



MYELOMA TODAY

A PUBLICATION OF THE INTERNATIONAL MYELOMA FOUNDATION

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Dear Reader,

Over the years, I've often heard people say, "You know, as odd as it sounds, being diagnosed with myeloma was one of the best things that's happened to me." Those of us who live in myeloma-land know only too well what a strange place it is – horrible and wonderful at the same time.

The horrible part is myeloma's impact on both the patient and the entire family. The wonderful part is focusing on what's really important, heightening how sweet life can be, taking time to smell the roses. And reaching out to help others. I have made many wonderful friends in myeloma-land, each special in their own way. Two people we lost recently had a huge impact on me.

Mary Lou Porter was a true lady – a soft-spoken and gentle person who extended a helping hand to myeloma patients, their families, and the IMF. She volunteered at the Foundation's headquarters and was an active member of the L.A.-based Circle of Friends, helping to raise thousands of dollars for myeloma research. When she knew that she was losing her battle with myeloma, Mary Lou and her husband Clyde established a Charitable Remainder Trust to ensure continued support of the needs of the myeloma community. The IMF is privileged to administer the Trust on Mary Lou's behalf.

I first saw Bubs Tamlyn at the March in Washington, DC in 1998, holding a sign that read "Bone Marrow Cancer – What About US?" Bubs was a passionate advocate, lobbying hard to increase the level of federal funding for myeloma research. He was also committed to helping others through the support group he founded in Ft. Myers, Florida. Bubs and his daughter Scheri were a dynamic team, attending IMF seminars and raising money to support myeloma research. Sadly, we lost Bubs this past January. In his memory, Scheri continues her commitment to help the IMF help others.

Mary Lou and Bubs made a difference for our myeloma family. Their memory, and the support and encouragement of other patients and caregivers, inspires and reaffirms my dedication to the IMF and the work we do.

Susie Novis

This issue of Myeloma Today is dedicated to the memory of **Mary Lou Porter and Howard "Bubs" Tamlyn**

THE IMF PRESENTS: "MYELOMA MATRIX"

The International Myeloma Foundation is proud to introduce the Myeloma Matrix, a reference tool for use by both patients and physicians. The chart tracks drugs of interest to the multiple myeloma community from Phase I clinical trials through FDA approval. The Myeloma Matrix will track drugs that are:

- "Corporate sponsored" – developed by a drug company, usually as part of a plan to obtain FDA approval to market the drug to myeloma patients.
- "Investigator initiated" – developed by investigator(s) in collaboration with pharmaceutical companies to further evaluate a drug which has already shown some evidence of promise for use in myeloma.
- "NCI sponsored" – for trials through cooperative groups such as SWOG and ECOG.

For in-depth information about drugs being tracked by the Myeloma Matrix, we invite our members to contact the toll-free IMF Hotline at (800) 452-2873. A web-based version of the Myeloma Matrix is in development – please visit www.myeloma.org and check for a launch announcement. 🌸

Phase	Product Name	Company	Indication
Recently FDA Approved	Zometa®	Novartis	For treatment of bone metastases
	NESP (ARANESP)	Amgen	For persistent anemia
Phase III	Thalidomid® NOT YET APPROVED FOR MYELOMA	Celgene	Has orphan drug status, available through Celgene's S.T.E.P.S.™ program
	DOXIL®	Ortho Biotech	Used as VDD combination in which Doxil® substitutes for Adriamycin in VAD
	Genesense™	Genla	Combined with Dexamethasone for relapse
Phase II	Skeletal Targeted Radiotherapy (STR)	NeoRx	To achieve better CR with stem cell
	Beta LT™	Lifetime Pharmaceuticals	Biologic therapy for relapse
	Gallium maltolate	Titan Pharmaceuticals	Treatment for bone pain
	PS-341 (formerly known as LDP 341)	Millennium Pharmaceuticals	Refractory and relapsed myeloma
	Myeloma-derived idiotypic antigen vaccine	National Cancer Institute	As immune maintenance therapy
	Mylovenge™ (APC 8020)	Dendreon	As active immune therapy
	Neovastat® AE-941	Aeterna Laboratories	Cartilage extract: anti-angiogenic for relapse
	O-6-benzylguanine	National Cancer Institute Pacific Pharmaceuticals	Novel chemotherapy for relapse
	Panzem (2ME2)	EntreMed	Anti-angiogenic agent for relapse
	Thalidomid®	National Cancer Institute Celgene	Biologic agent: multiple studies for relapse & front line
	Trisenox™ Arsenic trioxide injection	Cell Therapeutics	Apoptosis inducer for relapse
	Trisenox™ Arsenic trioxide injection	Cell Therapeutics	Relapsed/refractory multiple myeloma in combination with vitamin C
	Phase I	BrevaRex® MAb	Alta Rex
CC- 5013 (formerly CDC-501)		Celgene	Thalidomide analog in early testing

The IMF is dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure.

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The information presented in *Myeloma Today* is not intended to take the place of medical care or the advice of a physician. Your doctor should always be consulted regarding diagnosis and treatment.

2002 CALENDAR OF EVENTS

March 8-9, 2002	IMF Patient & Family Seminar	Atlanta, GA
March 12, 2002	Cancer Care Teleconference: New Approaches to Managing Pain Breakthrough Pain & the Discomforts of Cancer	*see below
March 15, 2002	March Madness Basketball Tournament	Sharon, MA
March 16, 2002	Fashions 4 A Cure	Williamsville, NY
March 20, 2002	Cancer Care Teleconference: Understanding Anemia & Fatigue, Part III	*see below
April 14, 2002	Second Annual Myeloma March Rocky Neck State Park Contact: Christine Cardillo (860) 204-9810	Niantic, CT
April 18-21, 2002	ONS Annual Meeting (Oncology Nursing Society)	Washington, D.C.
April 24, 2002	Cancer Care Teleconference: Understanding Anemia & Fatigue, Part IV	*see below
April 27-28, 2002	IMF Patient & Family Seminar	Vienna, AUSTRIA
April 30 - May 1, 2002	Advocacy Day	Washington, D.C.
May 11-15, 2002	IMF Scientific Advisory Board Retreat	St. John, USVI
May 18, 2002	3 rd Annual JC Invitational Golf Tournament	St. Cloud, MN
May 18-21, 2002	ASCO Annual Meeting (American Society of Clinical Oncology)	Orlando, FL
June 3-4, 2002	OVAC Advocacy Day	Washington, D.C.
June 7-8, 2002	IMF Patient & Family Seminar	Washington, D.C.
June 24, 2002	International Myeloma Golf Challenge 2002	Stamford, CT
August 10, 2002	Challenging Cases	New York, NY
September 13-15, 2002	IMF Patient & Family Seminar	Sydney, AUSTRALIA
October 5, 2002	IMF Ribbon of Hope Annual Gala	Washington, D.C.
October 10, 2002	IMF Support Group Leaders Retreat	Durham, NC
November 8-9, 2002	IMF Patient & Family Seminar	Seattle, WA
December 6-10, 2002	ASH Annual Meeting (American Society of Hematology)	Philadelphia, PA

For more information about IMF events, please check the IMF website at www.myeloma.org or contact the International Myeloma Foundation at (800) 452-CURE.

