MYELOMA TODAY

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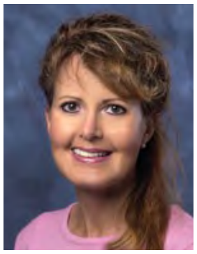
Dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

Scientific & Clinical News

Dr. S. Vincent Rajkumar of the Mayo Clinic in Rochester, MN, discusses the concept of "cure versus control" in multiple myeloma. He weighs the pros and cons of the two treatment philosophies. Should myeloma patients be treated aggressively in an attempt to potentially cure the disease, knowing that this is unlikely and that such therapies come with the risk of adverse events and substantially decreased quality of life? Should myeloma be treated as an incurable but manageable condition with the goal of controlling the disease for as long as possible, balancing efficacy and quality of life? ***PAGE 5***

Prof. Antonio Palumbo of the University of Torino and the Italian Multiple Myeloma Study Group responds to a retrospective study performed by investigators at the Mayo Clinic who looked at the impact of response failure with thalidomide or lenalidomide regimen as induction therapy prior to autologous stem cell transplantation in multiple myeloma. The value of the study finding is in the possibility of predicting response early in the therapy, thus allowing for a better assessment of treatment choices available to the patient after the initial courses of induction therapy. ***PAGE 7***

Supportive Care



Sandra Rome, member of the IMF Nurse Leadership Board (NLB) and leader of the NLB Functional Mobility and Safety task force, answers questions about optimal functioning, fall risk, and planned activity for newly diagnosed multiple myeloma patients, patients undergoing treatment, and long-term survivors. Mobility challenges vary among survivors, but problems with a lack of mobility or activity affect quality of life and also may be a hindrance to continuing treatment. ***PAGE 12***

IMF Hotline Coordinators answer a question about myeloma information provided via computer and internet. Information includes IMF website resources, the Myeloma Listserv, the Myeloma Manager™ Personal Care Assistant™ and Personal Memory Stick, and miscellaneous other resources and services. There are many computer-based resources and services that might be useful to patients and caregivers. ***PAGE 13***

Profiles in the News

Allan Weinstein, myeloma patient and member of the IMF Board of Directors, is profiled in the "Investing in the Future" feature as an individual who is making a substantial investment in the myeloma community and the path to a cure. We hope that his story of how and why he has chosen to commit to the fight against myeloma will inspire you, as it inspires us. ***PAGE 18***

Charty Bassett, a recently diagnosed myeloma patient, shares the story of how a sore hip led to the diagnosis that dropped Charty and her husband into what felt like another dimension, a bleak period of uncertainty and fear faced by many newly diagnosed patients and their loved ones. Charty writes about the empowerment of knowledge and the "web of caring" that has materialized as a profound reminder that she is not alone on this journey. ***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,

Spring is generally a time when things just seem to just "pop." Sometimes it's expected and sometimes it's a wonderful surprise. This spring the IMF experienced two unexpected and remarkable surprises!

The first happened on May 7th, when Michael McKean won the Jeopardy! Million Dollar Celebrity Invitational and the IMF was his chosen charity. One Million Dollars for the IMF – now that's what I call an unexpected and incredibly fantastic, heart-stopping surprise. Dr. Durie, Suzanne Battaglia and I were in the audience for both days of the tournament. We sat there perched on the edge of our seats, clutching good luck charms and each other. I think the only other person who was as nervous as we were was Michael's wife Annette O'Toole who was also in the audience cheering for her husband. When it came to the final Jeopardy question – this was it, the moment we were waiting for… Jane Curtin played a great game but got the answer wrong and had bet everything. Cheech Marin played a so-so game (unlike him as he's really smart), got the answer right but didn't have enough money to win. Then it came to Michael, he too got the answer wrong, BUT he didn't bet that much, so his winnings from the day before combined with his total for that day made him the MILLION DOLLAR winner!! We leapt out of our seats, cheering, crying and hugging everyone in sight. In Michael's honor and in memory of his friend Lee Grayson who died of myeloma, we've established the McKean/Grayson Fund and you'll learn more about that in the near future.

Now you'd think that would do it for "Spring Surprises" – but wait there's more…

On Friday, May 20, 2010, the IMF kicked off our annual Patient & Family Seminar program in Portland, Oregon at the downtown Embassy Suites Hotel. Each year, we visit four cities across the country, bringing with us an esteemed faculty ranging from top myeloma physicians to nutritional specialists and more. Patients and their caregivers in attendance spend two days learning about the disease, treatments, side effects and quality-of-life issues that affect them, and often leave filled with a sense of renewed hope and camaraderie with their fellow patients. But one special couple made the Portland seminar one of the most unforgettable events in IMF's twenty-year history.

Robin Laughlin and Paul Daurelle met in high school nearly 40 years ago. Over the years, their friendship dwindled as they drifted apart. A few years ago the two reconnected on Facebook and last year, they became engaged.

Paul is a patient with multiple myeloma. For the past year, their continued attempts to get married were thwarted by his unrelenting health issues. Most recently, they had to cancel plans to go to Hawaii when Paul's arm was broken and his doctor told him not to lift anything heavier than a half gallon of milk.

While at the Portland IMF Patient & Family Seminar, the couple realized that there was no time like the present, so they asked me if I knew anybody that could marry them the next day.

As it turned out, Dr. Brian Durie, co-founder of the IMF and Chairman of the its Board of Directors, had previously registered as a minister with the Universal Life Church at the request of some dear friends who wanted him to perform their ceremony last year. As a faculty member at the Portland seminar, he was on hand to perform the ceremony for Paul and Robin.

During the breakout sessions on Saturday afternoon, we worked with the hotel to make the wedding as memorable and special for the couple as we could. The hotel prepared a bouquet for the bride, a three-tier white wedding cake, and poured sparkling apple cider into champagne glasses. Then we went to work writing a ceremony, displaying an image of a Hawaiian beachfront wedding arch on the projection screen, and creating a playlist of music for the entrance and recessional.

Dr. Robert Kyle, one of the world's leading experts on myeloma who is often called the "father of myeloma," stepped in to walk the bride down the aisle. When they entered the banquet room, everyone stood and applauded as the bride was escorted to front of the room to stand next to her groom.

There was something very touching about this impromptu wedding, and all of us in attendance were keenly aware of this as we stood to witness the joining of such longtime friends. Who better to appreciate the trials and tribulations of living with myeloma than the 150 people who have experienced exactly the same thing?

When Dr. Durie pronounced Paul and Robin as husband and wife, the room erupted into a joyful blend of cheers, tears, and applause. It was, in fact, the perfect way to close the first IMF seminar of 2010 – with hope, happiness, and a true sense of family.

I can't wait to see what the summer holds in store for all of us!

Warm regards,

Susie Novis

Letters to the IMF

IMF Hotline

Dear Debbie,

It has been TWO WEEKS since we spoke on the phone – you were kind enough to stay late to walk me through all kinds of things I am facing with this still relatively new diagnosis. I am so very thankful, and you can hardly imagine what an encouragement and a comfort it is to know that you are right there, available to give help and advice. I am already awed by this IMF, and I am only barely getting started!

My husband and I have signed up for the upcoming IMF Patient & Family Seminar, and I am really looking forward to it. I am still not really up on my light chains, heavy chains, IgA kappas and all that, but little by little I am learning. I also plan to go to the next local support group meeting.

Charty Bassett

Editor's Note: To read about Charty Bassett's experience as a newly diagnosed myeloma patient, please see page 21.

Hi Debbie,

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 sheets about the "hand and foot syndrome" my husband was experiencing, and we followed what the sheets said. The IMF publications you sent us have arrived and they are also a big help. Thanks again. We couldn't get through this without people like you.

Christine Lawrence

Hi Nancy,

I just wanted you to know how much the members of Rhode Island Multiple Myeloma Support Group (RIMMSG) appreciate the benefits of your extensive myeloma knowledge and the impressive manner in which you explain the complexities of this disease in a language that patients can understand. As patients and caregivers, we are just so comforted and grateful, knowing that expert advice from the compassionate members of the IMF team is guiding us through the myeloma journey. Angels appear to us in many forms… they happen to hang out at the IMF!

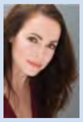
Carol Murray-Rossi & members of the RIMMSG

IMF Website

I just want to say thank you. My 51-year-old husband was diagnosed with myeloma in January and is starting treatment tomorrow. The information on your website has been so incredibly helpful and has answered every question we have... far better than our consultant in the UK has been able to! I really do wish the foundation the very best and want you to know how appreciative we are of the work you are doing. My very best regards.

Tina Spencer-Keyse

If you would like to share your thoughts with the IMF or with readers of *Myeloma Today*, or if you wish to suggest or contribute future content for this newsletter, please contact:



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CURE VERSUS CONTROL

Myeloma Today in conversation with Dr. S. Vincent Rajkumar

Please summarize the concept of "cure versus control" in myeloma.

This is a very important subject. Myeloma is a devastating and complicated disease that is still not curable. All of us who treat myeloma patients recognize the gravity of the situation. If we had treatments for myeloma with a reasonable probability of cure and acceptable toxicity, there would not be a cure-vs-control debate. All of us would surely choose cure. But the available treatment options, while excellent, fall far short of being curative. Therefore we must weigh the pros and cons of cure versus control treatment strategies.

Cure-vs-control is the key philosophical point of debate among physicians and patients about the management of myeloma. Unlike certain hematologic malignancies, such as large cell lymphoma, myeloma cannot be cured as traditionally defined, at least for the vast majority of patients. So, should we treat myeloma patients aggressively in an attempt to potentially cure the disease, knowing that this is unlikely and that aggressive therapies come with the risk of adverse events and substantially decreased quality of life? Or, should we treat myeloma as an incurable but chronic, manageable condition with the goal of controlling the disease for as long as possible, balancing efficacy and quality of life?

S. Vincent Rajkumar, MD
Professor of Medicine
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Rochester, MN

The cure approach involves multi-agent therapy applied in combination early in the disease course with a goal of achieving a complete response (CR), and then sustaining it. The control approach involves administering treatments in a sequential approach with a goal of preventing disease progression rather than CR, but emphasizing low toxicity and quality of life. On the one hand, proponents of a curative approach generally feel that therapies that work in high-risk disease tend to work even better in low-risk disease and therefore should be used for all patients with myeloma. On the other hand, proponents of the control approach employ an individualized, risk-adapted approach, targeting CR for high-risk patients with aggressive therapy, and a sequential, gentler therapy for low-risk patients with an emphasis on avoiding serious toxicity (such as neuropathy) at all costs since low-risk patients are destined to live an average of 7-10 or more years regardless of what the sequence of treatment is.

