collaborative effort, rather than each center working alone. Upon the one year anniversary of Peter's passing, I flew to Los Angeles to learn more about how I could get involved with the IMF. Susie Novis and Dr. Brian Durie made suggestions as to how I might be best able to help further the work of the IMF and help others whose lives are touched by myeloma. Like Susie and Brian, I continue to believe that the key to moving toward a cure for myeloma is through collaborative research, and that the key to making a positive difference in patients' lives is through doctor and patient education. I have seen this in action during Peter's fight with myeloma, and have observed how other families are struggling on their journeys with a disease that can be quite devastating.

Years ago, when someone was diagnosed with a serious illness, the accepted logic was to go to the treatment center known as the best for that disease, assuming that the patient was in a position to take such action. But what if that center is not located in your backyard? What if you cannot afford to travel or if you have family obligations that make it impossible to receive treatment far from home? One sign of the progress made in the field of myeloma is that today's patients can get good quality care without leaving their homes and families behind to seek treatment elsewhere. The most current scientific and clinical information about myeloma is

CONTINUES ON PAGE 21

IMFers RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

A Wedding Celebration to Remember

When Brenda Fake and Tom Rushfeldt got engaged, they decided to forgo the traditional wedding. "This is the second marriage for both of us," says Brenda, "But our friends and family still wanted to attend a celebration, so I started thinking creatively." For the past eight years, on behalf of her wine club in the Minneapolis/St. Paul area, Brenda has organized benefits to support a children's orphanage. And Tom was a member of a monthly business round table, where another member is a major wine distributor. So Brenda and Tom decided to plan their wedding as a wine benefit to support two charities.

(left to right) Kelly Cox, Breda Fake & Tom Rushfeldt, Pat Harwood, Dr. Brian Van Ness, and Sharon & Lou Quast

"Our agreement was to select one global and one local non-profit organization. We chose a group in Nepal, where I had trekked with a Sherpa, and the IMF's Bank On A Cure® research project at the University of Minnesota. Tom's cousin Sharon Quast has multiple myeloma, and he has kept abreast of her experiences with the disease through Sharon's online journal. Tom has been very touched by her struggle." It was Sharon Quast and her husband Lou who introduced the couple to the IMF and, since Brenda and Tom are both graduates of the University of Minnesota, being able to support myeloma research at the institution had added significance for them. "We got in touch with IMF's Suzanne Battaglia, and the event planning got under way very quickly."

"I would not have considered throwing another traditional wedding, but I can put together a wine benefit in my sleep," says Brenda, "So the evening was easy to plan and a lot of fun for all the guests." One hundred and seventy-five guests enjoyed six wine selections presented during the evening, along with the chef's prepared pairings. In addition, the couple hosted Dr. Brian Van Ness (IMF Scientific Advisor and Bank On A Cure researcher at the University of Minnesota), who gave a talk about his work, as well as Kelly Cox (IMF Director of Support Groups Outreach) and Pat Harwood (Twin Cities Area Myeloma Support Group).

Young Artist Chooses the IMF as Honored Charity

Jeffrey Owen Hanson, who celebrated his 15th birthday on September 30th, is a young artist from Kansas who is committed to helping create "kinder communities, more compassionate nations and a better world for all." Legally blind from neurofibromatosis, he started painting in 2006, because his visual impairment prevented him from doing the usual "kid stuff." Jeff's vision does not permit him to create any concrete images, so his work is abstract, with bright and bold color combinations. He recently published a calendar, which features his art, and plans to gift $10,000 to each of the 12 charities he has chosen to honor. The IMF is proud to be one of Jeff's chosen foundations. To learn more about Jeff and his work, please visit www.jeffreyowenhanson.com.

Young Yard Sale

Susan Young's brother Doug was diagnosed with myeloma three years ago. Doug is an active member of the IMF and holds a couple of fundraisers every year to support the work of the Foundation. So, as a surprise to her brother, Susan decided to organize a yard sale in his honor at her home on Long Island in New York. Friends and co-workers donated many items for the sale and, rainy weather notwithstanding, the event was a terrific success. "It was a memorable day," says Susan. "We sold many items and also distributed a lot of educational materials about myeloma that the IMF had provided. And, besides shoppers, there were people who came to the yard sale just to make donations. I met several people whose families had also been affected by myeloma, and I was touched by their support. We are thrilled to be able to contribute that money to the IMF for its programs and services supporting the myeloma community."

Turn Your Vacations Into Donations

Visit our new travel website, www.myelomatravel.com, to book your personal and business travel. Every time you do, the IMF will receive a portion of the travel commissions. You get the same low rates offered by other travel websites while helping to raise funds for the IMF's education and research programs. It's that simple!