*To register for a Cancer Care teleconference, please call (800) 813-4673 at least 2 weeks in advance or check the CancerCare website at www.cancercare.org.

ASK THE EXPERTS: Infection in Multiple Myeloma



Brian G.M. Durie, M.D.
Cedars Sinai Comprehensive Cancer Center
Los Angeles, California

By Brian G.M. Durie, M.D.

Infections are both common complications in myeloma patients as well as potential trigger factors for the disease:

- Infections can precede the onset of active myeloma. The most commonly recognized infections are **shingles** (varicella zoster) and **pneumonia**, which prior to the last two decades was typically pneumococcal in type. The compromised immunity associated with the evolution of myeloma predisposes to the infections, which in recent years have become more diverse. **Viral infections** now include: herpes of different types, mononucleosis (EBV: Epstein Barr Virus), hepatitis (A,B,C,D,E...), cytomegalovirus (CMV), human papilloma virus (HPV), and many others. Non-viral infections include the whole range of **bacteria**, such as streptococcus ("strep"), staphylococcus ("staph"), E. Coli and the like, plus so called opportunistic infections such as **fungal infection**, **tuberculosis**, **pneumocystis**, and others.

- **The range of potential infections** is truly mind boggling and ever increasing.

- **As soon as treatment starts**, the immune suppression (e.g., with steroids, such as prednisone and dexamethasone) and reduction in white blood cell count (particularly neutrophils) increase the risks. The first three months of treatment carry the greatest risk of infection complications. The main sites of infection are the respiratory system (e.g., pneumonia/bronchitis or sinusitis), urinary infections (bladder or kidneys), and skin.

- The infections that have been linked to myeloma as trigger or causative factors include herpes virus 8 (HHV8), simian virus 40 (SV40), and a cytomegalovirus (CMV) variant called

STATUS	% CHANCE OF INFECTION
MGUS	no increased risk
Active myeloma at diagnosis	5-15%
During first three months of treatment	30-40%
Dropping to a remission level of:	5-10%
Increasing progressively with recurrent disease to:	40-60% or higher over time*

* During induction and relapse therapy, the chance and severity of infection depend upon several factors including aggressiveness of myeloma, the type of treatment, the presence of an indwelling catheter, and patient age.

stealth adapted CMV. The role of these viruses is currently unclear. These viruses are also impacted by treatment and may lead to special complications, particularly neurological, since these viruses grow in the nerve tissue.

What can be done about this constellation of potential infections? The following strategies are frequently recommended:

- Be alert and aware about the susceptibility to infection. **Since the risk varies considerably from patient to patient** (from very low to very high risk), **it is very important to discuss with your doctor the level of risk in your case.** Maybe minimal or no major precautions are required or perhaps quite the contrary.

- **Caution** is required. See Table 2.
- **Being proactive** is the way to avoid infections and reduce the risks of serious complications.
- **Discuss with your doctor** if a small face mask and/or a portable air purifier are indicated at times of high risk.
- Although it is important to avoid sources of infection in day-to-day life (children with infections; crowded places; eating sushi or shellfish), most infections originate internally because of the depressed immune system associated with active myeloma and treatment. The goal is therefore to achieve remission and keep ongoing maintenance treatments as safe and simple as possible. 🐾

LOW RISK	POSSIBLE ACTIONS
<ul style="list-style-type: none"> • No history of infections • No active myeloma treatment • Normal blood count values • No unusual risks of infection exposure 	<ul style="list-style-type: none"> • Consider flu vaccination • Promptly evaluate all possible infections • Carry a course of broad spectrum antibiotics when you travel (e.g. Cipro[®], Bactrim^{®*})
HIGH RISK	POSSIBLE ACTIONS
<ul style="list-style-type: none"> • One or more infections in the past • Low white cell count • Ongoing treatment for myeloma, especially high dose therapy • Hickman catheter in place • Slow recovery and/or complications with prior infections 	<ul style="list-style-type: none"> • Strongly consider preventative or prophylactic antibiotics to include possibly: virus (e.g. Zovirax[®]), bacteria (e.g. Cipro[®] or Biaxin[®]), fungal (e.g. Diflucan[®]), pneumocystis (e.g. Bactrim^{®*}) • Consider reducing or stopping steroids such as Prednisone or Dexamethasone. • Use Neupogen[®] to improve the white blood cell count if it is low • Remove any catheter or any "foreign object" if it is a problem. • Consider high dose intravenous gamma-globulin (IVIG) as a preventative.**

* These antibiotics are just examples: others are available.
** Only used in very high risk settings.

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BOOK REVIEW: "Living Proof"

By Brian G.M. Durie, M.D.

"LIVING PROOF"

By Michael Gearin-Tosh
Simon & Schuster, Inc. U.K. Ltd.
ISBN 07432-0677-0

An inspiring new book written by a myeloma patient has just been published in Britain. Michael Gearin-Tosh, a teacher of Theatre Arts at Oxford University, was diagnosed with IgG multiple myeloma in June

1994 at age 54 years. "This medical mutiny... is a story which is both powerful and thought provoking." Now, almost 8 years after diagnosis,

Michael is doing well overall having taken no chemotherapy treatment for his disease. This medical mutiny, as he calls it, is a story which is both powerful and thought-provoking. The mainstay of his treatment has been the Gerson Therapy*, a nutritional approach with some modifications and additions.

"Living Proof" is a testament to the fact that "here he is," having been told, as he says in the book's opening, that he would be "a goner."