The cure-vs-control debate has an impact on most clinical decisions in both symptomatic and asymptomatic myeloma, including choice of drugs and intensity and duration of therapy. It also colors our interpretation of clinical trial results, with well-meaning investigators interpreting the same clinical trial data in opposite ways depending on whether they subscribe to the cure or control philosophy as they approach the care of patients with myeloma. Interestingly, the journal Nature recently published an article which called for a change of strategy in the war on cancer. The author makes the point that trying to control the disease may prove to be a better plan biologically than striving to cure it. He draws a parallel with agriculturalists who have abandoned efforts to eliminate invasive species, and now apply insecticides only when infestation exceeds some threshold level, with the goal of producing a sustainable and satisfactory crop.

What is the background of this debate?

Before the introduction of high-dose therapy with autologous stem cell transplant (ASCT) in the 1990s, the goal was to control myeloma as much as possible, providing the best quality of life to the patient for the longest duration by use of the available chemotherapeutic agents. Subsequently, bisphosphonates were found to be effective in decreasing the incidence of bone lesions. In the past decade, three novel agents (thalidomide, bortezomib, and lenalidomide) emerged as effective anti-myeloma drugs, producing remarkable results in numerous treatment regimens in terms of CR rate, progression-free survival (PFS), time-to-progression (TTP), and overall survival (OS). We expect upcoming newer drugs, like pomalidomide and carfilzomib, to improve on these outcomes. These results have prompted a new philosophy of treating myeloma with the goal of potential cure rather than disease control.

Some groups such as the Mayo Clinic myeloma group are pursuing both strategies in clinical trials, allowing patient choice. For example, we are currently pursuing an approach with single-agent lenalidomide as initial therapy for myeloma with other drugs added as needed, with an emphasis on quality of life and disease control. At the same time, we are testing a 4-drug combination strategy in a separate trial in an attempt to develop a curative regimen for myeloma.

Please share the logic of each approach.

If cure is the goal, then CR is the logical first step, and maintaining the CR is the second step. The best time to attempt to achieve a CR is early in the disease course. Moreover, administering the best treatments early on will provide a greater chance at success. Trying to achieve and maintain the highest CR rate requires more intense, more toxic therapy. However, many side effects are reversible, and many patients are willing to accept high toxicity rates in exchange for the possibility of longer life. It must be kept in mind that although OS is usually better in patients who achieve CR than in those who do not, this could be more a reflection of some patients having inherently more favorable disease prognosis. It is still unclear whether intensifying therapy with the sole purpose of achieving CR for patients who are otherwise responding well to therapy actually prolongs OS. In addition, there are many problems with our definitions of CR; in myeloma, unlike in other cancers, CR really reflects profound disease reduction, but not elimination, and thus is not a surrogate for true cure (unlike diseases such as large cell lymphoma, where the majority of patients achieving CR are cured).

If control is the goal, CR becomes a desirable event, but it is not the goal. In many myeloma patients, reduction of the disease to a state similar to that of monoclonal gammopathy of undetermined significance (MGUS) by achieving very good partial response (VGPR) may be all that is required for best long-term survival. The logic of the control approach is that not everyone needs to be subjected to the toxicity of aggressive therapy, and that drugs administered sequentially with a goal of optimal quality of life

CONTINUES ON PAGE 6

RAJKUMAR / CURE VERSUS CONTROL — continued from page 5

will result in equally long duration of life for low-risk patients with lower morbidity. The control approach recognizes that myeloma is a marathon, not a sprint, and that preserving options for later is important.

Is there a conclusion to be drawn from interpretation of available clinical trials data?

I think that there are three big factors that are of concern. They are: 1) Overestimating the clinical benefit of endpoints like PFS and TTP; 2) Overestimating the value of a CR; and 3) Considering and treating myeloma as if it were acute leukemia. These factors are affecting the way in which clinical trials are interpreted and ultimately are affecting the way in which patients are treated clinically.

The metrics for a new drug going through the clinical trials process in order to receive FDA approval differ from the metrics that need to be applied to non-regulatory trials, where the goal is to determine the place of that new drug in the overall treatment strategy. Although with the best of intentions, it is not unusual for pharmaceutical companies, researchers, and practicing clinicians to lose sight of this. And most patients and caregivers do not have the training to correctly process statistical terminology or clinical trial data.

In regulatory clinical trials, endpoints such as PFS and TTP are meaningful because they often suggest clinical benefit, and since the drug being tested is not approved, patients in the control arm (and patients at large) do not have the option of getting the drug later on in the disease course. In contrast, in non-regulatory trials, PFS and TTP do not carry the same value because patients in the control arm do have the option of getting the same drug later. Thus, in most non-regulatory studies, prolonged PFS or TTP does not necessarily imply clinical benefit (which would be prolonged OS or patient-reported improvement in quality of life). In these situations, PFS or TTP in the control arm must ideally be measured at second relapse, after the patient has failed use of the experimental treatment in question that was administered at first relapse.

The ultimate goal of our therapy should be improved OS. The problem is OS data in regulatory clinical trials is impractical because the required sample size is too large and the duration of follow-up needed is too long, and it would significantly delay the FDA approval of a drug that might be quite useful to myeloma patients.

Where is your position in the cure-vs-control debate?

The answer to this question depends on what kind of myeloma we are talking about. Outside of a clinical trial setting, I suggest a risk-adapted approach.

In high-risk patients – about 15% to 25% of the myeloma population – an aggressive approach to achieving CR may be the only route to long-term survival. We use cytogenetic abnormalities to identify these high-risk patients. These patients should consider: 1) a multi-drug regimen, including bortezomib early in the disease course; 2) CR as a treatment goal; and 3) routine maintenance therapy.

In standard-risk patients – about 75% of the myeloma population – I favor a control approach. In clinical trials before the introduction of novel agents, patients under the age of 65 lived an average of 7 to 10 years, and the current availability of novel agents will increase their survival further. For low-risk patients, my approach involves:

1) Using non-neurotoxic initial therapy such as lenalidomide plus low-dose dexamethasone (Rd), and avoiding bortezomib except if patients have renal failure or need urgent control of disease. My rationale is to avoid the risk of neurotoxicity (which can be severe) in low-risk patients when there is no OS data indicating that using bortezomib early rather than later at first relapse improves survival compared with Rd

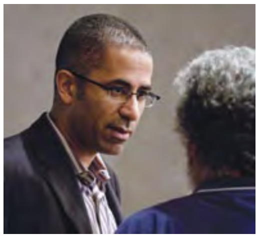
2) Targeting VGPR rather than CR as a goal, using treatments at the minimal effective dose with a sequential approach of less intense therapy first and more aggressive approaches only when the need arises

3) Allowing patients to decide between early versus delayed transplant, and

4) Employing maintenance therapy primarily in patients who have failed to achieve a VGPR or better.

In clinical trials, of course, we need to continue the search for a cure, and we need to explore both the cure and control strategies. The treatment algorithm must also take into account patients' needs, goals, and attitudes toward prolonged survival versus a better quality of life. Some patients prefer a potentially curative approach despite the risk of adverse events; others think that quality of life is more important than a potential cure. **MT**

WHAT DO YOU GET AT AN IMF PATIENT & FAMILY SEMINAR?



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If you cannot get to a P&F Seminar, consider attending a Regional Community Workshop. These half-day meetings provide Education, Access to Experts, and Camaraderie. Registration is free *but you must register*. It's a great way to learn from myeloma experts, as well as share experiences and gain strength from others in the IMF family. Find more details about the next RCW near you at our website.

Go to our website **www.myeloma.org** *and click on the* "meetings & events" *tab for more details, the most up-to-date faculty, hotels and registration information.*

INDUCTION THERAPY PRIOR TO AUTOLOGOUS STEM CELL TRANSPLANTATION

Myeloma Today in conversation with Prof. Antonio Palumbo

Your response to a study performed by investigators at the Mayo Clinic was recently published in Blood. Would you please explain the complex issues involved to our readers?

This retrospective study looked at the impact of response failure with thalidomide or lenalidomide regimen as induction therapy prior to autologous stem cell transplantation (ASCT) in multiple myeloma. The study analyzed progression-free survival (PFS) and overall survival (OS) in 286 patients, comparing patients who achieved a partial response (PR) to those who did not achieve at least a PR or progressed during therapy after induction with a regimen that contains thalidomide or lenalidomide.


Antonio Palumbo, MD
University of Torino and
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The Mayo investigators conclude that an absence of a response to induction therapy with thalidomide or lenalidomide predicts a poorer outcome receiving high-dose therapy and ASCT. Study patients who did not achieve PR during induction therapy, or those who progressed despite a short initial response during induction therapy, had a significantly shorter OS from transplantation and a shorter PFS.

How do you assess the value of those results?

In many clinical studies, the achievement of response, in particular the achievement of complete response (CR) or very good partial response (VGPR) has been considered a strong predictor of outcome, especially for myeloma patients undergoing ASCT. In a recent study, both 5-year PFS and 5-year OS rates were significantly increased in patients achieving at least VGPR after ASCT. Unfortunately, this outcome can only be measured at the end of the entire treatment procedure including both induction and transplantation.

The value of the finding of The Mayo Clinic study is in the possibility of predicting response early in the therapy, thus allowing for a better assessment of treatment choices available to the patient after the initial courses of induction therapy.

Cytogenetic markers can predict a poor outcome and the need for a more intense treatment approach but suboptimal response in the early phases of treatment may represent an advantage over biological markers for the treatment choice of an individual patient.

What is your opinion about the therapy options for patients who do not respond to induction therapy?

If a patient has a suboptimal response to the initial treatment regimen – if the patient does not achieve PR on a two-drug combination therapy – from a practical point of view, an intensification of treatment should be considered to attempt to increase the patient's chances of reaching CR:

- Increasing the potency of the two-drug induction regimen by moving to a three-drug combination that includes an additional agent, then possibly a four-drug combination.
- Prolongation of induction therapy from three to six cycles.
- Consider the advantage of a tandem instead of a single ASCT.
- Decide on consolidation or no consolidation, although few data are available on the role of consolidation and maintenance therapy after ASCT. Three different phase 3 studies found that thalidomide maintenance improved PFS and OS. Large randomized trials are now investigating the role of lenalidomide maintenance, which might offer the same benefits as thalidomide but with less toxicity. Data on bortezomib maintenance are also showing benefits in this setting.

Which are the appropriate choices to overcome poor outcome still remains an open question. Despite this, in newly diagnosed patients, it is reasonable to use all available options to improve suboptimal responses.

What is your opinion about the therapy options for good-prognosis patients?

In good-prognosis patients, the best treatment option should be considered upfront to maximize the chance of a significant reduction of disease and a prolonged duration of remission. Clinicians should avoid the risk of under-treating patients who respond to induction therapy or ASCT. A recent study showed that in patients who have a good prognosis, the addition of consolidation after ASCT improved the CR rate from 15% after transplantation to 50% after consolidation.