Join Us

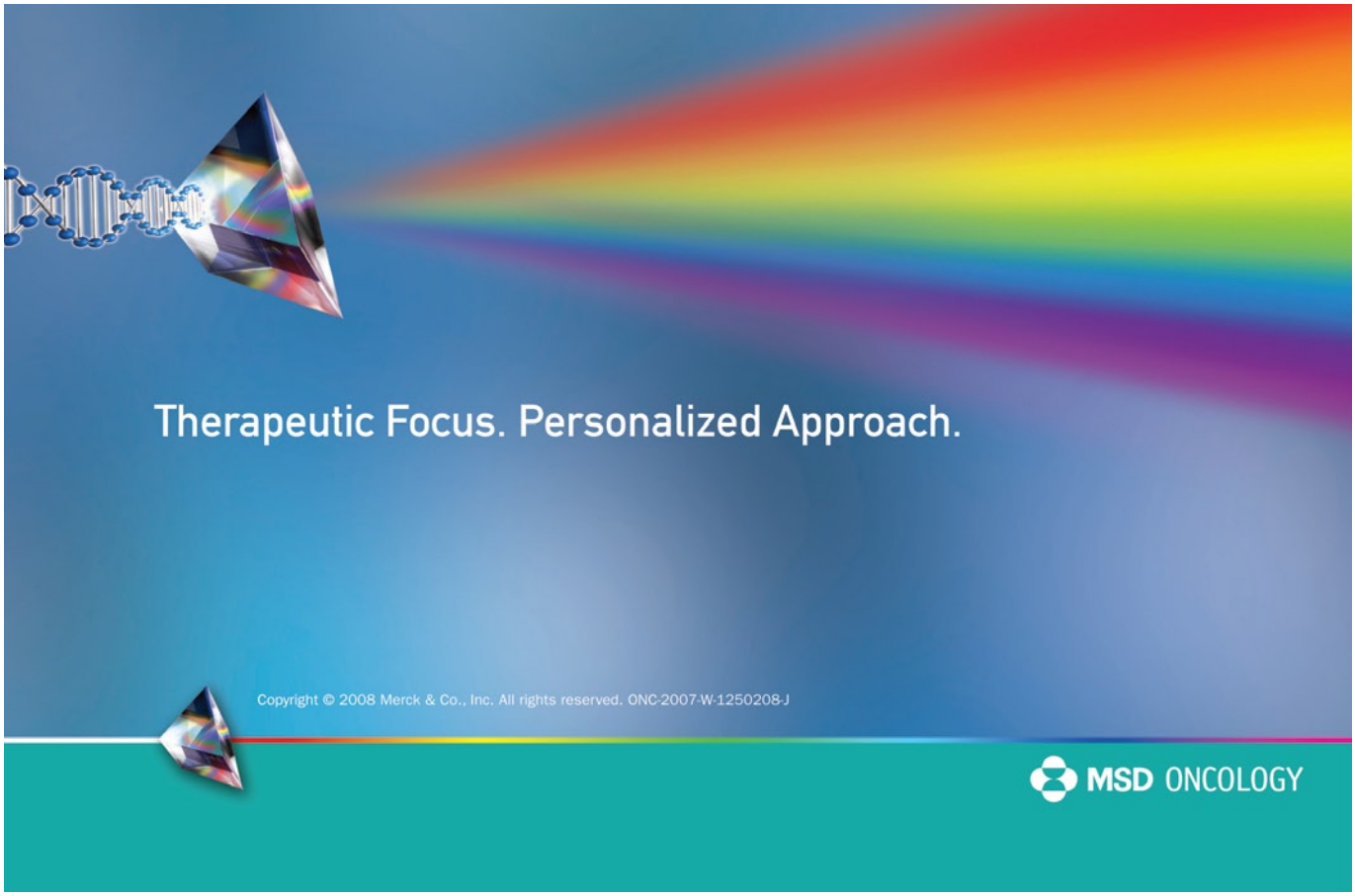
We are grateful to all IMFers who contribute their time, imagination, and hard work to benefit the myeloma community. Our FUNdraising program provides you with the tools, assistance, and expertise to make your event a success. Choose an established event model or create your own – no idea is too large or too small. Join us in working together toward our common goal... a CURE. Please contact me, Suzanne Battaglia, at sbattaglia@myeloma.org or 800-452-CURE (2873). **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
- Gifts of Securities (Stocks)
- Gifts of Real Estate
- Charitable Lead or Remainder Trusts
- Annuity Trusts
- Unitrusts
- Term-of-year Trusts
- Gifts 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.



Turn Your Old Cell Phone Into Cell Phones for a Cure

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.

CONVERSATION WITH LESLIE BYRNES — continued from page 20

now widely available, and it is not uncommon for myeloma experts to be available to patients and/or their doctors via telephone consultation. It is not unusual for an oncologist from a local community center to seek advice from a myeloma expert who, in turn, is tapped into a network of collaborating specialists. While doctors may still differ in their opinions about which treatment is best suited to an individual patient, a forum now exists for discussion. In addition to emerging treatments, this has made a very positive difference in patient care, quality of life, and outcome.

After losing Peter, I needed to find a sense of purpose, and making a commitment to an improved future for the myeloma community is one way for me to honor Peter and to continue my connection to him. So I will continue to support myeloma research and offer to act as an advocate for the patient and caregiver community. **MT**

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 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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1 Katzmann, J.A., *et al*. Mayo Clinic Proc. 2006;**81**(12):1575-78
2 Pratt, G. *et al*. Leukemia and Lymphoma. 2006;**47**(1):21-28

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2009 IMF Calendar of Events

Feb 26 – March 1	XII Int'l Myeloma Conference – New Delhi, INDIA
April 17–18	IMF Patient & Family Seminar – San Francisco, CA
April 22 – 26	Southwest Oncology Group (SWOG) – San Francisco, CA
April 30 – May 3	Oncology Nursing Society (ONS) – San Antonio, TX
May 29 – June 2	American Society of Clinical Oncology (ASCO) – Orlando, FL
June 4–7	European Hematology Association (EHA) – Berlin, GERMANY
June 12–14	Eastern Cooperative Oncology Group (ECOG) – Philadelphia, PA
June 26–27	IMF Patient & Family Seminar – Dallas, TX
July 10–12	IMF Support Group Leaders' Retreat – Dallas, TX
August 7–8	IMF Patient & Family Seminar – Washington, DC
August 28–29	IMF Patient & Family Seminar – Minneapolis, MN
September 11–12	Myeloma Canada Patient & Family Seminar – Calgary, CANADA
October 21–25	Southwest Oncology Group (SWOG) – Chicago, IL
November 6–8	Eastern Cooperative Oncology Group (ECOG) – Baltimore, MD

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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