With encouragement and support from friends, plus consultations around the world, Gearin-Tosh analyzed the medical advice that he received. His conclusions are very sobering for the medical profession. Do we really know what we are doing? Did he really have active myeloma which required transplantation and/or chemotherapy recommended by top consultants? If he did not have active myeloma, why the confusion? And what about other patients who may not be as insightful and persistent in their search for the true answers to the many concerns and questions?

His case history summarizes early stage disease, classified as Stage IA: the IgG monoclonal protein has ranged from 3.1 Gms% to a high of 4.53 Gms%, most recently being 3.54 Gms%. These numbers are right at the cutoff between MGUS and myeloma. The bone marrow tests have never shown a high percentage of plasma cells: ranging from 5-6% to a high of 22%. Anemia has been the persistent problem, supporting the diagnosis of myeloma versus MGUS with hemoglobin levels in the 9-10 Gms% range. Bone x-rays and bone density testing have indicated osteopenia (osteoporosis), but no discrete myeloma lesions. Serum 2 microglobulin and CRP levels have been low.

Conclusion: the findings are consistent with a low level non-aggressive type of myeloma, which can have a variable, but sometimes very long, natural history including survival of at least 8 years.

Is this type of longer survival predictable? Unfortunately, not in a definitive fashion for an individual patient. However, as

mentioned in one of the later chapters, some tests such as a labeling index can predict disease activity. Initial emphasis was on finding "the cure," which Gearin-Tosh finally discovered was like locating the end of a rainbow – maybe close, but not yet accessible. Bravely, he set recommended options aside and followed his intuition to the Gerson Therapy, additional orthomolecular oncology and enzymes, plus acupuncture and "mind over matter" visualization and breathing exercises. It is extreme-

ly important to note two additional points. Firstly, he

did take Clodronate initially, followed more recently by Ibandronate (both bisphosphonates which can help bones and myeloma overall). Secondly, he has taken a variety of "anti-inflammatory" medications which can suppress myeloma activity. In animal model systems, anti-inflammatory medications can be sufficient to suppress myeloma growth. Is Gearin-Tosh doing well because of these treatments? Maybe, maybe not. It is impossible to dissect the role of the various interventions, including the Gerson Therapy. Certainly his indomitable spirit and positive commitment to recovery are key elements.

Of interest, Gearin-Tosh used Vitamin C at very high doses and has done well with it. This is not normally recommended in myeloma patients in part because of kidney toxicity.

What does all this say about the medical profession? We need to do a better job delineating and communicating areas of medical uncertainty, especially when aggressive therapy is involved. With low-level disease, a non-aggressive approach can be perfectly acceptable. On the downside of accepting milder treatment is the acknowledgment of "not going for the cure."

Gearin-Tosh highlights the conflicts and emotions dealing with physicians, friends, and literary insights as he selects his course to become "Living Proof" of his own successful choices. It takes a rare personal confidence to fully trust one's instincts. As physicians, we need to support such individual decisions provided they are not "medically crazy." Was Michael crazy to take his life in his own hands? Perhaps some physicians thought so, but the proof is always in the end result. Thank you, Michael, for writing your story and so eloquently discussing your life and the impact of decisions and recommendations that physicians make. You are the "Living Proof" that we don't have all the answers. 🍷

* For more information about the Gerson Therapy, visit www.gerson.org or call (888) 4-GERSON.

IMFER PROFILE: Lee Grayson



Lee Grayson

Many of you may already know the warmhearted Lee Grayson, a talented musician who performed at the IMF *Ribbon of Hope – Making a World of Difference* gala in New York in October 2000. In addition to donating his musical talent to the IMF, Lee also gives generously of his time – spending hours on the phone with newly diagnosed patients, sharing his story and offering encouragement. Diagnosed with myeloma eight years ago, Lee pursued alternative therapies before and during his conventional myeloma treatments. He has once again been generous in sharing his experiences with us.

Myeloma Today: Which alternative treatment did you try first, and why?

Lee Grayson: I was diagnosed with early stage myeloma by Dr. Phil Greipp at the Mayo clinic. He told me that, at the time, my immune system was controlling the disease better than anything modern medicine could offer. Dr. Greipp recommended to hold off on treatment and revisit the issue in 3 months. I expressed an interest in looking at some alternative therapies, and he did not discourage me. He did warn me to avoid high-dose vitamin C, since it seems to encourage myeloma cells to grow. He had a great approach and attitude and I appreciated getting some guidelines from him. I made contact with another myeloma patient who recommended I look into the Gerson Therapy; a diet that was supposed to boost the immune system seemed logical to me. I began by consulting a biochemist who was working with an oncologist on a nutritional program for cancer patients. It was similar to the Gerson program and included lots of carrot, beet, and celery juice along with herbs, and the addition of other vegetables over time.

MT: What was your experience with the Gerson diet?

LG: My myeloma protein levels remained the same, so it's hard to say. I don't know if it helped, but it didn't seem to hurt.

MT: What was your next step?

LG: I had heard about a vaccine therapy in Tijuana from a woman with myeloma who felt that the vaccine helped her. I flew to Tijuana, and while there I visited the Gerson Clinic. Since I was already following a similar diet, and the Gerson people had no published or anecdotal data in their research department on the benefits of the Gerson program for myeloma patients, I didn't follow up with Gerson. A consultant there told me that with myeloma, it's as if you're in a research study with only one patient enrolled: you. Instead, I chose to try the vaccine.

MT: What was your response to the vaccine?

LG: The vaccine didn't cure the myeloma, but didn't seem to make it worse, either. I did get big, red, irritated patches on my thigh where the vaccine was injected. I continued to drink the organic vegetable juice with the herbal additives, such as red clover tops and echinacea, and I continued to feel fine and my myeloma level remained stable. I stopped the vaccine after 2 to 3 months in Tijuana. During that time I was also keeping in touch with Dr. Greipp and seeing a hematologist-oncologist weekly at the Scripps Clinic in La Jolla, California.

MT: What was your next step?

LG: I had read about Dr. Nicholas Gonzalez's treatment for pancreatic and other cancers. What he said made sense to me and I went to see him in New York. I was at first rejected by Dr. Gonzalez because he didn't think I would be a compliant enough patient. Through the intervention of a friend, he later accepted me for his Protocol.

MT: What did the Gonzalez Protocol involve? How does it differ from the Gerson Therapy?