Any closing comments?

It is difficult to give patients a clear message. Further studies are needed to assess the role of tailored therapy in myeloma. But physicians and patients should not underestimate the difference between the outcome of a phase 3 trial with 600 patients and the outcome of a phase 2 trial with 30 patients. It is risky to base standard of care regimens on small Phase 2 clinical trials. Evidence-based prospective phase 3 randomized clinical trials are essential to validate the standard of care treatment regimens for myeloma. **MT**

Editor's Note: The Continuing Medical Education (CME) article "Stem cell transplantation in multiple myeloma: impact of response failure with thalidomide or lenalidomide induction" by Drs. Gertz, Kumar, Lacy, Dispenzieri, Dingli, Hayman, Buadi, and Hogan (Division of Hematology, Mayo Clinic, Rochester, MN) was published in *Blood* on March 25, 2010.

SPOTLIGHT ON ADVOCACY

Important policies and political issues that impact the myeloma community

By Christine Murphy

Annual Budget and Appropriations Process Begins

Earlier this year, the President released his budget for fiscal year (FY) 2011. Included in the President's Budget was $32.09 billion for the National Institutes of Health (NIH), an increase of $1 billion (3.2 percent) over the FY 2010. The proposed NIH budget included $5.26 billion for the National Cancer Institute (NCI), an increase of $161 million (3.16 percent). While this is good news for cancer research, the President's Budget eliminated the Geraldine Ferraro Blood Cancer Program at the Centers for Disease Control and Prevention (CDC), which received $4.7 million in FY 2010.

The President's budget is a "blueprint" and does not have the force of law. It is merely his formal request to Congress, and Congress is not required to adopt his recommendations. Generally, the president's budget is a political document that the Congress can consider and use as a guideline. It may follow it exactly, or reject it entirely. After the release of the President's budget, the House and Senate begin working on a budget resolution. The budget resolution sets spending ceilings (limitations) and determines the amount of federal spending available to the Appropriations committees. While the Senate Budget Committee adopted its $3.7 trillion resolution on April 22, it has yet to come to the Senate floor for a vote.

Meanwhile in the House, House Democratic leaders continue to push factions in their caucus to agree on a budget plan that could be moved to the floor, but they will soon have to decide what to do if no deal can be reached. They are having trouble reconciling the demands of fiscal conservatives, who want sharp spending cuts, and the remainder of the caucus, which is concerned that such cuts would harm education and other domestic programs.

If the House and the Senate do not adopt a final, unified budget resolution, lawmakers could turn to a process called "deeming" to set caps on discretionary spending for the 12 annual appropriations bills, or they could try to move the bills without such guidance. But either course comes with difficulties. Adoption of a final budget resolution would clear the way for the Appropriations committees to begin their work, and that reality is putting pressure on leaders to decide whether to move forward with a fiscal 2011 budget resolution.

The budget resolution establishes the total amount of discretionary spending that can be divided among the appropriations bills. But the cap can also be set without a resolution through deeming, which has been used in previous years when no final budget blueprint was adopted. The last time the cap was deemed was in 2006. The deeming resolution, which can be passed on its own or as part of another bill, also serves as a procedural enforcement tool on spending totals absent a budget resolution.

For now, Democratic leaders do not want to discuss what fallback options are being considered, saying their immediate focus is on producing a budget resolution that all factions of their caucus can support. Technically, May 15 is the date when appropriations bills can come to the House floor in the absence of a budget resolution, although that timeline does not have to be followed.

While the House and Senate work to put together some form of a budget resolution, the IMF is working to ensure Congress supports increased funding for critical myeloma research and outreach programs in FY 2011. Specifically, IMF advocates:

- $33.349 billion to the NIH and $5.957 billion to the NCI;
- $6 million to the Geraldine Ferraro Blood Cancer Program at the CDC; and
- $50 million for the Peer-Reviewed Cancer Research Program (PRCRP), funded through the Department of Defense (DoD) Congressionally Directed Medical Research Programs (CDMRP).

NIH Testifies About FY 2011 Research Budget

The NIH recently testified before the House Appropriations Subcommittee on Labor, Health and Human Services, and Education (LHHS) about the "crunch" NIH will face in FY 2011 when a two-year allotment of $10.4 billion in stimulus funding for research runs out. The LHHS Subcommittee determines the annual funding level for the NIH.

In the hearing, House appropriators spent two hours exploring topics as varied as pancreatic cancer, children's health and the success rate in completing cancer trials. But the ever-present scramble for money was a continuing theme. According to NIH Director Francis Collins, NIH grant applicants had a 25 to 30 percent chance of success at obtaining funding, but more recently that has dropped to 20 percent during the last 30 years. In FY 2011, Collins predicted that just 15 percent of grants would be funded as the spigot of money provided through the economic stimulus law shuts off.

Are You a Member of the Myeloma Action Network?

Want to stay informed about IMF's advocacy activities? All you need to do is to join the Myeloma Action Network at www.advocacy.myeloma.org and you will automatically receive e-mail advocacy alerts from the IMF. To learn more about health care reform and other important advocacy issues that impact the myeloma community, please visit the IMF advocacy page at www.myeloma.org. **MT**

How to contact the IMF Advocacy Team

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SPOTLIGHT ON ADVOCACY

Report on the Myeloma Awareness Month

By Arin Assero

Myeloma Awareness Month and Beyond

As most of you know, March was Myeloma Awareness Month. The IMF was busy across the country doing our part raising awareness about multiple myeloma, educating patients and their families as well as the general public, and continuing our dialogue with members of Congress and local legislators about important issues facing the myeloma community.

One of our most successful Myeloma Awareness Month activities was a free four-part teleconference series that highlighted the pillars of the IMF: SUPPORT • EDUCATION • RESEARCH • ADVOCACY.

I'd like to take this opportunity to thank everyone who participated, including Tiffany Richards, MS, ANP, AOCNP, an experienced myeloma nursing specialist at MD Anderson Cancer Center (Houston, TX) and member of the IMF's Nurse Leadership Board who was the host of the first call of the series covering ***Support***, the members of our IMF Hotline, Debbie Birns, Nancy Baxter, Paul Hewitt, and Missy Klepetar, who took on ***Education***, Dr. Brian Durie, world-recognized myeloma expert and Chairman of the IMF Board of Directors, who discussed the latest ***Research*** in frontline therapy, and, finally, the IMF ***Advocacy*** Team and our guest panelists Michael & Robin Tuohy and Jerry Walton, who shared their experiences as IMF advocates and discussed the importance of this role in the myeloma community. If you didn't get a chance to dial in and be a part of the discussion, audio recordings of each teleconference are available on the IMF website www.myeloma.org.

In addition to the teleconference series, our advocacy team has been very busy expanding our grassroots outreach by hosting training webinars for advocates from all around the US. Webinar topics included building relationships with your legislators, congressional visits in Washington, the top 10 DOs and DON'Ts for legislative visits, effective use of the IMF's Advocacy Action Center, and the IMF's 2010 public policy agenda. Thanks to all who participated! All of these tips can be found in our Advocacy Toolkit on the IMF website www.myeloma.org or directly at toolkit.myeloma.org.

IN THE COMMUNITY:

Support Group Leaders fight for access to treatment – The Oral Drug Reimbursement Parity

In Connecticut, myeloma support group leaders Michael and Robin Tuohy participated by giving testimony in a local hearing on SB 50, an act concerning oral chemotherapy treatments. In the last few years, we have seen dramatic and important advances in treatments for multiple myeloma. However, the needless disparity in insurance coverage between oral drugs and intravenous (i.v.) chemotherapy is a critical issue for many myeloma patients. The IMF believes patients and their doctors should be able to take advantage of the treatment that is best for them, regardless of how it is administered. What we need is a 21st century system in place to keep up with the innovation. As follow up to this hearing, we're happy to report that SB50 passed unanimously through the House on May 3rd! Congratulations to the Michael and Robin for being a part of the solution!

> *"Never doubt that a small group of thoughtful, committed citizens can change the world; indeed, it's the only thing that ever has."*
>
> **– Margaret Mead, American anthropologist**

In a similar hearing in the state of New Hampshire, support group leader and myeloma patient Tom Liebert testified: "Personally, I am in remission because of an i.v. drug. An oral version that is currently being developed would be more convenient to take. It would eliminate the time and expense required for treatment in a medical center – time that keeps some patients from going back to work. And it would be less expensive

CONTINUES ON PAGE 16

The IMF Advocacy Voice

Get Fired Up! Raise Your Voice! Get Out There and Take Action!

In order to make a change, we must focus our legislators on critical elements affecting ALL myeloma patients. A personal visit is the MOST effective way to communicate your concerns, so take the time to take a stand!

Not sure where to start? No worries. Our Advocacy team will supply you with all the tools you need and walk you through each step. Email Meghan Buzby at mbuzby@myeloma.org for more information or visit us at myeloma.org and click on **Advocacy** to learn what you can do to make a difference.

Sign up *NOW* for the MYELOMA ACTION NETWORK to stay informed of critical issues affecting the myeloma community. Visit www.advocacy.myeloma.org.

Based on our "Cancer Patient Statement of Principles," the IMF calls on the US Congress and the White House to:

- **Ensure equality of access for all cancer patients;**
- **Reform and streamline policies and procedures for early approval of new cancer treatments;**
- **Support innovation to develop more effective cancer treatments; and**
- **Support research uncovering the causes of cancer.**

IMF PATIENT & FAMILY SEMINAR

A newly diagnosed patient shares her first IMF seminar experience

By Nancy Holleran Dupont

It was with some trepidation that my husband and I attended our first IMF Patient & Family Seminar in the Fall of 2009. My shocking diagnosis of Stage III multiple myeloma, just 8 months prior, followed by chemo and stem cell transplant still had me reeling. And so tired!

I'd experienced what was thought to be a torn muscle in my side in December 2008 and, when the pain didn't resolve, I sought further diagnosis. On New Years' Eve we received the call from my internist: two broken ribs and a compression fracture to my spine. Although I didn't "exactly" know what that meant, I knew my condition was grave.

Nancy Holleran Dupont & Howard Dupont

Fortunately, friends told us about the IMF seminar in Minnesota. As a registered nurse, I'd been to many conferences, some more helpful than others. As a patient, could I get through this one? Would we learn anything? Would my husband Howard feel the support I hoped he would find among other caregivers? And finally, was it worth the investment of time and energy, or would staying home for continued rest be the right decision?

I must admit I convinced my husband that we must go, that if for no other reason, the networking with other myeloma patients and family members would make the time worthwhile. Thankfully my wish came true.

The conference was held in a beautiful venue, a really lovely hotel. At a time like this, beautiful spaces help to nurture and support.