LG: It is similar to the Gerson program – juicing and coffee enemas – but it includes high doses of pancreatic enzymes four times a day and lots of pills as well. Dr. Gonzalez adjusted his dietary program to suit my needs as a myeloma patient. The diet he designed to balance my body chemistry included almost daily meat and potatoes and required that I eat a piece of cheesecake once a week! There were also many dietary supplements which had to be ordered through the doctor's office.

MT: Were you continuing your regular

follow-up with Dr. Greipp at Mayo as well?

LG: Yes. I was being monitored by Dr. Greipp, and he continued to check my IgG levels every 3 months. My first series of blood tests after I started working with Dr. Gonzales showed that my IgG level dipped a bit, so I was encouraged. Three months later, I went to Mayo for a check-up, and my IgG level had gone way up. I also had a plasmacytoma in my chest. At that point, I discontinued working with Dr. Gonzales and began conventional treatment with dexamethasone and Aredia. This was two and a half years after I was diagnosed with myeloma!

MT: Do you think that the alternative therapies had any effect on prolonging the time that your myeloma remained in abeyance?

LG: It's hard to say. While they certainly didn't cure the myeloma, I felt fine and did not require treatment for two and a half years. And good nutrition makes sense to me.

MT: So was that the end of the line for complementary medicine for you?

LG: No. I had heard about Dr. Nieper's work in Germany through a myeloma patient in Florida. Dr. Nieper's program was a combination of the juices I had been taking plus the injection of a substance that is supposed to boost the effectiveness of the thymus gland, which is part of the immune system. The medication was expensive, had to be self-injected, and had to be shipped from Germany. After a short period, I had to stop – it was just too expensive and too difficult to import the drug. In any case, my disease continued to progress. My doctor said my disease was "primary refractory" (non-responsive to chemo) and started me on thalidomide which helped me achieve a complete remission within months. As a result, I enjoyed a good quality of life for a period of 2 years. When I stopped responding to thalidomide and my condition worsened, I underwent a stem cell transplant. Today, once again I feel strong and vibrant and, short of monthly infusions of Zometa, do not require treatment.

MT: What would be your advice to other myeloma patients?

LG: If you have the time, the resources, and the inclination, don't be afraid to look at alternatives as long as you are also being followed by a multiple myeloma expert. Ask to speak with other myeloma patients who have successfully used the therapy you are considering. Always run things by your doctor before doing anything, and proceed with caution. 🍀

DALLAS DALLAS IMF PATIENT & FAMILY SEMINAR REPORT



IMFer Tom Ferguson with Chairman of the Board Dr. Brian Durie

The first 2002 IMF Patient & Family Seminar took place in Dallas, Texas on January 8-9th. Faculty speakers from around the country shared their expertise and knowledge on a variety of myeloma topics. Key data on advances in the field of myeloma, presented at the 43rd American Society of Hematology (ASH) meeting, were shared with the 200 IMF members in attendance. (ASH abstracts are available upon request from the IMF).

The seminar commenced with a popular presentation by Dr. Brian Durie (Cedars Sinai Comprehensive Cancer Center)



IMFers Benetta and Bob Tindall with IMF Director Michael Katz

on biology and staging of myeloma and how it relates to treatment options. As always, this presentation was a big hit with the many newly diagnosed myeloma patients in the audience.

Dr. Gregory Mundy (University of Texas) lectured on bone disease, addressing the issue of hypercalcemia associated with increased bone resorption and, frequently, with impairment of renal function. Dr. Mundy's opinion is that the best approach is to effectively treat the myeloma itself, and to treat the hypercalcemia with drugs that inhibit bone resorption combined with the careful and judicious use of intravenous fluids. He also spoke of the efficacy of bisphosphonates in the treatment of hypercalcemia as well as in the treatment of myeloma bone disease in patients who do not have hypercalcemia.

Dr. Philip Greipp (Mayo Clinic) discussed standard therapy for myeloma, followed by Dr. Jayesh Mehta (Northwestern University Medical School and The Robert H. Lurie Comprehensive Cancer Center), who reviewed the latest advances with high dose therapy and the role of transplantation. Dr. Durie followed with a presentation on novel therapies, focusing on the latest about IMiDs & PS-34 as revealed at ASH.

As a break from the expert presentations, a patient panel featuring IMFers Helen Shifrin, Yelak Biru, and Michael Katz, offered helpful tips to other patients regarding the challenges of living with myeloma.

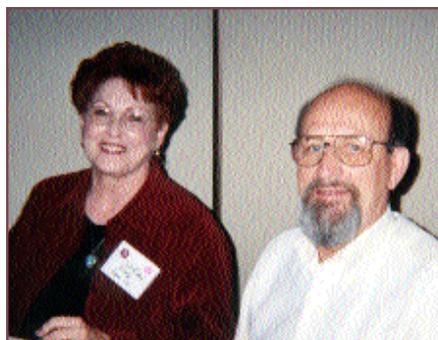


IMF President Susie Novis with IMFers Lucy and Peter Tischler

Following the patient panel, the expert presentations resumed with a talk by Dr. Mehta on the latest clinical trial data about the role of thalidomide in myeloma, as well as proper dosing and combination therapy of thalidomide and dexamethasone.

The final presentation by Dr. Marvin Stone (Baylor-Charles A. Sammons Cancer Center) focused on supportive care – initial pain assessment, common symptoms of myeloma, and the role of bisphosphonate therapy and anti-agent 6.

The patients and caregivers eagerly participated in the stimulating discussions that followed each presentation. The plethora of questions raised and answers received make clear the need for such educational programs. IMF Patient & Family Seminars are designed to allow for a comprehensive



IMFers Shirley and John Fish



Susie Novis with IMFer Carolyn Wickwire

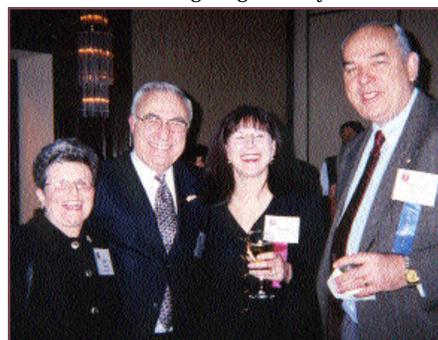
overview of various topics and an interactive exchange between the faculty panel and the patient community. The IMF is committed to serving our members through our seminars, hotline, published materials, and website.