We were greeted warmly by the staff of the IMF. At a time like this, feeling welcome provides a healing balm. A good start, a good omen.

We learned a lot about myeloma, and that information came from many sources. The speakers were innovative, bright and caring. Did we understand all the terms and jargon used? No. But the written materials given to us, and the people from the IMF who welcomed our questions made it usable information.

> *"I was very impressed with the concentration of experts at the IMF Patient & Family Seminar. We heard from many speakers and the information was at all levels. Some of it was a bit complex for a newcomer to the world of myeloma, but it was all backed up with visuals that helped us to absorb the information. Booklets and pamphlets were available for us to take home. We learned a lot about my wife's myeloma in a short period of time.*
>
> *It was amazing to me that there was actually a special session held just for family members of myeloma patients. We were included throughout the conference, but one session was held just for us. Amazing. I would highly recommend attending a conference, you won't be sorry."*
>
> **– Howard Dupont**

You see, the people at the IMF understand "us." In some cases, we've just been diagnosed with myeloma and we're often still adjusting to the diagnosis. Often, our energy levels are at an all-time low. Or, we might be veterans of the disease, having lots of information through living with myeloma and continuing to learn. Perhaps we've ridden the wave, going from diagnosis to treatment, to re-treatment. At the IMF seminar, there were patients at many levels, sharing their experiences with treatment, medical decisions, and ups and downs that accompany. These people are our peers, our new friends, our support network. They are experts in their own right.

I had received my treatments and stem cell transplant in Wisconsin. At lunch, my husband and I shared that we were having difficulty finding the right place to be seen and treated in Florida, where we live during the Winter months. Through much research we'd chosen a place we thought might meet our needs. One of the IMF Hotline counselors listened carefully and said that a colleague had the best knowledge of physicians and medical facilities dealing with myeloma. That's when we met IMF's Debbie Birns, one of the IMF staff members and Hotline Coordinators.

Debbie easily had the recommendations we'd been searching for the past few months. This had been a grueling task at a time when research was a daunting for us. She had it at her fingertips and shared it with professionalism and ease. During the remainder of our time at the IMF seminar, we developed a friendship with Deb, a real bonus as she continues to be our resource person.

In November, after extensive tests had been done at Moffitt Cancer Center in Tampa, I got a long list of test results from which all appearances seemed to joyously shout "normal!" But I still longed to hear that I was really in remission. I contacted Deb, who after reviewing the test results said, "Yes, Nan, you are IN REMISSION." I just needed another person to view those lab results and say the magic words we all long to hear.

Of course there are no guarantees for any of us at any time. Myeloma may try to take residence with me again, or it may never return. I may encounter other obstacles in my life that are life threatening and as challenging as myeloma. But I have chosen to live my life in the most positive way possible. Although this outlook on life is not new for me, it has taken on even greater meaning. I have garnered more points on the "I can overcome" scale through this experience. Yoga, exercise, healthy food, loving and supporting relationships with family and friends, and positive thought… those are the tools I choose to use to stay well.

I would highly recommend that other myeloma patients and family members consider attending an IMF seminar if they can. And don't hesitate to call the IMF Hotline for advice and support, the IMF staff really is there for us. They consider no question a silly one. We're family now.

How fortunate we are to have them. **MT**

Nurse Leadership Board

REPORT ON RECENT NLB ACTIVITIES

Myeloma Today in conversation with Joseph D. Tariman

Joseph D. Tariman, PhC, MN, APRN,BC, OCN
PhD Candidate
Research Fellow, National Institute of Nursing Research
Predoctoral Fellow, Biobehavioral Nursing Research
Fellow, ARCS Foundation
School of Nursing, University of Washington
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Please give our readers an update on NLB activities at the recent ONS annual meeting.

I was a member of the NLB faculty presenting at the ONS 35th Annual Congress, held on May 14, 2010, in San Diego, CA. Our presentation encompassed a summary of the five core elements of the NLB Survivorship Care Plan. (In the last issue of *Myeloma Today*, two team leaders described the work of their task forces. In this issue, Sandra Rome discusses her section of the Survivorship Care Plan on page 12.) As myeloma patients are living longer, in part due to the advent of novel agents, there is a clear need for a care plan that deals with the issues on survivorship. The Survivorship Care Plan manuscript is currently being prepared for publication, and is being submitted to a peer-reviewed medical journal.

The NLB presentation was attended by 625 nurses. The meeting room was packed, and 75 additional chairs had to be brought in to accommodate the crowd. There were an additional 75-100 nurses that, unfortunately, had to be turned away because we had reached capacity for the hall where the presentation was held. Clearly, the attendance was this high because more and more nurses are seeing myeloma patients in their practice, and through recognition of its contributions to advancing the care of myeloma patients the NLB has developed a strong following. As patients are living longer, it is important for the nurses who care for them to be up-to-date in their myeloma education. The NLB members are very committed to the task of disseminating myeloma education to the nursing community.

You are also publishing a myeloma textbook for nurses. How did this project originate?

There has never been a textbook for nurses on multiple myeloma. I discovered this in the year 2000, when I was working as nurse practitioner at the Northwestern University Myeloma Program. Almost 10 years later, this was still the case. I felt that it was very important for nurses who work with myeloma patients to have a book that would guide them in their practice.

I made a proposal to the Oncology Nursing Society (ONS), which included the conceptualization of the content. Then I started looking for contributors to work on the various book chapters. As a member of the IMF's Nurse Leadership Board, I work with some of the best nurses working in myeloma today, and I invited my colleagues to become contributors to the book. Nine NLB members contributed one or two chapters each, and I contributed two chapters. As the textbook's editor, I was responsible for the entire content of the publication. It was a lot of work. Given the scope of the book, it has been quite an achievement to get it published just one year after my proposal. All the contributors worked so hard to make this book timely and relevant to oncology nurses.

How would you assess the value of this textbook?

The book delivers meaningful and comprehensive content. The major strength of this book is that it has a chapter on every aspect of myeloma:

- Historical accounts of advances in myeloma
- Anatomy and Physiology
- Pathophysiology
- Epidemiology, Prevention, and Detection
- Patient Assessment
- Treatment Modalities
- Newly Diagnosed, Transplant Eligible
- Relapsed and/or Refractory
- Patient Management and Evaluation
- Patient Receiving High-Dose Chemotherapy with SCT
- Patient Receiving Novel Agents
- Patient Teaching
- Survivorship Issues
- Nursing Research
- On the Horizon: Future Considerations

(left to right) Beth Faiman, Tiffany Richards, Joseph Tariman, Elizabeth Bilotti, and Kena Miller at the book launch during ONS Congress

How and where is the textbook available?

It is currently available through orders placed with ONS customer service by calling 866-257-4667, and it will shortly be available through Amazon and Barnes & Noble as well. I would like to reiterate that this is a textbook written in technical language for nursing professionals.

For publications intended to be read by patients and caregivers, I would highly recommend the IMF library of free publications, which covers a wide range of topics in patient-friendly terms.

Any closing comments?

Yes, I would like to thank the IMF and Susie Novis in particular for organizing the NLB. Our membership has become a very close network that represents the best nurses in the field of myeloma, and my colleagues were invaluable throughout the development of the textbook. **MT**

MOBILITY AND SAFETY IN THE MULTIPLE MYELOMA SURVIVOR

Myeloma Today in conversation with Sandra Rome

The NLB manuscript is being prepared for health care professionals. What can you share with the patients and caregivers who read Myeloma Today?

People with myeloma are surviving longer due to newly available treatment options. Not unlike other cancer survivors, long-term myeloma survivors must deal with issues that include treatment, recovery from therapies, and the effects of the disease itself. Optimal functioning is key to the quality of life of long-term myeloma survivors.

Multiple myeloma causes anemia and bone disease in as many as 90% of patients. The impact of the side effects at diagnosis and throughout treatment includes decreased mobility, pain, metabolic disturbances from bone loss, neurological compromises, weakness, and fatigue. Mobility challenges vary among survivors, but problems with a lack of mobility or activity affect quality of life and also may be a hindrance to continuing treatment.

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

The purpose of my section of the NLB Survivorship Care Plan is to provide the health care professional with information on mobility, fall risk, and planned activity as an integral part of the myeloma patient's plan of care. The intent is to provide tools for nurses and physicians assessing and evaluating the newly diagnosed myeloma patient, the patient undergoing treatment, and the long-term survivor.

Patients with myeloma may experience physical changes related to treatment. Some of these changes include peripheral neuropathy, muscle wasting, fatigue, and gastrointestinal problems. These, along with other patient factors, may interfere with daily mobility, safety, and the ability to function safely.

Myeloma patients have particular risk factors related to falls as compared with other individuals ≥ 65 years, regardless of their health status. A myeloma patient may have one or more fall risk factors (e.g. visual problems, orthostatic hypotension, gait and balance problems, medication side-effects, and degenerative joint disease), so a single factor might not necessarily predict a patient's risk for falling. Given the bone problems in myeloma, falls more frequently lead to bone fractures.

What are the recommendations of the NLB regarding mobility?

We recommend that an evaluation of the patient's baseline history and physical assessment is performed with a focus on neurologic function, muscle strength and balance, and visual acuity. Laboratory tests and other health conditions and medications should be reviewed in terms of the impact on the patient's functioning. MRIs or other imaging studies may be indicated prior to prescribing an exercise program. Bone density scans are beneficial for evaluation at diagnosis and annually for guiding the use of bisphosphonates, a class of drugs that prevent the loss of bone mass. Since a patient's condition can change over time, it is crucial that baseline as well as ongoing assessment be performed at every encounter with the healthcare team.

What are some NLB recommendations regarding physical activity?

Planned physical activity and/or exercise should be part of an overall health program that includes nutrition, weight management, and potential complementary therapies, such as support groups. All assessments prior to an activity or exercise plan should include patient's previous activities and exercise preferences, which may be unique and varied.

There are three types of exercise: aerobic, resistance, and flexibility. The choice of exercises depends on the person's goals, health status, exercise history, and cancer experience. Studies with myeloma patients have included an aerobic component, usually walking, but in some instances, running or cycling plus strength resistance training using exercise stretch bands.

Activity may improve physical fitness, which may improve physical functioning. Studies have shown the feasibility of exercise in all categories of cancer survivors. The benefits of adequate physical functioning and exercise have been shown to have physical as well as psychological benefits. Physical activity has been shown to improve cardio-respiratory fitness during and after cancer treatment, symptoms and physiologic effects during treatment, and vigor post-treatment.

Positive effects of exercise in cancer patients include improved sleep quality, mood, overall quality of life, functional and physical measures, as well as a reduction in cancer-related distress and cancer-related symptoms. Emotional benefits, such as decreased tension, depression, irritability, pain, and fatigue, and higher levels of invigoration and relaxation have been observed with moderate stretching exercise, such as yoga. Exercise may improve treatment completion and possibly reduce toxicity. It may help patients with advanced-stage disease improve physical strength and health, reduce fatigue, and improve emotional status.