The broad range of services the IMF provides are made possible by the support of our members. At the Dallas seminar, the IMF was honored to recognize those special members who have gone above and



IMFers Marcia and Jerry Sawyer

beyond the call of duty on behalf of the IMF and the myeloma community. IMF President Susie Novis made presentations to several members who have joined the IMF Donor Recognition Program. We are grateful for their support and the contributions of time, money and valued services. Together, we will continue our fight against myeloma. 🍷



IMFers Judy and George Goldman with Susie Novis and Dr. Phil Greipp

MYELOMA TOP 10

What did the experts find most promising in myeloma research for 2001?

The IMF polled the members of its Scientific Advisory Board about what they considered to be the "Top 10" steps forward in the field of myeloma. Although the rankings varied between Advisors and not all gave 10 items, the same answers came from around the globe.

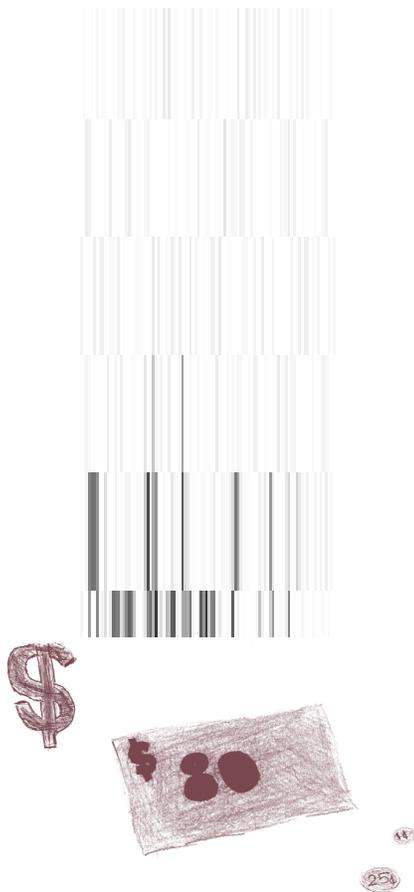
1. **PS 341 – Promising activity as new treatment for myeloma.**
2. **Mini-Allo transplantation – shows early benefit although complications still high.**

Better understanding of bone disease mechanisms accounted for the next 3 items:

- 3, 4, 5. **MIP-1 α , OPG (Osteoprotegerin), and Rank.Fc identified as important mediators of myeloma bone disease and new targets for treatment.**
6. **Progress with IMiD trials – CC5013 (thalidomide analog).**
7. **The use of genomics and proteomics to classify myeloma and understand growth pathways.**
8. **Increased myeloma awareness – Geraldine Ferraro's diagnosis is top news story.**
9. **Anti-angiogenesis as a possible treatment approach for myeloma – however direct anti-VEGF results disappointing thus far.**
10. **Double Auto Transplant still shows no clear benefit versus Single Auto Transplant. Even role of Single Auto Transplant becoming more controversial (ASH 2001).**

To learn more about these issues or other breaking news and features, stay tuned to *Myeloma Today*, check out the IMF web-based weekly newsletter *The Myeloma Minute*, or call the toll-free IMF Hotline at (800) 452-2873. 🐾

BENSON KLEIN'S TROOPERS ANSWER THE CALL



HONOR ROLL UPDATE

The International Myeloma Foundation would like to acknowledge the following contributors to the Foundation's programs and projects for monetary gifts made between November 1, 2000 and October 31, 2001:

Over \$9,999

Estate of Marjorie Rutherford
Estate of Harry C. Turner

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Bob & Benetta Tindall

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Donald & Patricia Yost

The IMF is dedicated to improving the quality of life of myeloma patients while working toward prevention and a cure. The support of our members makes possible the IMF's research, education, and advocacy activities. Thank you. 🐾

WE SALUTE YOU

The IMF applauds the efforts of the following members who have recently started a multiple myeloma support group in their area:

- **Cherry Hill, NJ**
Helen Rose (856) 414-9149
- **Denver, CO**
Diane Seccombe (303) 722-2289
shred2@mindspring.com
- **Portland, OR***
Kathy Shaw (503) 245-9866
shawk@or.leukemia-lymphoma.org
*This is a myeloma-specific support group started by the Oregon and SW Washington Chapter of the LLS.
- **Panama City Beach, FL**
Sheila Hall (850) 236-5957
rhall41563@aol.com

For a complete list of multiple myeloma support groups across the U.S. and abroad, please visit www.myeloma.org and click on the "People Helping People" tab.

If you would like help with setting up a new multiple myeloma support group in your area, please contact the IMF at (800) 452-CURE. 🐾

Dear IMF,

I am writing to give you an update on the project titled "DNA Double Strand Break Repair By Non-Homologous End Joining (NHEJ) In Multiple Myeloma," which had been awarded the 2001 IMF Junior Research Grant for the year 2000 in memory of Sharon Newman.

In February of 2001, I took a position at Loyola University's Stricht School of Medicine as an Assistant Professor in the division of Hematology and Oncology, section of Bone Marrow Transplantation. The project was submitted to and approved by the Cancer Center protocol review committee and then submitted to the Loyola University's Institutional Review Board, which gave the final approval.

I have been extremely fortunate in getting excellent mentorship from Dr. Andrew Vaughan, who is an expert in the field of apoptosis and DNA repair by non-homologous end joining. Dr. Vaughan has a specific interest in the mechanisms of translocation formation, concentrating on elements of the apoptotic and NHEJ pathways. Under his guidance, we have made some novel observations in multiple myeloma cell lines which we are eager to carry through and study in primary myeloma patient samples.

Hopefully, this will give us new insights into the management of multiple myeloma.

PROJECT'S AIMS

1. Study the expression of NHEJ proteins in MM cell lines.
2. Evaluate NHEJ function in MM cell lines *ex vivo*.
3. Determine the relationship between karyotypic instability and NHEJ activity in myeloma cell lines.
4. Study NHEJ protein expression and function in primary MM samples.

Our preliminary studies conducted on multiple myeloma cell lines had indicated that two cell lines, RPMI 8226 and ARK, had reduced levels of XRCC4 expression as determined by Western blotting using XRCC4 MoAb. In addition a truncated, ~34kD transcript was seen in both these cell lines. This data suggested that XRCC4 expression is abnormal in some MM cell lines. This may result from transcriptional abnormalities in XRCC4 expression or as a result of a truncating XRCC4 mutation that may render the molecule nonfunctional.