Exercise intervention studies in myeloma survivors who participate in exercise programs show that it can be done safely. Even myeloma patients undergoing aggressive treatment, such as a stem cell transplant, can safely participate in an individualized strengthening and endurance exercise program.

It is clear that improvement in functional ability, strength, and balance reduces an individual's risk of falling and having a fall-related injury. For patients with mobility problems and potential risk of falling, the following should be specifically addressed:

- Immediate needs for safety (hospital fall-precautions program, in-home assistance, use of assistive devices)
- Treat or manage the underlying disorder or problem, e.g. neuropathy

CONTINUES ON PAGE 14

IMF HOTLINE COORDINATORS ANSWER YOUR QUESTIONS

The IMF Hotline 800-452-CURE (2873) consistently provides callers with the best information about myeloma in a caring and compassionate manner. The Hotline is staffed by Paul Hewitt, Missy Klepetar, Nancy Baxter, and Debbie Birns. The phone lines are open Monday through Friday, 9am to 4pm (Pacific Time). To submit your question online, please email TheIMF@myeloma.org.

I have recently become somewhat computer literate and am wondering what information you provide via computer other than your website?

That is a great question because the International Myeloma Foundation (IMF) is also becoming more computer savvy and is able to provide more help via computer to patients regarding all aspects of their journey with myeloma.


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

Website

You mentioned that you are familiar with our website, but we'd like to remind everyone what is readily accessible via our website www.myeloma.org:

1. A full library of PDF versions of all IMF publications, including the Patient Handbook, the Concise Review, and all booklets from the *Understanding* series.

2. Webcasts from medical meetings held by the American Society of Hematology (ASH) and the American Society of Clinical Oncology (ASCO), as well as the bi-annual International Myeloma Workshop, and the IMF Patient & Family Seminars. Just click on the "Webcasts" tab at the top of the IMF home page and you will get a dropdown menu of all of our webcasts or go directly to http://webcasts.myeloma.org.

3. The publications of the International Myeloma Working Group (IMWG) are also on our website. There are over 30 IMWG publications, with subjects ranging from diagnostic criteria to response criteria. These can be found under the "Research" tab and then under "Myeloma Working Group." In addition to the full papers, we have begun to create summary guidelines of each of these papers, which are also listed on that page.

4. The links to clinical trials and clinical trial search tools are constantly being updated on the IMF website, and these are a good way to find relevant clinical trials. Just click on "Clinical Trials" on our website.

5. Our support group directory can help you find a group in your area. Just click on "Find Support" and you will go to http://support.myeloma.org page. Myeloma support groups in the US are listed by state, and international groups are listed by region and country. Some of the groups have their own websites that feature specific details on their activities and upcoming meetings, and those links can be found in the group descriptions.

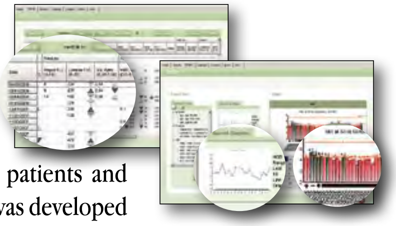
6. The IMF website also features an index of links to other online resources that range from financial help to advice for caregivers. This is available as the last item on the drop-down menu under "Living with Myeloma."

Myeloma Listserv

In addition to face-to-face local support groups, the IMF has created a cyber community of patients and caregivers in conjunction with the Association of Online Cancer Resources (ACOR). The listserv helps members communicate quickly and easily via e-mail. This incredibly supportive and informative "family" of 1700 participants can be found by clicking on the "Find Support" and then the "Online group" tab. It is easy to sign up for this list by following the directions on the ACOR link provided or you can go directly to http://listserv.myeloma.org.

While the listserv is a wonderful source of all sorts of information, we remind everyone, as always, to verify anything you have read with your physician and not to follow any suggestions or advice offered that you might receive without talking to your doctor.

Myeloma Manager™ Personal Care Assistant™



The Myeloma Manager™ Personal Care Assistant™ (MMPCA) is a software program designed specifically for patients and caregivers battling multiple myeloma. It was developed by the IMF to help patients and caregivers deal with the glut of information and constantly increasing complexity of myeloma treatment programs. The program runs on your computer and stores all personal data on your computer. None of your data is transmitted to anyone. Access to the Myeloma Manager is password-protected and the data is encrypted (scrambled) so that it cannot be accessed from outside of the Myeloma Manager.

At its core, the Myeloma Manager provides a tool to capture laboratory results and display and print tables and charts to show how those results change over time. Other features include automatic backup of your data each time you shut down the program, calendars, and graph features such as plotting multiple tests on one graph and time-scaled graphs. The software also includes real-time news feeds from the IMF website and a reference shelf, with links to useful publications and web pages.

CONTINUES ON PAGE 14

SANDRA ROME / MOBILITY & SAFETY — continued from page 12

- Adjust medications
- Recommend an exercise program that includes training in gait and balance, and stretching
- Assessment and modification of daily routines
- Safety of home environment

What precautions should be considered?

Patients need to be educated as to when they need to modify or abstain from their exercise regimen. For example, when they have a fever, patients should avoid group participation; if they have low platelets, a greater concern for strenuous activity and maintaining security of balance needs to be emphasized. Patients with balance problems may need to use a chair or wall for balance.

Patients must be cautioned to listen to their own bodies and abstain from activities that cause discomfort. Clinicians should recommend safe activity as part of the plan of care for every patient. On the one hand, a patient who had been active previously may not want to adhere to restrictions such as calling for help or using a walker. On the other, a sedentary individual may not understand the importance of exercise on bone health. Safe mobility and physical activity programs need to be tailored to the needs of each individual patient.

In any setting, the immediate need for patient safety (e.g. prevention of falling) should be the priority, and the patient's environment should be assessed and modified to maximize safe mobility (e.g. rug placement, handrails, and grab bars).

What about ongoing assessment and readjustment?

Cancer rehabilitation is seldom linear; myeloma survivors may have varied problems and symptoms over time, such as pain, neuropathies, etc. Ongoing patient assessment of risk of falling, physical activity, medications and their side-effects, laboratory and diagnostic tests, nutrition, and adequate management of other health issues is essential.

Maintaining a weekly exercise log helps patients track the frequency, intensity, and duration of the exercises they perform. Based on patients' documented exercise performance, programs could be altered to best accommodate their physical functioning (e.g. if the patient is feeling very fatigued the intensity of the exercises can be lowered accordingly).

Any closing comments?

Whatever is recommended or endorsed as exercise or activity needs to be carefully evaluated by the patient's healthcare providers. Patients and their family members should be instructed to tailor the patient's activities based on daily health status and communicate with the healthcare team regarding any questions or concerns they might have. **MT**

IMF HOTLINE — continued from page 13

At this time, the Myeloma Manager is available for Windows computers running XP, Vista, or Windows 7. It is not yet available for Macintosh, although it can be run on a "dual boot" Mac running Windows.

You can find the Myeloma Manager on the IMF website and download the program by either clicking on "Living with Myeloma" and then going to Myeloma Manager or going directly to the link http://manager.myeloma.org.

Personal Memory Stick

In an ideal world, every person would create, update, and carry around a small memory drive on which the store their health history, medications, and current year's laboratory data. Some institutions like the Kaiser system in California, which has fully implemented electronic medical records, make these small memory sticks and all laboratory results available to their patients. Storing and carrying your medical data on a memory stick is a safe and reliable way to share medical information when visiting different doctors who need to know your medical history, what medications and dosages you're taking, and what your current lab values are. If you already have all this information stored in your computer on your Myeloma Manager, it is a small step to transfer all the information on that program to a memory stick and carry it with you in your pocket, ready to share with your doctor.

Webinars

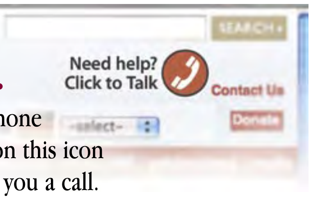
A "webinar" is a web-based seminar. The IMF's first webinar was a training session for people interested in learning about the Myeloma Manager. Look for more webinars from the IMF in the future. On a smaller scale, we have the capacity to hold virtual meetings between two people who are logged on to their computers. This is a tool that has come in handy for our webmaster, Abbie Rich, as she assists support groups in building their own websites.

Miscellaneous resources

The are a lot of other computer-based resources and services that you might find useful. For example, the CaringBridge website at www.CaringBridge.org allows patients or their caregivers to create a free personalized website to connect family and friends. These personalized websites are private and accessible 24 hours a day and can greatly ease the burden of keeping family and friends up-to-date with a patient's progress. For example, if someone is having a stem cell transplant or is hospitalized for some other reason, the author can provide health updates and even photos to share their story. Visitors to the CaringBridge webpages can leave messages of love and support in the guestbook for the patient and family.

Finally, we want to remind everyone that while computers are great, there is sometimes nothing better than a live human being at the end of the phone. So don't forget about the IMF Hotline, even if you just need help finding something on our website. **MT**

Need telephone help fast? Go to the web, click to talk.



Check out the new instant Hotline telephone access. Go to the IMF website and click on this icon in the upper right corner...and we'll give you a call.

PEOPLE HELPING PEOPLE

You are never alone in your battle against myeloma

Central Florida Multiple Myeloma Support Group Takes Action

To celebrate the 2010 Myeloma Awareness Month, the Central Florida Multiple Myeloma Support Group members decided to organize a series of events.

(left to right, standing) John Kearney, Robin Kearney, Roy Leader, Janet Leader, Kelly Bodiford, Lureen Keyser, Patricia Wells, Richard Wells, Charles Cain, Barbara Cain, Monica Chill, Arlene McCutcheon, Victor Alas, Ishwar Khamare, and Alpesh Patel. *(left to right, seated)* Ken Fabian Uma Khamare, Lois Sain, and Julius Sain.

On March 13, support group members Uma Khamare, Lureen Keyser, and Ken Fabian, along with SCC nursing student and volunteer, Arlene McCutcheon, set up a booth at the Winter Park Farmers Market to provide myeloma information and to promote awareness. Several patients and others whose lives have been touched by myeloma stopped at the booth to share their experiences and offer support. Many friendly people who had never heard of the disease came by to chat and pick up copies of IMF publications that were distributed at the booth. A local news crew interviewed Arlene McCutcheon and the segment appeared on the evening news. All in all, this was such a rewarding experience for the support group that a plan is in the works to repeat this event annually.

Lureen Keyser, Arlene McCutcheon, and Uma Khamare promoting myeloma awareness.

The following weekend, group members gathered at the Sanford Farmers Market to pass out IMF literature. Arlene and Kelly Bodiford volunteered for a special event with the Seminole State College Student Nurses Association, which hosted a National Bone Marrow Donor registry. Arlene and Kelly successfully registered 171 new prospective donors!

One week later, on March 27, support group members organized a Car Wash and Bake Sale. The weather was beautiful, and everyone who participated had a great time. Many friends and supporters showed up to wash cars, hold up signs, or sell a variety of delicious baked goods. The Car Wash and Bake Sale events were a huge success and a great way to close out the Central Florida Multiple Myeloma Support Group's activities for the 2010 Myeloma Awareness Month.

Editor's Note: The Central Florida Multiple Myeloma Support Group meets on the second Monday of each month from 6 p.m. to 8 p.m. in the Asbury Methodist Church in Maitland, FL. For more information, please contact Ken Fabian at kenfabian011107@yahoo.com or 407-928-2808, or Dick Wells at richard.wells@celebration.fl.us or 321-939-2594.

Primera Reunión del Grupo de Soporte de Mieloma – Los Angeles (en español)

The inaugural Los Angeles Spanish-language Myeloma Support Group Meeting was held on May 1, 2010. We believe that this is the first such group in the US. If you know a myeloma patient and/or family that would benefit from this group, please give them this article – or they can call Betty Arévalo at 818-487-7455, ext. 242 in Spanish. The next meeting of this group is scheduled to take place on Saturday, July 10, 2010 from 10am to Noon in the Conference Room of the IMF offices located at 12650 Riverside Drive, Suite 206, North Hollywood, California.

Myeloma Today tiene el placer de notificar a nuestros lectores de la lengua hispana que la IMF se celebró la reunión inaugural del Grupo de Soporte de Mieloma – Los Angeles en español el día primero de mayo del año en curso en el salón ejecutivo del hotel Sheraton Universal. Estuvieron presentes varias personas de la plantilla de la IMF para apoyar a miembros de dos familias hispanas afectadas por el mieloma múltiple. Aunque la comunidad hispana en los EE UU sufre del mieloma en cifras similares de incidencia a la población anglosajona, hasta la fecha, no haya existido ningún grupo de soporte de mieloma – realizado únicamente en español – en los Estados Unidos.

(Nota: ¡si estamos equivocados, les rogamos a nuestros amables lectores de actualizarnos, por favor!)

Los hispanos en los EE UU con mieloma y sus familias luchan contra las mismas dificultades y padecen de las mismas necesidades que los anglosajones. Las familias presentes el primero de mayo se levantaron varias preguntas sobre los tratamientos actuales y anteriores, los efectos secundarios de ellos, la posibilidad de conseguir una segunda opinión, los seguros médicos, la duración probable de la remisión y las opciones en el caso de recaída en el transcurso de la mañana. Suenan como los tópicos típicos de cualquier grupo de soporte, ¿verdad?

Con un vistazo rápido del equipo IMF presente en la foto adjunta, se nota que hay apoyo por parte de la IMF para lograr el éxito del grupo. Pero hay que señalar el trabajo determinado de una enfermera y miembro de la plantilla de la IMF, la Sra. Mirna (Betty) Arévalo, por la planeación

CONTINUES ON PAGE 16

PEOPLE HELPING PEOPLE — continued from page 15

Betty Arevalo, Mr. & Mrs. Lorenzo Garcia, Noemi Fuentes and her daughter Vanessa, Selma Plascencia, David Girard, Debbie Birns

de la reunión y sus esfuerzos de comunicación con las familias hispanas de el área metropolitana de Los Angeles. La IMF dice que la educación de solamente una persona en una reunión hace exitosa el evento – con un comienzo pequeño pero sincero y la divulgación de la existencia del grupo en la comunidad, se puede lograr educar a más que una sola persona, mucho más.

La siguiente reunión del Grupo de Soporte de Mieloma – Los Angeles en español se llevará a cabo el día sábado, 10 de julio, de las 12:00 a 2:00 p.m. en la Sala de Conferencias de las oficinas de la IMF. La dirección es: 12650 Riverside Drive, suite 206 (2do Piso) North Hollywood, California. Para más información, llame por favor a Betty Arévalo al 818-487-7455, extensión 242 o por email a: marevalo@myeloma.org.

2010 IMF Annual Support Group Leaders' Summit

This year's Support Group Leaders' Summit will commence at 1 p.m. on July 23rd at the beautiful Four Seasons Resort & Club, Dallas at Las Colinas, in Irving, TX. The retreat will conclude at noon on July 25th. Alan Kumomoto will once again serve as facilitator. We are confident that everyone who attends the summit will take away lots of helpful information to bring back to their group to make it even better! **MT**

ADVOCACY — continued from page 9

to administer. Yet most insurance plans would require us to pay so much more out-of-pocket, that the oral drug would not be affordable for the patient." Because of Tom's efforts, the state of New Hampshire is setting up a panel to explore the issue further and, hopefully, move forward with a bill next year. This is another prime example of how patients really are making a difference. Way to go, Tom!

The IMF Advocacy Team would also like to thank… Carol Klein, wife and caregiver for IMF board member Benson Klein for participating in the hearing in Maryland… Caethe Goetz, support group leader from California for giving testimony in the hearing on SB 961… and Dr. Marcelo Pakman, myeloma patient from Massachusetts, for submitting written testimony in support of SB 2271, An Act Relative to Oral Cancer Therapy. I think Dr. Pakman put it best, when he said, "An update of current laws is necessary to prevent inequalities to deny access to treatments that the medical and research communities struggle to bring to cancer patients."

IN WASHINGTON:
Support Group Leaders go to Capitol Hill

The IMF has helped facilitate meetings in Washington, DC with members of Congress for patients and support group members to voice issues of concern to the myeloma community. These issues include oral-drug reimbursement parity, funding for blood cancer research, and support for the 21st Century Cancer ALERT (Access to Life-Saving Early detection, Research and Treatment) Act (S. 717). **MT**

Jerry Walton, Support Group Leader, Southeastern VA, met with Representative Glenn Nye (D-VA-2) to talk about the issue of access to treatment, and more specifically, HR 2366-which was introduced by Representative Brian Higgins (D-NY-27), and would end the disparity in insurance coverage between oral and IV treatments. Jerry highlighted the fact that this is a critical piece of legislation for myeloma patients since there's a very good chance at some point in treatment, patients will have to use both therapies.

Jack Aiello (left), Support Group Leader, Bay Area, CA and **Marti Hill** (right), Support Group Leader, Tampa, FL focused their meetings primarily on funding for research. Since Marti's Representative, Bill Young, is a member of the House Appropriations Committee, but more importantly, Ranking Member of the Department of Defense (DoD) Appropriations Subcommittee she spoke with Representative Young's staff about the need for establishing a blood cancer research initiative in the Congressionally Directed Medical Research Program (CDMRP) at the DoD.

In Jack's meeting with the staff of Senator Barbara Boxer (D-CA), one of his requests was for the senator to become a cosponsor of the 21st Century Cancer ALERT, which was introduced by the late Senator Edward Kennedy (D-MA) and Senator Kay Bailey Hutchison (R-TX). This is an important piece of legislation that would require the Secretary of Health and Human Services to award grants for research on rare cancers and cancers with a low five-year survival rate, which would include myeloma. It also provides procedures for the National Cancer Institute to advance new technologies in cancer research, support tissue collection for cancer research, and clarifies issues governing clinical trials, including ethical and privacy standards.

The IMF would like to thank Jerry, Jack, and Marti for their time, diligence, and dedication to the myeloma community. Patients like you set such high standards for the rest of us!

Editor's Note: Please visit the IMF action center at advocacy.myeloma.org and become a part of the solution.

UPDATES FROM AROUND THE GLOBE

Australia: National Myeloma Day

The inaugural National Myeloma Day in Australia was held on May 19, 2010. Celebrated across Australia with 12 patient and family events and two myeloma education sessions for clinicians in general practice, the National Myeloma Day was an unqualified success. Organized by the Leukaemia Foundation Austalia, this special day aimed to achieve three things:

- increasing myeloma awareness among clinicians to support its diagnosis,
- promoting myeloma awareness among the general public, and
- celebrating achievements including early access to novel treatments in Australia

Patient groups and health professionals in Australia have recognized that diagnosing myeloma can be difficult due to a limited awareness of the condition and its general unspecific symptoms. Symptoms of the disease can be mistaken for other conditions, potentially delaying correct diagnosis and prompt treatment, and clinicians who encounter few myeloma patients during their career may have limited awareness of the condition. To promote myeloma awareness and improve the diagnosis of the disease, 40,000 copies of a new diagnostic tool developed specifically for use within the Australian health care system were circulated in two publications for medical professionals. The aim of the tool is to encourage clinicians to consider myeloma as a diagnosis when generalized symptoms occur, so that the patients can then be referred to a specialist treatment center. In addition, an awareness survey was also conducted of myeloma and its impact in the wider community.


Kaye Hose and Jasmine Latash of the Leukaemia Foundation Australia with Dr. Silvia Ling, a recipient of the 2008 IMF Brian D. Novis Research Grant


Dr. Mathew Wright during his presentation at the patient and family seminar in Perth Western Australia

In a significant step forward, in the last 12 months, myeloma patients in Australia were granted earlier access to various drugs used to treat myeloma through the Pharmaceutical Benefits Scheme (PBS) system. Early access to novel therapies can potentially improve the outcome for many myeloma patients in Australia.

Myeloma is the second most common blood cancer in Australia. It accounts for around 15% of all blood cancers in the country, and the incidence of myeloma is growing at the fastest rate of all the blood cancers. Around 1,500 new cases will be diagnosed in Australia this year. **MT**

Editor's Note: For more information, please contact Kaye Hose at myeloma@leukaemia.org.au. To locate a myeloma support group in Australia, please visit the IMF website and click on the "find support" tab.

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.

عربي ▪ Česky ▪ 中文 ▪ English
Français ▪ Deutsch ▪ Ελληνικά ▪ עברית
Italiano ▪ 日本語 ▪ 한국어 ▪ Polski
Português ▪ Русский ▪ Español ▪ Türkçe

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

MYELOMA TODAY IN CONVERSATION WITH ALLAN WEINSTEIN

"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.

Please share with our readers your history with myeloma.

I was diagnosed in 2002 as a result of a recurring infection. I felt fine but laboratory tests showed an elevated IgG level. Further testing found a bone lesion in my sacrum. My myeloma was (and remains) mostly asymptomatic. I was treated with three rounds of VAD, then three rounds of thalidomide plus dexamethasone. In July 2003 I had an autologous stem cell transplant. After that I was on a thalidomide maintenance program and, up until last year, my myeloma was stable, except for a vertebral fracture about two and a half years ago. A year ago, my IgG numbers started going up and my peripheral neuropathy was getting worse. At that point, I decided to switch to lenalidomide (Revlimid®) and we've been doing a gradual dose escalation, from 5 mg to 10 mg to 25 mg about a month ago. I have not attained the desired response, so I am moving on to other treatment options. But I still feel fine.