FUNCTIONAL ASSAY -LM-PCR

Following up on these XRCC4 abnormalities, we conducted functional DNA double strand break repair assays to confirm their significance. These DNA repair assays were performed using *total cellular protein extracts*. Briefly an LM-PCR strategy was employed to evaluate the efficiency of ligation of a double stranded oligonucleotide linker to a linearized vector. This was followed by PCR, using one primer complementary to the linker and one primer complementary to the vector. Samples with successful ligation demonstrated a bright PCR band.

For this procedure, cells were collected and cellular extracts were prepared by a modification of the protocol described by Baumann *et al* (PNAS, 1998; 95(24):14066). Extracts were snap-frozen in liquid nitrogen and stored at -80°C . Protein concentration was determined and equal protein was used for each assay. Substrate vector was prepared by digesting pCR-Script Amp with Srf I. The enzyme was then inactivated and linearized vector purified using a QiaQuick PCR Purification kit. A double-stranded linker was constructed, with a linker 25 bp oligo (5'-gcggtgaccgggagatcgaattc-3') and linker 11 bp oligo (5'-gaattc agatc-3'). Repair reaction was carried out using linearized pCR-Script, double-stranded linker, ATP, and protein extract. Control samples (to rule out repair activity by other mechanisms, e.g. homologous recombination etc.) were pretreated with wortmannin to inhibit DNA-PKcs, and linearized pCR-Script was added subsequent to pretreatment. Other controls included DNA ligase as well as DNA -PKcs incompetent and wild type cell lines (MO59K and MO59J). Circular vector as well as water controls were used as well.

Ligation Mediated-PCR amplification of the ligation reaction product was performed using repair reaction products, linker 25 oligo and rep1.1 oligo (5'-ggagccccgattagactgtgacg-3'). The products were size-fractionated on a 2.0% agarose gel and visualized by ethidium bromide staining.

RESULTS

Using this technique 3 cell lines have been analyzed: RPMI-8226, U266, and OPM-2. Whereas a clear band is seen when protein extracts from U266 and OPM-2 are used in LM-PCR, a very faint band, if any, is seen in the reaction using extracts from RPMI-8226. When controls with wortmannin were performed inhibiting DNA-PKcs kinase activity, DNA ligation was abrogated in all 3

myeloma cell lines as well as in the controls, indicating that the repair activity was mediated by NHEJ. These observations have been confirmed in repeated experiments. This finding is indicative of impaired capability of DNA double strand break repair by non-homologous end joining in cells from the multiple myeloma cell line RPMI-8226. Indeed this finding corroborates the earlier finding of reduced expression and possible truncation of XRCC4 in this cell line.

Having identified a functional deficit in DNA double strand break repair by NHEJ in this cell line, further work is planned to evaluate this in other myeloma cell lines. For this purpose, we are trying to obtain myeloma cell lines ARK, ARP1, HS Sultan. Further work is being conducted to:

1. Identify the truncating mutation in XRCC4. This will be done using RT-PCR using primers spanning short distances on the mRNA molecule, to isolate the truncated version (if any). Subsequently, sequencing of the transcripts may be performed to identify possible mutations. If a truncating mutation is identified, the readily applicable RT-PCR assay will be applied to patient samples to detect XRCC4 abnormalities in primary myeloma samples.
2. Assess the fidelity of DNA double strand break repair using a reporter assay utilizing a linearized plasmid with a double strand break introduced in the beta-galactosidase insert of this construct. Colored colonies will give a semi-quantitative estimate of repair of the plasmid and give an evaluation of the fidelity of the repair reaction.

FUTURE DIRECTIONS

Once further data has been generated consolidating the novel findings described here, further funding will be sought from other extramural sources to expand this study and evaluate the role of DNA double strand break repair in the pathogenesis of multiple myeloma. Since this assay is readily applicable to clinical samples of purified plasma cells, it may give invaluable insight into the origin of complex karyotypic abnormalities in malignant plasma cells.

With sincere regards,
Amir A. Toor, M.D.
Assistant Professor of Medicine
Division of Hematology/Oncology
Cardinal Bernardin Cancer Center
Loyola University Medical Center
Maywood, Illinois 🌸

PATIENT UPDATE: MedX Lumbar Extension Treatment



Roy Meyer with certified physical therapist John Schaefer

by Roy F. Meyer

Those of us who are coping with multiple myeloma and those who help care for us know there are no sure things when it comes to fighting this dreadful disease. There are good days and not so good days, some treatment and drugs that work – and some that don't.

Often, there seems to be more to cope with than most people will ever understand. Thus, when someone comes along and suggests that we need to add even more stress and physical exertion to our already difficult daily routines, it is normally not well received. But, not always.

In the August 2000 issue of *Myeloma Today*, I wrote about my positive experiences with supervised physical therapy, and especially with a revolutionary program called MedX Lumbar Extension Machine. The MedX is designed to isolate the spine so that the machine can work on strengthening the back muscles and nerve endings to relieve the spine. For me, this was critical in shoring up the three spinal fractures caused by myeloma. The program worked for me and it has worked for others, but that's not the end of the story.

As a result of the article I wrote on my MedX experience, I received more than 25 phone calls and e-mails asking for more information. I was pleased to have gotten such interest. It made me feel as though my experiences might prove helpful to others.

Thomas G. Montebell, the owner and general manager of the rehabilitation and fitness center where I do my training, the National Fitness Institute in Rockville, Maryland, agrees. "Most people have not had a positive experience with exercise," he says. "The hardest part for most patients is making it beyond the first two or three weeks.

It's not like taking a Tylenol for a headache, there's going to be some discomfort."

But getting someone who is already in pain and feeling poorly besides to start exercising on a regular basis is not easy. And, I found out what happens when things go well – and when they don't. There are no sure things in dealing with myeloma. Benefitting from a physical training routine is not easy; it takes time.

I began my physical conditioning a year and a half ago on a twice a week schedule. My Exer-Med workouts included the MedX, limited cardiovascular work, a few body stretches, and gradually some weight-resistance exercise. When I started, I was unable to walk without a walker and was wearing a full body brace. Within three months, I was out of the brace and off the walker. I was still in pain, but, thank goodness, I was mobile again.

This twice-a-week training routine continued until March of 2001, when I was knocked for a loop by a staph infection, two bouts of bronchitis, and a severe back spasm which was hauntingly reminiscent of my earlier spinal fractures. I was paralyzed for several hours before getting to the hospital for a series of tests, including several x-rays and an updated MRI. For nearly two months, I was not able to resume physical therapy. The good news was that the MRI revealed a surprising result. First off, there had not been another spinal fracture, and more importantly, it revealed that there had been no additional bone deterioration since my initial MRI almost two years before. My oncologist found this to be absolutely amazing. She attributed it mainly to my monthly Aredia infusions, which undoubtedly has helped, but like most medical doctors, she was reluctant to give any credit to physical therapy.