Allan Weinstein
Member, IMF Board of Directors

Please tell us about your history with the IMF.

After I was diagnosed, I started to research myeloma online and found the IMF. I attended the very next IMF Patient & Family Seminar and have continued attending IMF meetings, which offer excellent educational value. In 2009, I was a presenter at the Patient & Family Seminar in San Francisco – my session aimed to help patients and caregivers understand scientific literature. I'm looking forward to being a presenter again at seminars this year.

When the IMF launched its Bank On A Cure® research initiative, I was asked to join its management committee because of my background. I am retired, but had been a professor of Bioengineering and Orthopaedic Surgery and ran a research department at Tulane University, then I ran a company in the orthopaedics area and another company involved in spinal disc prostheses. Because of my background in bone replacement materials and devices, I have a thorough understanding of the bone aspect of myeloma.

When I was invited to join the IMF Board of Directors, I was happy to do so. Currently, I am Chairman of the Finance Committee and I also serve on the Executive Committee. The Finance Committee prepares the annual budget, provides financial oversight to the Board, and conducts a monthly review of the financial performance of the organization. The Executive Committee is charged with acting in place of the Board if an emergency decision needs to be made before the full Board can be convened – frankly, I don't even remember the last time this happened.

Why have you chosen to invest in the IMF and its programs?

There is a direct connection between my disease and my support for the organization that does so much for so many people in the myeloma community. I like the fact that the IMF is so patient-centric. Given that myeloma is as yet incurable, addressing the needs of the patients is extremely important. In some cancers, if you make it through the first five years, you know you'll probably be alright. That's not the case with myeloma. Nearly everyone relapses eventually. So there is a constant patient need for the work that the IMF does on that front. The Hotline, as well as the seminars and community workshops do a great job at providing information to the patient and caregiver, and this is extremely important.

Obviously, I'd like to see a cure for myeloma found, the "silver bullet," and I'm encouraged by the research being done in the field. The IMF has a big role in this and we have seen some very promising results in recent years. But the commitment to finding a cure is likely a long-term one. In the meantime, the IMF has a large number of doctors who are committed to the organization. Their collaborative work has produced many important publications and guidelines, as well as treatment advice that is very helpful to keeping the disease under control for as long as possible for those who are living with myeloma today.

In a way, finding financial support for research projects is easier than getting support for patient programs, because we all want to wake up tomorrow to the news that a cure for myeloma has been found. This is such a strong motivator, but unlikely to happen overnight. We must not only look into the future but also support today's patients. While we are searching for a cure, we can't ignore the needs of those who are being diagnosed and those who are living with the disease. The IMF strikes a good balance patient services and progressive research. This is a major strength of the organization.

I would love to see the day when the cure is found and the IMF is no longer needed. But most cancers don't have a "silver bullet" cure, and patients still need to be well-informed about their disease in order to make the best decisions in selecting among the available treatment options. It is because I believe in the work that the IMF is doing that I want to help the organization in every way I can, including making an annual contribution to support its programs and services. **MT**

In 2009, Mr. Weinstein was a presenter at the IMF Patient & Family Seminar in San Francisco

BOLT FROM THE BLUE

By Charty Bassett

The sore hip seemed like just another one of those aggravating aches and pains that come with "getting older." At age 60, newly retired and in seemingly good health, I had recently moved with my husband Brant from the East Coast to San Diego County where he was born and raised. The heavenly climate, a garden that churned out fruits and vegetables every month of the year, and endless opportunities for hiking, biking and swimming in gorgeous mountain, desert, and oceanside settings – how could one help but be healthy? Yet this sore hip, starting in November 2009, would not go away. Physical therapy didn't solve it, so in late February 2010 (two months ago as I write this) I went to an orthopedist, who ordered an MRI.


Charty Bassett and her husband Brant

That same afternoon the orthopedist called and informed me that the MRI showed bone lesions and "a destructive mass on the acetabulum." This is difficult information to process, even apart from the fact that I had never heard of an acetabulum. The phone call dropped my husband and me into what felt like another dimension – a time which has been to date the darkest and most difficult period of dealing with this disease. Something was radically wrong, clearly life-threatening, yet it had no name and we knew nothing specific. No label was given, no indication of what to expect. Whom should we tell about this? What to say to our kids? We were stricken – fearful, confused, and completely at a loss.

The following day we met with our primary physician, who gave us more details on the MRI results, and expressed the hope that what I had was multiple myeloma. This also took us aback; what kind of "hope" is this? (and what IS multiple myeloma, anyway?)

He told us that myeloma is a disease of the plasma, and that it is "eminently treatable" – a phrase which I seized upon as the one positive little straw floating in an ocean of dark unknowns.

This bleak period of uncertainty and fear, which at the time felt like an eternity, was in fact only two days. Our primary physician called us with the results of my blood test, which showed an IgA protein spike of 2400. He said he was 90% sure it was myeloma, but that he would set me up with an oncologist for an initial consultation and official diagnosis.

It is strange how liberating and empowering a bit of knowledge can be. Suddenly we had a name for what was happening. We could do research. We were going to confer with doctors who know these issues. We were no longer helpless and bewildered. We immediately began notifying our children, our family, our friends – a difficult and uncomfortable process. On the medical front, the pace picked up. Within days we met with our oncologist, who impressed us as extremely knowledgeable, accessible and pro-active. He scheduled a bone marrow aspiration and biopsy for that same day, with radiation to my hip and chemo treatment to begin the following week.

As I write this I am finishing cycle three of chemo, and have just begun consulting with doctors at the UC San Diego Moores Cancer Center regarding a possible stem cell transplant. I feel that we have the best of all worlds in medical care: an excellent oncologist/hematologist well versed in myeloma, in an office that is small, close to home and with friendly and highly competent nurses and office managers. Our oncologist communicates directly with doctors at UCSD, making my transition to a possible stem cell transplant smooth and seamless. In the meantime, we have had wonderful support from the IMF – the initial information packet which was promptly mailed to us gave us a wealth of material to get us started on this steep learning curve. The counsel I have gotten from the IMF Hotline has been outstanding – everything from handholding and encouragement to medical pointers and answers to very specific technical questions. We are planning to travel to the next IMF Patient & Family Seminar, and look forward to getting more involved in San Diego's active myeloma support group.

In addition to first-rate, multi-faceted medical support, we are blessed with an extraordinary circle of family and friends who have reached out to us with encouragement, help and love that have sustained us and kept our spirits up day by day – a true lifeline for me. This web of caring that has materialized around us is a profound reminder that we are not alone on this journey. Because we are recent transplants to Southern California and our family and friends are so widely scattered, we have found keeping a blog an ideal way of keeping everyone informed of our medical developments. (For us, the CaringBridge website www.caringbridge.org has proven to be a wonderful vehicle for communication.)

I never would have chosen to come down with myeloma. I realize that the road ahead will be difficult. Yet these last two months since my diagnosis have been a time of lessons, gifts and silver linings. The unwanted turn of events has caused me to cross paths with some remarkable people I otherwise would have never encountered. It has reminded me of the value and real power of love and friendship and of how much I cherish my family and friends. It has tied me even closer to my husband, who is alongside me at each step of the way. It has brought into focus just how fragile and how very precious life is, and has enabled me – even forced me – to live and relish one day at a time.

I am very much a novice on this strange myeloma journey. Yet I have every hope to in time become, like so many who have written on these pages, a long-term veteran who can impart expertise, wisdom and even hope to those who are suddenly facing the challenge of multiple myeloma. **MT**

IMF MEMBERS RAISE FUNDS TO BENEFIT MYELOMA COMMUNITY

By Suzanne Battaglia

In 2010, the IMF is proud to mark its 20-year anniversary of service to the myeloma community. Our strength is in our members – a network of people like you from across the country and around the globe. IMFers are raising money for myeloma research and educational programs that have an impact on the lives of patients and family members worldwide.

Being involved is very fulfilling and empowering. Join us in our search for a cure for myeloma. By organizing an event in your community, you are also raising public awareness and helping those whose lives have been touched by this disease. You want to do something in your community, but deciding on what to do and how to do it can be confusing. That's where we come in! The IMF's Fundraising program is here to help you every step of the way. We make it as easy as possible for you to be involved, whether or not you have any previous experience with such activities.

FUNdraising is fun and easy to do, and brings with it the satisfaction of knowing that YOU have made a difference in many lives. 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). I am here to chat with you about any ideas you might have. Be part of making miracles happen!

Here is a sampling of past and upcoming events…

McKean's triumph creates the largest single donation ever for the IMF

Grammy Award winner, Academy Award nominee, Michael McKean is a multi-talented actor, singer, writer and director who is associated with some of pop culture's most iconographic film and television shows of the last three decades. He has appeared in hundreds of movies and TV shows. He is best known for creating memorable characters such as "Lenny" in "Laverne & Shirley" and lead singer/guitarist/songwriter in the classic motion picture "This is Spinal Tap." Most recently, Michael performed on Broadway in Tracy Letts' new play "Superior Donuts."

The IMF waited with great anticipation as Michael entered the semi-final round of the **"Jeopardy!"** ***Million Dollar Celebrity Invitational Tournament*** on behalf of the Foundation. He had already won $50,000 for the IMF in the quarter-final round in October 2009. Michael began supporting the IMF when his good friend and fellow guitar player Lee Grayson was battling myeloma, and he has continued that support in Lee's memory.

Playing in the 2010 semi-finals brings $100,000 to the charities represented by the celebrity competitors who do not win the big MILLION DOLLAR PRIZE — the largest amount ever awarded on "Celebrity Jeopardy!"

Michael successfully competed in his semi-final round against actor Charles Shaughnessy (AMC's "Mad Men" and "The Nanny") and fashion designer Isaac Mizrahi on May 4, 2010. The semi-final win qualified him to play in the two-show final round on May 6 and 7.

"Because of the money at stake, the material for this year's Celebrity Invitational Tournament was more difficult than our normal celebrity fare," said "Jeopardy!" host Alex Trebek. "I thought all three finalists, Michael McKean, Jane Curtin and Cheech Marin, proved that they were up to this challenging material. Michael, in particular, was strong in all categories, and the IMF was lucky to have him represent them in the competition."

After the two-day final, Michael remained undefeated as the "smartest man in Hollywood" as he won the top prize on the **"Jeopardy!"** ***Million Dollar Celebrity Invitational Tournament***. This is the largest single donation the IMF has ever received, and this is the first time "Jeopardy!" has ever awarded one million dollars in a celebrity tournament.