Fortunately, more and more people, including several medical experts, have begun to discover the value of supervised exercise. One of the leading proponents is Dr. Vert Mooney, a world-renowned orthopedic doctor, surgeon, professor, and lecturer. Dr. Mooney is currently the medical director at a series of spine clinics in California. He is a strong supporter of the MedX program, and it is Dr. Mooney who recommended the program to me. He is not a believer in the "no pain, no

gain" theory of exercise. "Properly used, training equipment is controlled so that the person will not be injured or hurt," he explains. If they understand that all their motions are controlled so they can't be hurt, they might

"When I started, I was unable to walk without a walker and was wearing a full body brace. Within three months, I was out of the brace and off the walker."

be able to overcome their fear of pain." It is the fear of pain more than the reality that is often at work.

"Controlling pain and improving mobility are the goal," he says.

Dr. Mooney feels that the value of physical exercise is not taught in medical school – a major reason most doctors don't recommend it to their patients. He believes medical doctors need a better understanding of muscular-skeletal training. One of the reasons physical exercise does not get the attention it deserves, he says, is that "physical training has never been appropriately measured." Yet, he feels attitudes are changing, even though it is happening very slowly. "The emergence of health clubs and increased access to training equipment is helping," he says.

Montebell is also concerned that medical doctors and insurance carriers do not recognize the value of physical training. He spoke to our myeloma support group in Fairfax, Virginia, in February 2001 and explained that exercise, like eating, is a vital part of everyday life. "Without structured exercise," he noted, "muscles atrophy and we are unable to perform the usual tasks we could when we were younger, much less disease-free." Inactivity takes it toll on us in many ways, and it's worsened when we are struggling with a debilitating illness. "I think patients who get involved in physical training realize they have a lot more energy and mobility. From a general standpoint, the physical changes and the ability to function act almost as an anti-depressant."

The benefits can be significant. Montebell points out that physical exercise increases the body's serotonin and triggers the release of endorphins, which reduce the sensation of pain. "The psychological benefits provide a real sense of empowerment that is more important than cosmetic or physical benefits. You feel so much better and you can do things you thought you wouldn't be able to do again."

Dr. Mooney puts it this way:

Please see page 10

SOUTHERN CALIFORNIA IMFERS START THE YEAR RIGHT!



Drs. James Berenson and Robert Vescio with event hostess Sheila Field.

by Janet Johnson

For the past three years, the myeloma support groups of Southern California have joined forces to hold the first support group meeting of the year. Area support group members look forward to this event with great anticipation. So it was no surprise that on January 12, 2002 the meeting attracted an over-capacity crowd of attendees. More than 125 southern California myeloma patients and caregivers gathered to rejoice, share, and learn.

The rejoicing came in the form of enjoying good food and good company. As a caregiver and member of the Los Angeles Area Multiple Myeloma Support Group, I have found participating in social events to be an important part of therapeutic care, contributing to a more positive mental attitude – an important underpinning in any treatment situation.

The sharing came through discussion and mutual support offered in friendly, informal conversation – learning from each other about personal reactions to a treatment regimen, a dosage adjustment, a lotion to reduce itching, or a chair that helps ease back pain.

The learning portion of the day consisted of presentations by three myeloma specialists from the Cedars-Sinai Comprehensive Cancer Center in Los Angeles – Drs. James Berenson, Robert Vescio, and Hank Yang. Education, a key empowering tool in a patient's battle with myeloma, is always a highlight of our meetings and we were honored to host such an excellent panel of speakers.

Dr. Berenson's presentation included basic information as well as updates on the latest results from clinical trials and other research projects presented at the December 2001 ASH conference.

Dr. Vescio's presentation focused on the various types of myeloma, risk factors, and drugs in clinical trials.

Dr. Yang discussed the research approach to multiple myeloma, including results of clinical trials investigating PS-341, arsenic trioxide, and others.

The sessions engaged all in attendance – from the newly diagnosed to the myeloma veterans – and the question and answer portion of the event encouraged the participants to engage in a dialogue with the myeloma

experts.

The meeting was sponsored by Novartis Pharmaceuticals and was held at The Colony at Fashion Island in Newport Beach, California. Hosted and organized by IMFer Sheila Field, the event was also supported by the Los Angeles and San Diego myeloma support groups, the International Myeloma Foundation, and the Leukemia & Lymphoma Society.

Support group meetings such as this are beneficial in many ways, offering support and encouragement, and exposing patients and caregivers to a broad range of useful information. I would encourage all members of the myeloma patient and caregiver community to seek out and join a myeloma support group. To learn about the support groups in your area, please contact the IMF. 🍷

Editor's Note: To date, the Los Angeles support group *Circle of Friends* fundraising efforts have generated more than \$300,000 for myeloma research through contributions to the IMF from patients, their families and friends.



Drs. Hank Yang and Robert Vescio prepare for their presentations.

IMFER FEEDBACK

Dear IMF,

As a new subscriber and myeloma patient in Norway, please allow me to express my acknowledgement and joy of receiving the IMF 'Myeloma Minute' direct to my computer – a lot of interesting information coming even more than once a week.

Thank you, thank you – it's a fantastic way of getting information and following what's up as a patient.

*Best regards and thanks,
Kurt Løvschal*

MEDX – continued

“When a professional athlete experiences a physical problem, he goes to the trainer and is put on the proper equipment in the training room. Ordinary people should recognize that they, too, can benefit from physical training and rehabilitation. Proper training is much more than simply doing sit-ups at home or pumping iron at the gym. It must be supervised by someone with training and experience.” Dr. Mooney doesn't consider physical exercise to be “working out” in a traditional sense, but sees it as a “safe and controlled way to counter muscular-skeletal problems.” Controlling pain and improving mobility are the goal.

During the several weeks it took for me to regain even limited strength, I was forced off my exercise schedule. This only compounded my problems. My back and leg were sore and my stoop returned. My orthopedic doctor felt that all of this was due to further weakening of the spine and increasing kyphosis, and that it would only worsen. The next day, I slowly resumed my physical exercise routine and within three weeks, much of the discomfort was gone and the 'stoop' was less pronounced. My orthopedic doctor told me he considered the improvement to be “significant.”