"This is an amazing and overwhelming moment for the IMF," said Susie Novis, IMF president and co-founder, as she received a check for one million dollars from the producers of "Jeopardy!" The money is earmarked to create the McKean/Grayson Fund in honor of Michael McKean and in memory of his friend Lee Grayson. "The International Myeloma Foundation continues its tireless fight regardless of who's helping foot the bill," said Michael McKean. "I'm glad I was able to kick in my share."

Susie added, "A million dollars will do so much to help the myeloma community, by empowering patients and their families through education and offering them realistic hope for a brighter future through research. Michael McKean and our new friends at 'Jeopardy!' have helped us beyond words, and touched the lives of people around the world."

The IMF plans to use the exceptionally generous winnings to fund research to find a cure for myeloma, and to help patients and their families through education, because informed patients do better medically and emotionally. Susie concluded, "Thanks to Michael McKean and everyone at 'Jeopardy!' we have the resources to empower patients and help change the lives of people all over the world!"

Editor's Note: Video of the winning moment can be found at http://www.jeopardy.com/minisites/celebrityjeopardy/.

Fishing For A Cure

By JoAnne Gunther

Bill Gunther and Huey.

On April 10, 2010, I hosted Fishing For A Cure, an event organized to honor the memory of my husband. Bill's myeloma diagnosis in 2001 was devastating to us. We lived on an emotional roller coaster, with much uncertainty and great apprehension. Then we found the IMF and gained the knowledge we needed to feel more in control of our lives.

Throughout the eight years we fought Bill's disease together – including transplants, chemotherapy, and blood transfusions – the IMF was an important part of our lives. My background as an operating room nurse helped me process a lot of the new information about Bill's myeloma and we made the most of our situation, faced the challenges head on, and tried to remain upbeat.

It was a difficult journey for both of us. Despite the challenges, Bill would try to befriend and comfort other patients at the clinic of the University of Maryland Medical Center and try to put them at ease with his kind and compassionate nature. During Bill's last hospitalization, I promised him that I would turn the pain we experienced into something positive and meaningful.

After I lost my wonderful husband and soulmate of 43 years, it meant everything to me to fulfill my promise. Through the guidance of Dr. Robert Kyle of the Mayo Clinic, I contacted IMF's Suzanne Battaglia. She offered much encouragement and support as I organized my first fundraiser. My son, Bill Gunther III, was a huge help in overseeing the details of the event. I was also sustained and uplifted by the generosity not only of family and friends but even complete strangers. All the support I received gave me the courage to continue to move forward to fulfill my promise to Bill.

Bill Gunther III

The night of the event was awesome! Positive energy filled the room that held a capacity crowd of 235 guests. The nurses who cared for Bill throughout his illness showed up for the event, as did his oncologist Dr. Ashraf Badros, who moved everyone when he shared his memories of Bill. The event was called Fishing For A Cure because my husband was a commercial fisherman and fulfilled his passion for the outdoors by making a living harvesting seafood. But the event I hosted was actually a Bull Roast, a typical social function in the DelMarVa area where I live. We cooked beef over a pit and served it buffet-style along with a wide variety of other dishes. We had a DJ playing music all evening, and there was lots of dancing. We raffled off 35 gift baskets of donated items. In addition, we had big-ticket items, including a Ray Lewis jersey and a weekend getaway. We also gave away 72 door prizes. It was great fun for everyone – a truly memorable evening – and people continue to inquire if we will hold another event next year!

Dr. Badros and JoAnne Gunther

It's dinner time!

Bill lived a life of faith with hope that someday a cure for myeloma would be found, and I pray that the nearly $14,000 we raised will help other myeloma patients and family members see the day that this disease becomes curable. Holding this event has been an inspirational experience and a gigantic step in helping me to reconcile my grief. I now truly comprehend how in giving we receive. **MT**

Conga line

UPCOMING MEMBER EVENTS

August 22, 2010 **"On The Fritz" theatre party**
El Portal Theatre – North Hollywood, CA
Contact 866-811-4111 and use "Fritz" promotional code

October 3, 2010 **"Afternoon Tea"** Four Seasons Hotel – Washington, DC
For information and reservations, please contact Carol Klein
at carol60klein@verizon.net

October 10, 2010 **Coach Rob's Benefit Bash** – Apopka, FL
For information and reservations, please contact Rob Bradford
at rbradford@crothall.com

October 11, 2010 **Coach Rob's Charity Golf Tournament** – Apopka, FL
For information and reservations, please contact Rob Bradford
at rbradford@crothall.com

November 6, 2010 **"Misbehave for Myeloma"** Harry Caray's – Wrigleyville, IL
Contact Alexandra Zousmer at aezous@gmail.com

Turn Your Old Cell Phone Into
Cell Phones for a Cure

Put your old cell phone to good use!

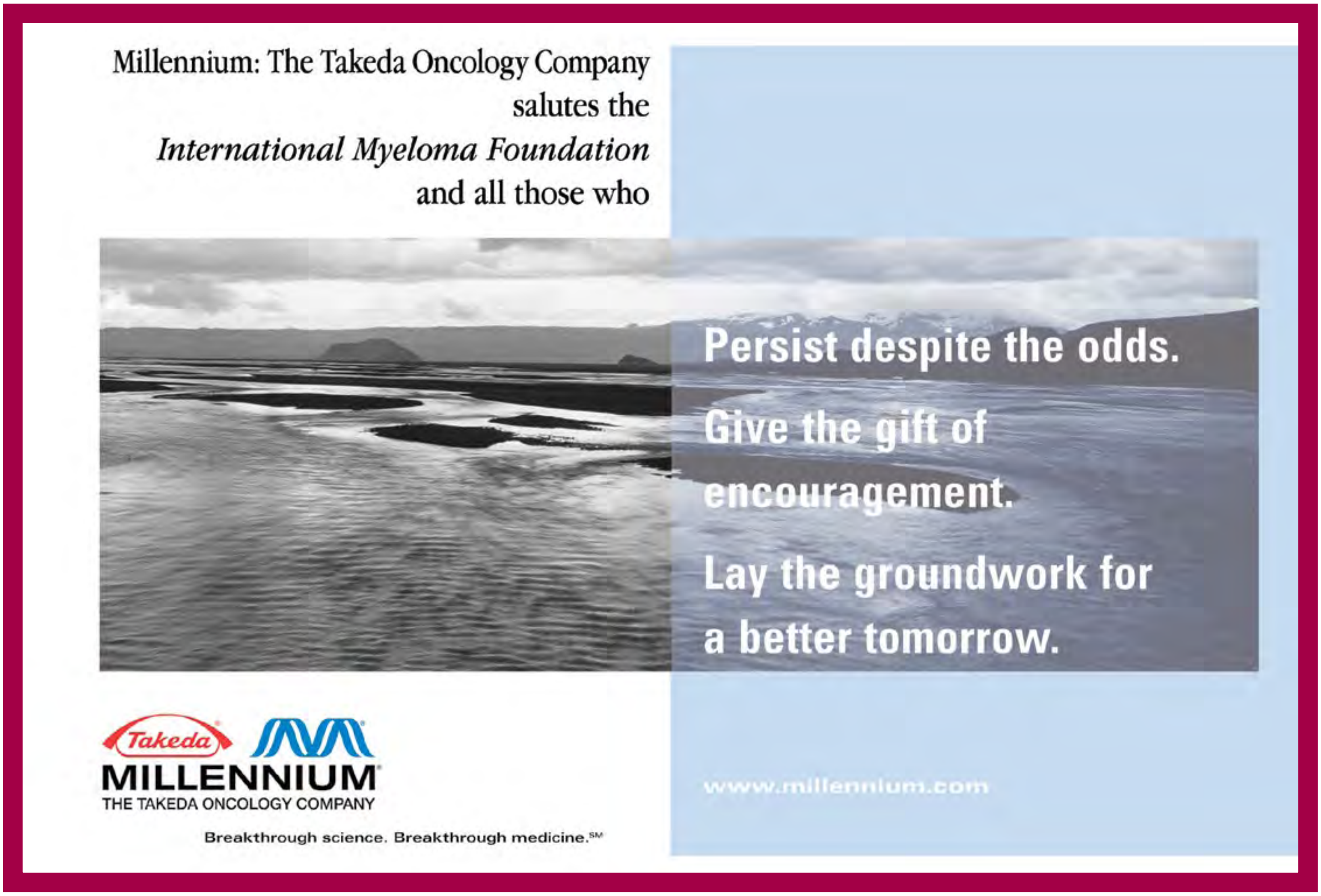
Donate your old cell phone and become part of finding the cure. The IMF has partnered with a cell phone recycling organization that makes a donation for every cell phone we turn in. Current cell phone models are worth up to $20 each. Many older models are worth $1 to $10.

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

The IMF thanks **Binding Site** *for becoming the first corporate sponsor of the IMF Cell Phones For A Cure program*



“Until There is a Cure… There is the IMF.”

International Myeloma Foundation
12650 Riverside Drive, Suite 206
North Hollywood, CA 91607-3421
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www.myeloma.org
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Dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

2010 IMF Calendar of Events

July 16-17	IMF Patient & Family Seminar – Cincinnati, OH
July 23-25	IMF Support Group Leaders’ Summit – Dallas, TX
Aug 6	IMF Regional Community Workshop – Honolulu, HI
Aug 13-14	IMF Patient & Family Seminar – Philadelphia, PA
Aug 21	IMF Regional Community Workshop – Salt Lake City, UT
Aug 27-28	IMF Patient & Family Seminar – Los Angeles, CA
Sept 5	International Community Workshop – Berlin, GERMANY
Sept 11-12	IMF Patient & Family Seminar – CZECH REPUBLIC
Sept 18	IMF Regional Community Workshop – Shreveport, LA
Sept 23-24	6th International Serum Free Light Symposium – Bath, UK
Sept 25	IMF Regional Community Workshop – Las Vegas, NV
Oct 15-16	MMHÖ/IMF Patient & Family Seminar – Vienna, AUSTRIA
Oct 16	IMF Regional Community Workshop – Raleigh/Durham, NC
Oct 18	IMF Patient & Family Seminar – Bologna, ITALY
Oct 23	IMF Regional Community Workshop – Overland Park, KS
Oct 23	Myeloma Canada Patient, Family, & Healthcare Professionals Conference – Richmond, BC, CANADA
Nov *TBD*	IMF Patient & Family Seminar – Barcelona, SPAIN
Nov 6	Southwest Symposium – Tempe, AZ
Nov 13	4th Annual Comedy Celebration – Los Angeles, CA
Nov 24	International Community Workshop – Heidelberg, GERMANY
Dec 4-6	American Society of Hematology (ASH) – Orlando, FL
Dec 18	IMF Patient & Family Seminar – Würzburg, GERMANY

Additional 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.

Thank you for your continued support of the IMF.