As a jury of one, I know ongoing physical therapy has helped me. I plan to continue this routine as long as I am able because I now know what can happen when physical exercise is not a part of my life. Like medication and other aspects of my myeloma treatment, I have learned that physical exercise, properly supervised, is simply too important to ignore.

If you are interested in learning more about my experience, please contact me at (703) 938-5574 or by e-mail at sailor1st@aol.com. Or check out the MedX website at www.medxonline.com. 🍷

AN OLYMPIC LIGHT SHINES ON MYELOMA

With the Torch a Mayo Doctor Carries Hope for a Cure

by Norma S. Holmes
Washington Independent Writer
Writer Editor (ret.) U.S. Information Agency

When a nationwide search was launched for people 'who are an inspiration to others' to carry the Olympic flame to the Salt Lake 2002 winter games, Washington D.C. area patients with incurable cancer saw their chance to say "thank you!" to a remarkable cancer doctor who sustains them.

"This nomination is my statement!" asserted Cynthia Weglicki, a Maryland patient. "I may have Multiple Myeloma, but I'm still going to live! We cannot run the relays ourselves - but because of him today we can walk! Let Philip Greipp carry the torch for us!" Her call became a rallying cry for patients nationwide, many severely impaired, who launched an Internet and letter writing campaign with the Salt Lake Organizing Committee.

Dr. Philip R. Greipp, Director of Hematology Research at the Mayo Clinic in Rochester, Minnesota is a familiar and much loved face to myeloma patients across America. Modern treatment and early diagnosis have extended the survival of some 50,000 Americans with myeloma. Finding a cure for the disease

is a life goal of this determined doctor, who is Professor of Medicine and Laboratory Medicine and Pathology at Mayo. But Philip Greipp is also a patient's doctor. He is 'always there' for them, encouraging and helping them to lead productive lives, and there for physicians who care for them in their local community.

Three U.S. Multiple Myeloma foundations quickly joined the effort to nominate the internationally known hematologist - the IMF, MMRF and Goldman Philanthropic Partnerships. "Doctor Phil" indeed became one of 11,500 torchbearers chosen out of 210,000 nominations across the country to carry the Olympic flame. On a 26-degree January night in Milwaukee, Wisconsin, the 59-year-old physician carried the torch in a five block uphill relay for a wildly cheering crowd of family and friends.

Few of those who nominated him could withstand the Northern trip into below freezing temperatures to watch the event, so the three foundations created banners signed by patients that were carried to Milwaukee. Patients, family and banners greeted him as he passed the flame and 10,000 jubilant Milwaukeeans continued the celebration into the night with 'Dr. Phil' and other torchbearers.

Patient involvement is continuing nationwide. A photo website has been created by Dr. Greipp's son, Dan, to enable them to view and share in events of the relay. Patient advocacy days in Washington are already forming in support of cancer legislation pending in Congress. HR 2629, a bill to further research in blood cancers has already passed the Senate and has wide Congressional support.

So the light of hope for a cure and a better quality of life is bright today because patients with incurable cancer wanted to make a difference, and because a committed doctor shared their dream. 🍀



Dr. Philip Greipp with wife Maureen and daughter Dr. Patricia Greipp, also a hematologist at Mayo Clinic

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News & Notes

CHALLENGING CASES IN MULTIPLE MYELOMA

The IMF has partnered with Network for Oncology Communication & Research (NOCR) to host the first ever "Challenging Cases in Multiple Myeloma and Other Plasma Cell Disorders" forum. The forum is designed to update oncologists on how to optimally treat their most challenging myeloma patients. This forum offers physicians a unique opportunity to participate in an interactive meeting and discuss the latest in the treatment and management of myeloma with a panel of world-renowned myeloma experts. "Challenging Cases in Multiple Myeloma and Other Plasma Cell Disorders" will be held in New York City on August 10, 2002. For more information please contact NOCR at (404) 845-3800.

MILLENNIUM PLANNING NEW TRIAL

Millennium Pharmaceuticals Inc. is planning to open two Phase III trials in April or May 2002 at 64 sites. All of the U.S. sites involved in the Phase I trials will participate, plus a number of additional sites. One randomized trial will accrue up to 560 relapsed/refractory patients who have had 1 to 3 prior treatments. The second trial will be non-randomized and will accrue up to 400 subjects who have failed 4 or more prior treatments. A complete list of IRB-approved sites is not yet available.

NCCAM CLEARINGHOUSE

The National Institutes of Health (NIH) is dedicated to exploring complementary and alternative medicine (CAM) in the context of rigorous science; training CAM researchers; and disseminating authoritative information. The NIH-sponsored National Center for Complementary and Alternative Medicine (NCCAM) facilitates and conducts biomedical research but does not serve as a referral agency for treatments or practitioners. However, NCCAM does offer a wealth of information to consumers and practitioners, including a number of fact sheets, consensus reports, access to CAM databases, and information about research and clinical trials. Further information is available through the NCCAM Clearinghouse online at www.ncaam.nih.gov or by calling (888) 644-6226.

SU5416 TRIALS DISCONTINUED

Trials with SU5416 have demonstrated that the drug provided no greater benefit to myeloma patients than current control therapies. There were a total of 34 patients in two trials. In the NCI trial, 7 patients were treated with no responses of any kind. In protocol 5016-210, 27 patients were treated with some showing stable disease, but no responses. As of this printing, all trials have been discontinued.

HELP THE IMF HELP YOU

The IMF has always been about people helping people, families helping families. Our financial support has always come from people like you – people who understand the importance of myeloma research and educational programs. We continue to need and rely on your support. However, we now need to raise significantly more funds to achieve our objectives... and you can help!

Giving USA 2001 reported that in 2000, corporations gave \$10.86 billion to charitable causes. Studies indicate that these corporations give to organizations that they know or with whom they have a "connection." And we know that many of our IMF members have unique relationships to businesses around the world. In fact, you or someone you know most probably has a connection that can provide the IMF with just the right entrée to a corporation and enable us to become a corporate partner.

If you know a key individual within a corporation, or if you have a link to someone in a corporation, please call Pam Jones of Corporate Development at (800) 452-2873 or email her at pjones@myeloma.org. With your help, we will obtain the corporate partnerships we need to dramatically enhance funding for myeloma research and education to a level never seen before!

We appreciate your assistance with this important initiative, and we look forward to hearing from you.



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